

Systems Change Grants for Community Living Evaluation

Partnership Development Activities: Comparative Analysis of FY 2001 Systems Change Grantees



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Acronym List

AAA	Area Agencies on Aging
CD	consumer direction
CMS	Centers for Medicare & Medicaid Services
CPASS	Community-Integrated Personal Assistance Services and Supports
FY	fiscal year
HUD	Housing and Urban Development
ILC	Independent Living Center
ILP	Independent Living Partnership
IRB	institutional review board
LTC	long-term care
NFT	Nursing Facility Transition
PAS	personal assistance services
RC	Real Choice
SP	State Program
WVUCED	West Virginia University Center for Excellence in Disabilities

Executive Summary

ES.1 INTRODUCTION

In 2001, the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS) awarded grants totaling approximately \$70 million to 37 States and Guam under the System Change Grants for Community Living program. The purpose of these Grants is to encourage States to implement enduring improvements in home and community long-term care (LTC) service systems on behalf of children and adults of any age who have a disability or long-term illness to

- Z live in the most integrated community setting appropriate to their support requirements and their preferences;
- Z exercise meaningful choices about their living environment, the providers of services they receive, the types of supports they use and the manner in which services are provided; and
- Z obtain quality services in a manner as consistent as possible with their community living preferences and priorities.

The awards made by CMS were divided among three types of Grants: 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 Independent Living Centers (ILCs) to promote partnerships between ILCs and States to support NFTs.

Both the Congress and CMS strongly encouraged all those applying for any of the Systems Change Grants to actively and continuously involve consumers and public and private partners in project design and implementation. In the Conference Report for the Fiscal Year (FY) 2001 Grants, Congress stated that the RC Grant applications should be developed jointly by the State and a Consumer Task Force. “The Task Force should be composed of individuals with disabilities from diverse backgrounds, representatives from organizations that provide services to individuals with disabilities, consumers of long-term services and supports and those who advocate on behalf of such individuals (H. Conf. Rep. No. 106-1033 at 150).” Congress intended to ensure that the identification of needs, goals and Grant activities would be jointly determined by the State and the Consumer Task Force. The Congressional report did not state that applicants for the CPASS and NFT Grants should also develop their applications with a Consumer Task Force but strongly encouraged them to do so with the input and assistance of consumers and other partners.

To reinforce the importance of consumer and other partner involvement, CMS listed partnership development as an evaluation criterion in its Notice of Funding Availability for the Systems Change Grants. CMS also awarded 54 noncompetitive \$50,000 Systems Change “Starter Grants” that could be used to develop and support Consumer Task Forces and other means for involving consumer, public and private partners in Grant planning.

This report provides a summary of the partnership development activities undertaken by the 52 Grantees that were awarded a Systems Change Grant in 2001. It describes the ways that Grantees involved consumers and public and private partners in the development of Grant applications and their plans for involving them in implementation activities. In addition, the report includes a more in-depth description of partnership involvement for nine Grantees (three from each Grant type), focusing in particular on how consumers were involved in and perceived the Grant development process.

ES.2 DATA AND ANALYTIC APPROACH

Our principal source of data for the comparative analysis of partnership development was the narrative sections of the

Systems Change Grant applications for the 52 Grantees. Because CMS received far more applications than it could fund—161 applications requesting \$240 million—all of the Grantees received less funding than requested due to the large applicant pool and CMS's desire to fund as many Grants as possible. Grantees were required to revise their Grant projects post-award to conform to the reduced amount of the award. To ensure that we had current information for the analysis, we extracted information about goals and activities from the original applications, compared it to information in a post-award two-page project description prepared by each Grantee, noted discrepancies and had the Grantees confirm the accuracy and completeness of our six- to eight-page summaries of their activities and other information about their Grants. The partnership development information in the Grant summaries that the Grantees approved was then analyzed.

The principal source of data for the in-depth description of partnership development for nine Grantees was telephone interviews with the primary State contact for the Grant, and consumer, public and private partners identified by the Grantees.

ES.3 MAJOR FINDINGS

ES.3.1 Comparative Analysis of Partnership Development

Consumer Partners

- Z All of the Grantees involved consumers and incorporated consumer viewpoints in planning activities. Consumer involvement was defined broadly, to include people with disabilities and their families as well as representatives of disability-related organizations.
- Z Almost two-thirds of Grantees used either existing or new Consumer Task Forces as the primary mechanism to solicit consumer input.
- Z A few States limited the level of consumer involvement and others did not have as much involvement as they wanted, due to the short time available to prepare the Grant applications.
- Z Consumers will function in a variety of roles in implementation activities. The most common role is oversight, primarily through membership on Grant oversight committees. Some Grantees will involve consumers in specific implementation tasks, such as

reviewing draft informational materials and testing a Website with information about home and community services. In Tennessee, consumers will be hired as employees to assist in Grant implementation activities.

Public Partners

- Z All Grantees partnered with other State agencies in some capacity, although CPASS Grantees did so to a lesser degree. RC Grantees appeared to have the broadest range of State agency partners. Both RC and NFT Grantees were more likely to include the agency that administers the State's Medicaid program as a public partner.
- Z Almost half of all Grantees identified public universities as collaborators that often assisted in the application-writing process. Public university partners were generally designated to assist with Grant implementation, provide technical assistance and evaluate the Grant project.
- Z The most common responsibility of public partners in the planning phase, across all Grantees, was coordinating and attending planning meetings and commenting on drafts of the Grant application. The involvement of public partners was less structured than the consumer input process.
- Z Many State agency public partners were identified as collaborators on specific Grant activities.

Private Partners

- Z The most commonly cited private partners were disability-specific organizations or consumer groups and ILCs.
- Z NFT-SP Grantees were more likely than the other Grantees to have ILCs as private partners, and ILCs were the most common type of private partner cited among NFT-SP Grantees.
- Z Many private partners participated in the Grant development process by attending planning sessions, helping to establish goals and objectives and reviewing, commenting on, and helping to write the Grant applications.
- Z In a number of States, the private partners strongly encouraged the State to apply for the Grant and/or led the planning process.
- Z Many private partners will continue to function as members of Consumer Task Forces or advisory councils and assist in Grant oversight and monitoring. Others will provide consulting services or technical assistance for specific objectives.

ES.3.2 In-Depth Look at Nine Grantees' Partnership Activities

- Z There was extensive variation in levels of involvement across all of the partners. In general, existing relationships and known expertise were the basis for many of the public and private partnerships.
- Z In a few States, lead agency respondents felt that it was difficult to get broad consumer involvement because the short time frame forced them to rely on existing organizations and advocates for consumer input. Many consumers and lead agency respondents felt that more participants and perspectives should have been included in the Grant application planning process, and about half of the lead agency respondents felt that more input from consumers and other stakeholders was necessary.
- Z Consumer Task Forces were viewed by many lead agency respondents as a key method for obtaining consumer input. Accommodating consumer needs throughout the process was viewed as either very helpful or essential.
- Z Approximately half of the public and private partner and lead agency respondents reported barriers to developing partnerships. The most common barriers cited were lack of time, scheduling conflicts and the need for education.
- Z Lead agency respondents who reported disagreements during the application process described a range of consumer concerns specific to the application processes in each State, but consumers noted that none of the disagreements resulted in a breakdown of collaboration or partnership. For the most part, consumers felt that all decisions were made by consensus.
- Z Approximately half of the lead agency and public and private partners reported disagreements in the planning process, which were resolved through discussion and compromise. Final decisions were based on the input of many stakeholders but were generally made by the lead agencies.
- Z A large majority of lead agencies and public and private partners felt that consumers were very influential in the planning process, but a few consumers did not share this view. While lead agency respondents thought that consumers were satisfied with their involvement in the planning process, only two-thirds of the consumers felt, and with some reservations, that their level of input was adequate. Three-quarters were satisfied with the final goals and activities, although a few consumers felt deliberately excluded because the State claimed it did not have adequate time to include them. Some consumers cited their own lack of time as the primary factor for a less-than-optimal role in the planning process.

- Z Lead agencies and public and private partners overwhelmingly said that consumer involvement made the planning process better and, in many instances, easier.
- Z All but one of the lead agencies indicated that public and private partners were highly influential in the planning process. In contrast, 75 percent of the public and private partners felt that they had been influential. Most public or private partners were satisfied with their roles in the process and felt that they had contributed a great deal and/or did not have the time to participate more than they did. In general, most were satisfied with the planning process. Many felt that partnership development should be an ongoing activity.

ES.4 NEXT STEPS

This is the second in a series of reports that RTI, in collaboration with the MEDSTAT Group, will prepare as part of a CMS-funded implementation evaluation designed to assist Grantees and other decision makers by documenting progress toward their goals and to assist them in developing solutions to problems encountered during project implementation. We will prepare annual reports based on the Grantees' semiannual and annual reports of Grant activities and topic papers that focus on specific issues that Grantees are addressing, such as workforce recruitment and retention. The topic papers will provide an overview of activities that Grantees have undertaken during the Grant period to address the specific issues and will describe effective approaches.

Introduction

1

1.1 BACKGROUND

In May 2001, the Centers for Medicare & Medicaid Services (CMS) invited applications from States and others to obtain Grants for implementing enduring improvements in long-term care (LTC) home and community service systems. The purpose of the Grants is to encourage States to make enduring changes in their LTC systems that will enable people of all ages with all types of disabilities or long-term illnesses 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 that they receive.

In September 2001, CMS awarded approximately \$70 million in Systems Change Grants for Community Living 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 SP initiatives and Independent Living Partnership (ILP) Grants made to Independent Living Centers (ILCs) to promote partnerships between ILCs and States to support NFTs. (A list of Grantees is provided in the appendix.) States receiving the awards will design and implement improvements in community LTC systems in partnership with their disability and aging communities.

52 Systems Change Grants were made to 37 States and Guam.

Both the Congress and CMS emphasized the importance of consumer involvement and public and private partnerships in the Grant application development and implementation process.

Both the Congress and CMS emphasized the importance of consumer involvement and public and private partnerships in the Grant application development and implementation process. In the Congressional Conference Report for the Fiscal Year (FY) 2001 Grants, Congress stated that the RC Grant applications should be developed jointly by the State and the Consumer Task Force. “The Task Force should be composed of individuals with disabilities from diverse backgrounds, representatives from organizations that provide services to individuals with disabilities, consumers of long-term services and supports and those who advocate on behalf of such individuals (H. Conf. Rep. No. 106-1033 at 150).” Congress wanted to ensure that the identification of needs, goals and Grant activities would be jointly determined by the State and the Consumer Task Force. The Congressional report did not state that applicants for the CPASS and NFT Grants should also develop their applications with a Consumer Task Force but strongly encouraged them to do so with the input and assistance of consumers and other partners.

CMS reinforced the importance of consumer and other partner involvement. In a January 2001 State Medicaid Director letter that alerted States to the impending Grant announcement, CMS emphasized the importance of developing broad-based Consumer Task Forces and involving public and private partners in Grant application planning efforts.¹ CMS encouraged States to invite persons with disabilities, family members of persons with disabilities and representatives of disability and aging organizations to participate in Consumer Task Forces at the State level. In February 2001, CMS announced the availability of noncompetitive \$50,000 Systems Change “Starter Grants” to any State that applied for them to support initial planning for Systems Change Grant applications. The money was to be used for developing Consumer Task Forces and public and private partnerships. CMS listed partnership development as an evaluation criterion in its Notice of Funding Availability (issued in May 2001) for all three types of Grants.

In May 2001, CMS sponsored a national conference—New Opportunities for Community Living: A Systems Change Conference—for States, consumers, advocates and providers to share information and ideas about home and community service

initiatives to facilitate more integrated community living for individuals with disabilities. The general purpose of the conference was to assist States in improving their LTC systems and to give attendees an opportunity to ask CMS questions about this major new grant initiative. In July 2001, CMS also sponsored a national teleconference to assist interested applicants. Grant submissions were due in July 2001.

1.2 CONTEXT FOR THE REPORT

In conjunction with the awarding of the Systems Change Grants for Community Living, CMS awarded a research contract to RTI, in collaboration with the MEDSTAT Group, to conduct an implementation evaluation. The primary purpose of this evaluation is to document Grantees' progress in completing their identified Grant activities and accomplishing project goals. Given the importance of consumer and public and private partner involvement to the success of the Systems Change Grants, CMS requested a report describing partnership involvement in Grant application activities as well as Grantees' plans for involving partners in implementation activities.

1.3 PURPOSE OF THE REPORT

The purpose of this report is to provide an overview of the various individuals and entities that the 52 Grantees partnered with in the development of their Grant applications, the ways these partners were involved and plans for partner involvement in Grant implementation activities.² The report also presents a more in-depth look at nine Grantees' partnership activities to provide a better understanding of the planning process and the perceptions of that process by those participating in it.

1.4 ORGANIZATION OF THE REPORT

Section 2—Comparative Analysis of Partnership Development and Activities—begins with a description of our methodological approach to the analysis and then presents a comparative description of the 52 Grantees' completed and planned partnership activities, broken down by consumer partners, public partners and private partners.

Section 3—In-Depth Study of Partner Involvement in the Planning Process—begins with a description of our methodological approach to the analysis and then presents the results of 42 interviews conducted with Grantees and their partners in the application development process.

The final section presents a brief discussion of next steps in the implementation evaluation.

Comparative Analysis of Partnership Development and Activities

2

2.1 METHODOLOGICAL APPROACH

2.1.1 Data Sources

The comparative analysis of partnership development and activities is based primarily on a review of partnership information provided in Grantees' initial Grant applications. To reduce the large volume of information to a more concise and manageable form, we reviewed each application and produced a six- to eight-page summary for each Grantee using a uniform template. The template for the summaries covered a range of important elements in the Grant applications, including the following:

1. strengths and weaknesses of the State's long-term care (LTC) system;
2. goals, objectives and activities;
3. consumer, public and private involvement in the development of Grant applications;
4. consumer, public and private involvement in Grant implementation;
5. Grant oversight activities; and
6. formative learning and evaluation activities.

This report presents a description and comparative analysis of elements three, four, and five (to the extent that oversight activities include consumers and partners). A companion report describes and compares elements one and two.

Due to the large applicant pool and CMS's desire to fund as many Grants as possible, all of the Grantees received less funding than requested. Grantees were then required to revise their Grant projects post-award to conform to the reduced amount of the award. To ensure that we had current information for the analysis, we extracted information about goals and activities from the original applications, compared it to information in a post-award two-page project description prepared by each Grantee and noted discrepancies. We then had Grantees confirm the accuracy and completeness of our description of their activities and other information about their Grants.

2.1.2 Analytic Approach

To prepare the information contained in all of the 52 summaries for comparison and analysis, we reviewed consumer, public and private partner-related information and further summarized it under three major headings:

1. types of partners,
2. involvement of partners in planning activities, and
3. involvement of partners in implementation activities.

We then grouped the information by partner type (consumer, public or private), and these summaries formed the basis for the analysis.

2.1.3 Limitations of the Data

Many of the Grant applications lacked detailed and comprehensive information about the consumer, public and private partners, and specifically, about how they were involved in the planning process and were to be involved in Grant implementation. In almost all cases, we asked the Grantees to provide additional information and clarifications in preparing the six- to eight-page Grant summaries. The accuracy of the data we used is dependent on the thoroughness of each Grantee's review of the Grant summaries we prepared and the supplemental information they provided.

2.2 ORGANIZATION OF FINDINGS

In general, the findings for each type of partner are presented across all three types of Grants—Real Choice (RC) Grants, Community-Integrated Personal Assistance Services and

Supports (CPASS) Grants and Nursing Facility Transition (NFT) Grants. The type of Grant is indicated only when there are distinct differences between the three types or when examples are provided.

2.3 CONSUMER PARTNERS

2.3.1 Types of Consumer Partners

Nearly all Grantees specifically identified persons with disabilities as consumer partners. About half of the Grantees stated that family members of persons with disabilities also served as consumer partners, and about three-quarters identified representatives of disability-related organizations as consumer partners. In New Jersey (RC), persons with disabilities, family members and advocates served on an existing *Olmstead* planning group and were invited to serve on a newly created Systems Change Advisory Council to guide the development of the application.³ In a few instances, States targeted specific groups to be part of the consumer input process. In Montana (CPASS), the State invited personal attendants and their representatives to participate in the consumer input process. In Minnesota (RC), the State asked family members of persons with mental illness to participate in the planning process.

Nearly all Grantees specifically identified persons with disabilities as consumer partners.

2.3.2 Consumer Involvement in Planning Activities

All of the Grantees involved consumers in the application development process (hereafter, called the planning process) through one or more means: establishing Consumer Task Forces, conducting public meetings and hearings, conducting focus groups and surveys or direct outreach. Almost two-thirds of Grantees used either existing or new Consumer Task Forces as the primary mechanism to solicit consumer feedback. Many of the existing task forces were *Olmstead* planning groups, but some were Governor's Councils on Disabilities. For example, Missouri (RC) used the *Olmstead* Stakeholder Group as an interim Consumer Task Force for the planning process. The Group reviewed 76 recommendations from a Home and Community-Based Services and Consumer-Directed Care Commission report and condensed them into several Grant objectives. However, while almost half of the RC Grantees described *Olmstead* planning groups and efforts associated with Grant development,

Almost two-thirds of Grantees used existing or new Consumer Task Forces.

only a third of NFT Grantees and none of the CPASS Grantees did so.

About a quarter of Grantees conducted focus groups and surveys to obtain consumer input.

States asked members of existing or new Consumer Task Forces to discuss LTC and disability issues, establish Grant goals and activities and/or review drafts of the Grant applications. Many States held task force meetings or other types of public meetings in several parts of their State to broaden consumer input. In Massachusetts (RC), the State solicited consumer input at several listening sessions around the State. In Tennessee (RC), the State held public forums at regional Consumer Task Force meetings and directed regional housing facilitators to go into communities to talk with consumers directly about the Grant application and their concerns.

About a quarter of Grantees conducted focus groups and surveys to obtain consumer input. In Alabama (RC), focus groups were conducted in six locations across the State to solicit consumer input, and a few States conducted consumer surveys.⁴ Finally, several States described having less consumer involvement and fewer and shorter meetings than they would have liked due to the limited amount of time available to prepare the Grant application. The limited time to prepare the application explains in part the extensive use of existing Consumer Task Forces to include consumers in the planning process.

2.3.3 Consumer Involvement in Implementation Activities

A majority of Grantees indicated that consumer partners will monitor the progress of Grant activities.

All Grantees plan to involve consumers in Grant implementation activities, but the nature and scope of the involvement varies considerably. A majority indicated that consumer partners will participate in Grant implementation by monitoring the progress of Grant activities—typically as members of a Consumer Task Force, Advisory Council or Committee. Some stated that consumers would be involved in work groups or committees that will be formed to implement specific activities, such as developing evaluation questions and measures and reviewing evaluation reports. In Oregon (RC), consumers will serve on the Grant Evaluation Group charged with monitoring and evaluating project activities in collaboration with Oregon Health Sciences University.

Approximately one-fifth of Grantees (mostly RC) also plan to involve consumers in addition to those serving on task forces, boards or work groups. They plan to use consumers to test information and resource materials (both print and Web-based), complete consumer satisfaction surveys and participate in focus groups on a range of issues. For example, in Maine (RC), the State plans to have consumers participate in focus groups to generate information on quality indicators and to develop content for and test the consumer information Website. In Tennessee (RC), consumers will be hired as employees to partner with regional housing specialists and participate in community education and outreach efforts.

2.4 PUBLIC PARTNERS

2.4.1 Types of Public Partners

Grantees listed an array of public agencies and other public or quasi-public entities as partners, including State and local agencies; governor councils, advisory bodies or offices; and educational entities such as public universities. All of the Grantees identified other State agencies as partners in the planning process and Grant implementation activities. Many of the relationships existed prior to the Grant announcement, but Grantees stated that they would be enhanced through Grant activities. The most frequently cited public partners were State agencies responsible for the Medicaid program, mental health, senior services/aging and developmental disabilities. Additional findings by type of Grant are as follows:

- Z NFT Grantees were more likely than CPASS Grantees to include as public partners State agencies responsible for the Medicaid program, mental health, senior services/aging and developmental disabilities.
- Z CPASS Grantees were less likely than the other two types of Grantees to identify other State agency partners in general. Of those they did include, they were more likely to include State agencies responsible for mental health and senior services/aging, but less than one-half indicated partnerships with either agency.
- Z RC Grantees were more likely to include as public partners State agencies responsible for the Medicaid program, mental health, senior services/aging, developmental disabilities and public health. Additionally, about one-fifth of RC Grantees also identified other State agencies as

One-fifth of Grantees plan to use consumers to test print and Web-based information, complete satisfaction surveys and participate in focus groups on a range of issues.

partners—those responsible for mental retardation, education, transportation and employment and labor.

- Z Approximately one-quarter of NFT and RC Grantees identified as public partners State agencies for housing, family and community services, rehabilitation services and public health.
- Z In Minnesota, the State agency planned to work with tribal governments.

All of the Grantees identified other State agencies as partners in the planning process and Grant implementation activities.

Many of the Grantees also involved advisory councils, commissions and offices established and sponsored by governors. These public entities frequently included consumers, advocates and representatives of private entities, in essence combining the three types of partners. In Alaska (CPASS), the State identified the Governor's Council on Disabilities and Special Education as a partner. In Maryland (NFT), the State identified the Governor's Office for Individuals with Disabilities as a partner. On the local level, NFT and RC Grantees most commonly identified local public housing authorities as partners, and one-fifth of all Grantees identified Area Agencies on Aging (AAA) as partners.⁵

Almost half of the Grantees identified public universities as partners.

Almost half of the Grantees identified public universities as partners. RC Grantees were more likely to indicate partnerships with public universities. Just over two-thirds identified public universities as key partners in the planning process and implementation and evaluation activities. In Kentucky (RC), the State plans to develop training programs for personal assistance workers through the Kentucky Community and Technical College System.⁶

While public universities were identified as primary partners in the planning process, a handful of other educational entities were identified for collaboration on specific Grant initiatives. For example, in New Jersey (RC), the State plans to develop a model curriculum and training program on self-directed care targeted at secondary school students with disabilities.

2.4.2 Public Partner Involvement in Planning Activities

Public partners participated in the planning process in some way, but Grantees provided little specific information about their participation. In general, public partners attended or coordinated

informal and formal planning sessions, helped to decide which Grants to apply for, assisted in the identification of goals and objectives, participated in or led consumer input activities, assisted in application writing or reviewed and commented on drafts of the application. The most common activity cited was coordinating and attending planning meetings and reviewing and commenting on application drafts.

For many Grantees, the process of involving public partners in general appeared less structured or formal than the process for involving consumers. However, some States used a more structured approach for involving public partners. For example, Delaware (RC) used starter Grant funds to form a Stakeholder Task Force comprising State agencies and contractors, which held several meetings and developed the outline for the Grant application. In several States, the lead agency established formal agreements with public entities to support proposed Grant activities. For example, in Indiana (NFT), the lead agency secured a commitment of Section 8 housing vouchers from the State Housing Authority to ensure the availability of housing for persons being transitioned from a nursing facility using Grant funds.

In several States, Governor-sponsored entities participated in the planning process, sometimes coordinating the process and planning and facilitating Consumer Task Force meetings. For example, in Florida (RC), the Americans with Disabilities Act Working Group established by the Governor hosted consumer and partnership meetings, provided necessary leadership and worked with the Department of Management Services to prepare the Grant application. In Alaska (CPASS), the Governor's Council on Disabilities and Special Education took a lead role in writing the Grant applications. Several Grantees reported that State agencies—in addition to consumers and advocates—are represented on these councils and advisory bodies.

In the majority of States that identified public universities as partners, primarily RC and CPASS Grantees, the universities assisted in the application-writing process, often taking the lead on this activity. In Michigan, the Wayne State Developmental Disabilities Institute assisted in writing and developing the CPASS Grant application. In Massachusetts, the University of

In several States, Governor-sponsored entities participated in the planning process, sometimes coordinating the process and planning and facilitating Consumer Task Force meetings.

Massachusetts Medical School's Center for Health Policy and Research prepared the RC Grant application and managed the process of gathering input, content and comments from the Grant application development team, which included State agencies.

2.4.3 Public Partner Involvement in Implementation Activities

All Grantees plan to utilize a broad array of public partners in some way in Grant implementation. However, as with descriptions about public partner involvement in planning activities, Grantees provided very little specific information about public partner participation in implementation activities, other than to say that they would be involved in Grant oversight and implementation. A few Grantees described plans to establish formal interdepartmental task forces to oversee Grant implementation. In New Jersey (RC), key public agencies will be represented on the Systems Change Management Team, and several of those agencies are responsible for leading specific Grant initiatives (e.g., workforce development and consumer direction [CD]). In Maine (RC), the State established four technical advisory groups comprising consumers and public agency staff to provide input and expertise on project activities, to develop evaluation criteria and to monitor progress in meeting those criteria.

In Guam (CPASS), the Department of Revenue and Taxation will provide guidance regarding tax issues for consumers who hire a personal care attendant.

Grantees identified many State agencies or governor-sponsored entities as collaborators on specific activities. For example, in Guam (CPASS), the Department of Revenue and Taxation will provide guidance regarding tax issues for consumers who hire a personal care attendant. In Guam (RC), the Developmental Disabilities Council will take an active and substantive role in the development of the information system and a printed guide to available services. In Michigan (RC), the Office of Services to the Aging will assist in the development of a Web-based service information site.

Where universities were identified as partners, many were also designated to assist with Grant implementation by providing technical assistance and evaluating Grant activities. The University of Arkansas Rehabilitation Continuing Education Center will provide technical assistance in workforce development under the RC Grant. In Missouri (RC), the University of Missouri-Kansas

City will facilitate consumer involvement in specific Grant activities. Under the New Hampshire CPASS Grant, the Franklin Pierce Law Center Institute for Health, Law and Ethics will assist in conducting a community services gap analysis, advocate implementation of recommended reforms and assist in developing backup coverage and worker retention benefit programs.⁷ In South Carolina (RC), the School of Public Health at the University of South Carolina will provide technical assistance and evaluation. Finally, in Maine (RC), the Muskie School of Public Service at the University of Southern Maine will provide leadership and staff support for the project through a cooperative agreement.

2.5 PRIVATE PARTNERS

2.5.1 Types of Private Partners

Grantees partnered with a wide array of private entities in the planning process and will also partner with them in implementation activities. The most commonly cited private partners were disability-specific organizations or consumer groups and Independent Living Centers (ILCs). Both were identified by approximately one-half of Grantees. Grantees also identified service providers, local service coordinators and private consultants as private partners. Exhibit 2-1 (below) presents types of private partners with specific examples from the Grant applications.

Grantees identified service providers, local service coordinators and private consultants as private partners.

Exhibit 2-1. Examples of Types of Private Partners

Disability-Specific Consumer Group or Organization	Nevada Alliance for the Mentally Ill Brain Injury Association of Florida
National or State Nonprofit Associations	Area Agencies on Aging Association of Michigan Association of Maryland Hospitals Arkansas Waiver Association
Centers for Independent Living	Illinois Centers for Independent Living
Local Service Coordination Agencies	Lifeways Mental Health Board (HI)
Service Providers	Oregon's Safe Haven Organizations (serving the homeless population) United Way (TN)
Consultants	AssistGuide (HI) Dual Diagnosis Management, Inc. (TN)

The partners most frequently mentioned by NFT-State Program (SP) Grantees were ILCs. Several NFT Grantees, including Alaska (NFT-SP), Georgia (NFT-SP and NFT-Independent Living Partnership [ILP]) and West Virginia (NFT-SP), also identified nursing home providers or provider associations as partners. Florida (RC) listed faith-based organizations as a group of private partners targeted for involvement with a formal stakeholder partnership. While most Grantees identified several private partners, many Grantees had one or more contractors yet to be determined.

2.5.2 Private Partner Involvement in Planning Activities

Grantees reported that many of the private partners participated in the planning process by assisting in the establishment of goals and objectives, reviewing and commenting on drafts and helping to write the application(s). Many of the disability-specific organizations, State and national nonprofit associations, ILCs and service providers are members of existing or new Consumer Task Forces. States also used other methods to obtain input from private partners. For example, Minnesota (CPASS) tried to ensure broad representation of stakeholders by meeting individually with representatives of private entities and surveying them about the focus of the Grant application.

Private partners in several States encouraged State agencies to apply for the Grants.

In several States, a few key private partners contributed significantly to the planning process. In some cases, especially with regard to the NFT-ILP Grants, this was expected. CMS required that ILCs lead the Grant writing effort for NFT-ILP Grants. In Alabama, the Birmingham ILC wrote the NFT-ILP Grant, and in Colorado, one of the leading ILCs, Atlantis, assisted in coordinating the planning process for the NFT-SP application. Private partners in several States were also credited with encouraging States to apply for Grants. In Vermont, the State credited the Vermont Center for Independent Living, Green Mountain Self-Advocates and the Vermont Self-Determination Project with strongly encouraging the State to apply for the RC Grant.

2.5.3 Private Partner Involvement in Implementation Activities

Many private partners who participated in the planning process as members of Consumer Task Forces or advisory councils will be involved in implementation activities through their continuing membership on those bodies. In this capacity, they will be involved in varying levels of Grant oversight and monitoring, depending on the Grantee. Some Grantees are planning to partner with entities that provide consulting services or technical assistance for the implementation of specific objectives. For example, the Nevada Community Enrichment Program (a personal assistance services [PAS] provider agency) will implement a number of Grant activities related to independent living and assistive technology (CPASS). In Maine (RC), TANerprise, Inc., Systems Engineering, Inc. and Client Network Services, Inc. were identified as subcontractors to assist with data integration efforts across several State agencies.

Some Grantees plan to use formal contracting arrangements with private entities. In New Jersey (RC), contractors will implement several activities, including (but not limited to) training on consumer direction, consulting on developing and testing an independent assessment process, conducting surveys and focus groups of front-line staff and creating a personal assistance registry.

Some Grantees are planning to partner with entities that provide consulting services or technical assistance for the implementation of specific Grant objectives.

In-Depth Study of Partner Involvement in the Planning Process

3

3.1 METHODOLOGICAL APPROACH

Given the Congressional instruction and encouragement to States to partner with consumers and other entities when developing their Grant applications, CMS requested a more in-depth look at partner involvement in the planning process than was possible using only the information provided in Grantees' applications. In particular, CMS was interested in how consumers were involved in and perceived the planning process, with a focus on commonalities and differences.

We read the sections on Consumer Partnerships and Public and Private Partnerships in all of the Grantees' applications to obtain an overview of partnership development approaches and to identify nine Grantees that used unique or exemplary approaches. The two major goals for our selection of States were (1) achieving a broad representation of different approaches and activities and (2) including unique or exemplary practices to ensure consumer input and involvement.

Based on our reading, we chose the following nine Grantees for our in-depth study of consumer and public and private partner involvement in the planning process:

- Z three Community-Integrated Personal Assistance Services and Supports (CPASS) Grantees (Alaska, Nevada and Oklahoma),
- Z three Nursing Facility Transition (NFT) Grantees (Colorado, Georgia and West Virginia), and
- Z three Real Choice (RC) Grantees (Iowa, Minnesota and Tennessee).

Some States wrote more about their partnership development process than others did. Since we based our selection on the descriptions provided, it is possible that the States that wrote less may have had equally inclusive and productive processes. Due to differences in the amount of information provided in Grant applications, the small sample size and nonrandom selection, the findings cannot be generalized across all 52 Grantees.

To ensure that all views were represented, we proposed to interview the lead agency, a public partner, a private partner and two consumer partners, for a total of five interviews per Grantee. We developed three interview protocols to guide the interviews, one for the lead agency, one for public and private partners and one for consumers. (Copies of these protocols are provided in the appendix.) The interview questions were based on the primary research topics presented in Exhibit 3-1.

In accordance with RTI's Institutional Review Board (IRB) policy, we developed informed consent procedures for all participants. Because the lead agency and partners involved in implementation activities are required to participate in CMS-sponsored research activities, the informed consent procedures for these respondents were less detailed than were those for consumers. (Copies of the informed consent procedures are provided in the appendix.)

We contacted each lead agency to confirm participation and to develop a list of potential interviewees in the three response categories (consumer, public and private partners).⁸ In each State, the lead agency contact readily provided a list of individuals and alternates (when needed). Staff successfully secured interviews with the lead agency contacts in each State and at least one public and private partner in each State.⁹ While we planned to conduct two consumer interviews for each Grantee, for some States (Alaska [CPASS], Colorado [NFT-State Program (SP)], Georgia [NFT-SP] and

Exhibit 3-1. Topics Addressed in Interviews

Partnership Formation

- Use of Planning or Starter Grants for Partnership Activities
- Ensuring Broad Consumer Involvement
- Consumer Involvement in Planning
- Accommodations and Resources for Consumer Participation
- Selection of Public and Private Partners
- Public and Private Partner Involvement in the Planning Process

Barriers to Participation in the Planning Process

- Barriers to Consumer Participation
- Barriers to Public and Private Partner Participation

Partnership Functioning

- Disagreement Among Consumers During Planning
- Disagreement Among Public and Private Partners During

- Decision Making about Grant Goals and Activities

Perceptions of Partnership Formation and Functioning

- Influence of Consumers on the Planning Process
- Consumer Satisfaction with the Planning Process
- Influence of Public and Private Partners on the Planning Process
- Public and Private Partner Satisfaction with the Planning

Nevada [CPASS]), we were only able to interview one consumer, despite numerous attempts via phone and e-mail to schedule interviews. We requested the names of additional consumers to interview in all cases, but these consumers were also unavailable within the time frame for producing this report.

Neither consumer in Oklahoma completed interviews. One consumer identified by the lead agency reported not being involved at all in planning or implementation activities. The other consumer asked to respond via e-mail rather than telephone due to her disabilities but did not respond after being sent the questions via e-mail, despite several reminders. When asked for alternates, the lead agency and other partners in the State did not identify additional consumers to be interviewed. Thus, a total of 12 consumers were interviewed across the nine States.

Telephone interviews were informal and semistructured, collecting a range of information on partnership development. We adapted questions to the circumstances and particular expertise of the

individual being interviewed, as needed. Interview responses were grouped according to the topics listed in Exhibit 3-1, and responses under each topic were analyzed by type of respondent (e.g., lead agency, consumer).

3.2 ORGANIZATION OF FINDINGS

The headings in this section follow the topics presented in Exhibit 3-1, with the exception that the findings for consumer partnerships are presented first, followed by the findings for public and private partnerships. The views of the lead agency about a topic are presented first, followed, when appropriate to the topic, by the views of consumer partners and public and private partners. The discussion compares and contrasts the perspectives of the lead agency and its partners, with a focus on commonalities and differences.

3.3 CONSUMER PARTNERSHIP FORMATION

3.3.1 Use of Planning Grants for Consumer Partnership Activities

Lead Agency Respondents. All of the nine Grantees reported that their agency, another public agency or a publicly sponsored entity (e.g., Governor's Council) received a CMS RC Systems Change "Starter Grant." These noncompetitive, \$50,000 Grants available to each State were intended to support Consumer Task Forces, public and private partnerships and initial planning for the Systems Change Grants (CMS Notice of Funding Availability, 2001). CMS records indicate that all nine States received these Grants. Five of these Grantees reported using the funds primarily to secure assistance with writing and coordinating multiple Grant applications.¹⁰ Several States used Starter Grant funds to support consumer involvement in the planning process by:

- Z recruiting consumers to participate on task forces,
- Z covering consumer travel expenses, and
- Z planning and conducting meetings with consumers.

In Georgia, the State used a portion of the Starter Grant funds to recruit consumers for a Consumer Task Force, raise awareness about systems change through presentations and targeted mailings and facilitate consumer involvement in its newly created Consumer Task Force, the Consumer Systems Change Network. West Virginia used the Grant to fund the West Virginia University Center for Excellence in Disabilities (WVUCED) to write the Grant application and to form a panel of consumers, advocates and other stakeholders to facilitate consumer input in the planning process.

Respondents in two States with CMS Starter Grants noted difficulties in spending Grant funds. In one State, the respondent said that they did not have enough time to use the funds prior to the due date for the Grant application. Instead, they used funds from another source to pay consumers' travel and other expenses to attend meetings, to fund a Grant writer and to sponsor a public assembly to raise awareness about the Grants. Another State was not able to spend all of the funds because they could not be used to cover State staff time to coordinate planning activities. This State used a portion of the funds to cover consumer expenses for participating in meetings and requested an extension of the period to spend the remaining funds.

3.3.2 Ensuring Broad Consumer Involvement

Lead Agency Respondents. Respondents in all nine States reported that their agency tried to ensure participation in the planning process by a broad range of consumers with different types of disabilities and long-term care (LTC) needs and by consumer disability groups. Lead agencies employed a variety of methods to recruit a broad consumer base, including sending mailings and educational materials to disability organizations, giving presentations to disability organizations and other community groups and holding public meetings. In Tennessee, the State used existing regional task forces (urban and rural) to encourage involvement by a wide array of consumers, their families and advocates.

Six of the nine respondents reported that collaborating with *Olmstead* planning groups or task forces and governor-sponsored councils or bodies helped them identify and involve a broad range

Several States used Grant funds to support consumer involvement in the planning process: recruiting consumers to participate on task forces, covering consumer travel expenses and planning and conducting meetings with consumers.

of consumers. In Colorado, the respondent remarked that the application development group represented a fair number of disability groups because it was formed from a broad base of consumers who had created an *Olmstead* planning report. In Iowa, the lead agency respondent said that they had relied heavily on the *Olmstead* Task Force coordinator's lists of consumers and advocates, who were diverse in geographic location, type of disability, age and ethnicity, noting that "This was the first time I had to think in terms of making sure all disabilities were represented." In Georgia, respondents said that the agency's relationship with the Governor's Blue Ribbon Task Force on Home and Community-Based Services and the Governor's Council on Developmental Disabilities helped them to identify and involve consumers and advocates.

Collaborating with Olmstead planning groups or task forces and governor-sponsored councils or bodies helped lead agencies identify and involve a broad range of consumers.

While most respondents felt that their States had achieved broad coverage, a few respondents shared challenges that they had faced. In West Virginia, the State increased recruiting efforts among persons with mental illness because a mental health consumer group felt that their concerns were not adequately represented in the planning process. The lead agency respondent in Nevada noted that while the State was successful in securing representation of a broad range of people with disabilities and chronic illnesses, it needed to increase the representation of children with autism and persons of all ages with serious behavioral disorders. In a few States, respondents felt that it was difficult to get broad consumer involvement in what they perceived as a relatively short Grant application period, forcing reliance on existing relationships with disability organizations and advocates to represent consumer input. One lead agency respondent felt her agency had to rely on a "convenience sample" of consumers.

3.3.3 Consumer Involvement in Planning

Lead Agency Respondents. When asked how consumers were involved in the planning process, respondents described the use of public meetings and hearings, Consumer Task Forces, dissemination of materials and direct outreach to consumers. Most Grantees used a combination of activities. Respondents from seven of the nine States reported the use of new or existing Consumer Task Forces. Five States created new Consumer Task Forces (at least three were created from existing *Olmstead*

planning groups). In Oklahoma, an existing *Olmstead* group participated in Grant development.

The respondent from Colorado felt that using the *Olmstead* planning group was the best method for obtaining consumer input. The respondent in Iowa felt it was beneficial to the planning process that 8 of the 25 task force members had served on the original *Olmstead* planning group because “it allowed for some continuity.” The respondent from Georgia reported that the State used both informal and formal methods to obtain consumer input, including contacting lead advocates, meeting with additional advocates at the CMS-sponsored Systems Change conference and working with advocates to establish a Consumer Task Force. In Iowa, the State used the *Olmstead* coordinator to conduct 20 meetings and to establish a committee of consumers and public agency representatives to assist in writing the Grant application.

In Tennessee, the lead agency used a combination of Consumer Task Force meetings and direct outreach to obtain consumer input. Direct outreach was enabled by regional task forces that were already in place for the locally driven, State-sponsored Creating Homes Initiative, which is an effort to expand housing options for people with mental illness. Each task force met four times a year to discuss gaps in current housing services and supports for persons with severe mental illness. After the Grant announcement, the task force forums were used to discuss broader systems change opportunities.

In addition, the State utilized regional housing facilitators to conduct direct consumer outreach. The facilitators, who are nonprofit employees, directly contacted consumers in the community, encouraged them to write to the State and asked them to participate in informal surveys about their primary housing needs. The Tennessee respondent said the State chose these different methods to identify what consumers and families found important. These methods allowed for a “multilevel, formal and informal consumer perspective” and are important because “some consumers might find it difficult to be heard at a large task force meeting with 70 to 75 stakeholders.” Another respondent felt that consumers should not just provide input at public hearings or be the sole consumer in a large group, but rather should be equal partners in the planning process.

Consumers provided input at public meetings and hearings, during Consumer Task Force meetings and through one-on-one meetings.

In the two States without formal Consumer Task Forces, Nevada and Minnesota, respondents reported obtaining consumer involvement and input through a variety of means. In Nevada, the lead agency used existing consumer input, including data from annual interviews with clients of the State's personal assistance services (PAS) program and meetings with the State's PAS Task Force. She also cited receiving assistance from Independent Living Centers (ILCs) that met with consumers informally about the Grant and stated that, prior to the recent enactment of PAS legislation, the State had received extensive consumer input, which was then used in the planning process.

In Minnesota, the State reached out to different consumer groups about the Grant and held several public meetings. The State did not have an existing *Olmstead* planning group, but the respondent felt that it was not a problem because the State worked closely with several existing advocacy and consumer groups on service and support development issues.

One respondent noted that consumers should not just provide input at public hearings or be the sole consumer in a large group, but rather should be equal partners in the planning process.

Consumer Respondents. Most consumer respondents stated or implied that they were associated with disability organizations, were family representatives for consumers or were themselves persons with disabilities. When asked about how they participated in the planning process, all but 1 of the 12 consumers reported serving in a formal capacity on a Consumer Task Force or attending planning sessions. Consumer respondents from three States said that they had been involved in *Olmstead* planning activities and that working on the Grant application was a continuation of their involvement in LTC and disability issues. Many of the consumers involved in the planning process indicated that they had multiple and varied responsibilities, including conducting research, providing feedback and completing surveys, reviewing and commenting on drafts, giving testimony and/or helping to write the Grant applications. As noted by one consumer, the process began as an all-inclusive, "round-table discussion" before different duties were delegated among the 14 people on the Consumer Task Force.

Most of the consumer respondents stated that they were actively involved in the planning process. For example, one consumer conducted education outreach in addition to serving on a task force. Another reported serving as the chairperson of the

Consumer Task Force, conducting background research and assisting in writing the application. Many others attended task force meetings and provided direct input. In contrast, one consumer was only required to write a letter of support and asked to participate in implementation training activities, while another consumer “was not asked to be part of a task force” although she was “happy to be involved” in the meetings that she attended. Another respondent stated that consumers had not been given the opportunity to take part in the actual writing of the application due to time constraints. This consumer seemed to feel that State budget limitations prevented an optimal level of consumer involvement. One respondent noted that some participants were better versed in the Grant application process than he was, resulting in “a bit of a learning curve,” but that they were provided with excellent reference materials and adequate lead time.

In general, all of the consumer respondents took part in the application planning process on some level and for various reasons. A consumer who was a member of a disability advocacy organization felt that her assistance in developing the Grant provided her organization with the chance to continue its mission and “...an opportunity to extend our work.” The family representative of another consumer also works for the ARC and an organization that designs, builds and arranges loans for housing for people with developmental disabilities. One consumer respondent summarized his involvement with the Grant application by quoting that State’s Consumer Task Force mission statement: “To be an integral participant in this Grant application process by providing information and direction in a timely, accurate and meaningful manner.”

All but 1 of the 12 consumers reported serving in a formal capacity on a Consumer Task Force or attending planning sessions associated with the planning process.

3.3.4 Accommodations and Resources for Consumer Participation

Lead Agency Respondents. Five of the nine Grantees covered consumers’ transportation expenses and other travel-related expenses, such as meals and lodging. The use of stipends for consumers participating in the planning phase was not reported; however, two States noted that stipends would be provided during Grant implementation. Tennessee covered expenses for State staff to travel to regional public meetings to ensure that consumers and their families could participate in their own

communities without extensive travel. As discussed in the previous section, the State also directed regional housing facilitators to interview consumers individually in their own communities. In addition, the State arranged for community space and refreshments through donations by public and private partners. In Colorado, the respondent noted that the State does not typically cover expenses for citizens to participate on advisory panels. However, travel expenses for consumer participation in Grant implementation under the newly established advisory group were included in the project budget.

Most consumers felt that their needs were accommodated.

Consumer Respondents. Consumer responses were consistent with reports by lead agency respondents that the States covered travel-related expenses. Most consumers felt that their needs were accommodated. One consumer said that the State was responsive and provided “anything that was needed to show up for the meetings.” Another consumer noted that in addition to reimbursement for transportation, meeting locations and work areas (e.g., computers and desks) were accessible. A consumer with visual impairment reported that the State gave him materials in electronic format and reimbursement for mileage-related expenses. While he felt there was a “learning curve” in the State’s effort (e.g., failure to convert the Grant timetable and budget into Braille), he still felt the State was responsive to his overall needs. Two consumers from the same State appreciated the State’s decision to arrange for regional Consumer Task Force meetings and to talk with consumers individually.

3.4 BARRIERS TO CONSUMER PARTICIPATION IN THE PLANNING PROCESS

Lead Agency Respondents. Although respondents in five States reported some difficulties in the planning process, none described significant barriers. Three stated that it was difficult to obtain comprehensive consumer input due to time constraints associated with the Grant application deadline. One respondent noted how difficult it was to incorporate so many ideas in a short amount of time: “It’s difficult to really listen when a group of people is brainstorming and putting out ideas quickly.”

Respondents from Alaska and Minnesota felt that their States had some difficulty in recruiting specific consumer populations, such as younger people with disabilities served through ILCs and consumers with cognitive impairments. One of these respondents felt that the State should have gone into the community and institutions to speak with consumers.

In one instance, the lead agency respondent was unsure whether consumers or advocates for consumers could best articulate consumer needs. The respondent from Tennessee described initial skepticism about the planning process among consumers and advocates who feared that their input would be discounted. However, she noted that continual encouragement from the State and its ability to directly engage consumers in planning activities greatly reduced consumer skepticism and increased their involvement.

Consumer Respondents. In four of the States, consumers reported no barriers or difficulties encountered in the planning process. One described an absence of barriers, noting that the State works very well with consumers. Another said that when she joined the task force at a later date than others, she was really pleased to receive prior meeting minutes to learn what had taken place at the earlier meetings.

Some consumers felt that elderly consumers were not adequately represented.

Consumers in the other four States reported a variety of barriers to participation, including confusion and lack of coordination at the State level in the process of applying for multiple Grants, lack of communication after receiving consumer input, choosing meeting locations that deterred consumer participation and not including the voice of the elderly community.

One consumer said she was not able to review the final Grant application and in the post-award phase has not received responses to inquiries about the implementation activities that her organization was supposed to lead. A consumer in a State that applied for multiple Grants felt that there was noticeable strain from applying for four different Grants and that his advocacy organization could have coordinated the entire application writing process a little better than the State did. He felt that one agency in particular was not very enthusiastic about applying for and leading the Grant, which slowed down the writing process.

A consumer in another State felt that the State's current budget problems hurt the planning process and would hurt implementation, saying that "responsibilities are being juggled between fewer staffers and the structure of the department has been reorganized." Another consumer reported that initial Grant planning meetings were held at an institution until several consumer complaints convinced the State to move the meeting location. Finally, a consumer who considered herself elderly and not receiving services generally delivered to individuals with disabilities felt strongly that her State was not soliciting input from the elderly, but only the broader disability community. She reported that she inadvertently found out about the Grant process and then became involved on her own initiative.

3.5 CONSUMER PARTNERSHIP FUNCTIONING

One respondent noted that there were no disagreements, partly because the State emphasized the need to compromise and prioritize in order to stay within budget.

3.5.1 Disagreements among Consumers during Planning

Lead Agency Respondents. Five of the respondents described no or minimal disagreements among consumers and consumer representatives regarding the selection of goals and activities. The Tennessee respondent stated that "there were no disagreements among consumers regarding the selection of goals and activities for the Grant application because it was all based on their input, with one common goal among them." The Alaska respondent felt that there were no disagreements, partly because the State repeatedly emphasized the need to compromise and prioritize in order to stay within budget and also because of the need to build on existing efforts in order to ensure the sustainability of Grant activities. However, she cited philosophical differences between consumers and State agencies that she felt could influence the sustainability of Grant activities. Some consumers want Grant funds to be used immediately, while State agencies want to proceed more cautiously, to "track and evaluate" progress, which they can later use to support requests for additional funding from the legislature.

Respondents who reported some consumer disagreement described a range of consumer concerns specific to the planning process in their States. In Nevada, the respondent reported that there was disagreement among consumers over the extent to

which consumer direction (CD) should be implemented. Two consumers felt that all PAS should be provided through a CD model, but others felt that there should be choice and that some consumers may not want to take on the full responsibility of hiring, supervising and paying personal assistant workers. One of these two consumers ultimately dropped out of the process.

In Oklahoma, the lead agency respondent reported that there was some disagreement over whether the goals of the Grant would ultimately benefit the full range of LTC needs of people with all types of disabilities. Lead agency respondents indicated that consumer advocates for persons with mental retardation at first thought the Grant was not relevant but ultimately understood how the Systems Change Grant activities could benefit their population.

One respondent noted that some consumers at the table were “less trusting” of the nursing facility providers who were also at the table and might have felt that they did not have enough influence in the planning process. Finally, one respondent noted that while consumers had more commonalities than differences during the planning process, historic tensions still resonated, including frustration with the system and lack of information, and a feeling among consumer groups representing different populations that other populations were getting more or better services and programs.

Consumer Respondents. The majority of consumers reported only a few disagreements over policy issues and the planning process. One consumer reported that there was little disagreement and felt that the State communicated a clear interest in hearing about gaps in the present system and “therefore listened to, and heeded, everything that everyone had to say.”

Several consumers mentioned specific policy and programmatic disagreements that were eventually resolved, such as whether to include nursing facilities as full partners in the planning process, which communities to target, how to balance funding for staff and direct services and the speed of systems change. One consumer felt that more was being spent on funding staff than on actual services, saying that “Grants usually fund someone to tell you

The majority of consumers reported only a few disagreements over policy issues and the planning process.

where to go to get the funding that you need—it would be nice to just get the funding to purchase those items.” Another consumer noted a level of frustration due to perceptions of slow progress in moving the “transitioning” agenda forward before the Grant was announced and spoke of the hope that the Grant would mean faster progress.

With regard to disagreements over the planning process, one consumer reported differences in opinion over the number of goals in the application, fearing that too many goals would make achievement difficult. Both consumers in one State noted strong disagreements among consumers participating in the planning process over which nongovernmental entity would administer the Grant. They both reported that the organization being considered eventually chose not to administer the Grant.

In general, consumers felt that decisions about the goals and objectives for the Grant were made by consensus.

Several consumers felt that the level of agreement was actually high due to the opportunity to secure funds for systems change. They described years of working for systems change and were quite pleased to have the chance to fund activities to bring about their plans. One consumer remarking on the congenial atmosphere stated that “people were happy to have an opportunity to fund this agenda. There’s a cadre of folks out there working on PAS issues since the 80s and it was clear what was needed.”

3.5.2 Decision Making on Grant Goals and Activities

Consumer Respondents. In general, consumers in eight States felt that decisions about the goals and objectives for the Grant were made by consensus but recognized that the State had the final decision-making ability given that the State was technically the lead agent for the Grant. One consumer felt that using a consensus process was made easier by the small size of the State. Another consumer remarked that he recognized that the Consumer Task Force was “purely advisory.” One consumer said that at some point, the planning process had to be turned over to the State in order to submit the Grant application to CMS, and at that time, “you have to have a certain level of trust in the process.” Both consumers in another State felt that the decision-making process was based on compromise and was very transparent. Another consumer said that the lead agency contact facilitated the

group decision-making process and acted as a mediator, noting that she had support for that role because of her previous work with those involved in the planning process.

3.6 PERCEPTIONS OF PARTNERSHIP FORMATION AND FUNCTION

3.6.1 Influence of Consumers in the Planning Process

Lead Agency Respondents. A large majority of agency respondents felt that input from consumers significantly influenced the Grant's goals and activities. As one pointed out, "the voice of each group and constituency was heard. The entire process was iterative, with opportunities for feedback and input every step along the way." Other respondents described their development process in similar terms. In Iowa, the lead agency respondent noted that the State's RC Grant application had been based on the Iowa Plan for Community Development, which was developed by the *Olmstead* Task Force and included extensive consumer input.

Another admitted that there were some initial challenges from other agency staff in terms of the government's role, but, through individual advocacy, the respondent, and others were able to ensure that the planning process was consumer-driven. Two of the respondents were more ambivalent about the extent of consumers' influence. One stated that she was "not sure" and another noted that "most [consumers] agreed with the activities and goals. Nothing specific changed as a result of the meetings."

All of the respondents indicated that consumer participation allowed for a much easier planning process, but one-third of these respondents stated that their participation made the process more difficult as well. In general, difficulties stemmed primarily from logistical problems, such as finding and paying for large meeting spaces. Regardless of the difficulties, respondents agreed that any difficulties were outweighed by the benefits of consumer participation: their personal knowledge, expertise and perspectives and their eagerness to participate in activities to bring about real change. A few respondents also noted that progress would not be possible without consumer buy-in, and another added that participation is empowering for consumers. As

Most lead agency respondents felt that consumers significantly influenced Grant goals and activities.

Respondents agreed that any difficulties were outweighed by the benefits of consumer participation: their personal knowledge, expertise and perspectives, and their eagerness to participate in activities to bring about real change.

one respondent pointed out, “the consumers make the Grant more effective and that only strengthens them and this process.”

When we asked specifically whether respondents felt that consumers should have had a larger role in the planning process, more than half said no. Two indicated that the consumers’ role was sufficient or adequate, but the others noted that consumers had a major role in the process. As one respondent noted, consumers “shaped the process and application and helped edit [the Grant].” Of those lead agency respondents who felt that the consumer role should have been more significant, lack of time to write the application was cited as the primary reason their participation was limited. Two respondents did not provide their views on this particular topic.

Some consumers had concerns that the voices of consumers, particularly nursing home residents and seniors, were not heard or adequately represented during the planning process.

Consumer Respondents. Two-thirds of consumer respondents felt that there was adequate input from consumers in the target population(s) to be served by the Grant. Some of those respondents were highly satisfied with the level of consumer representation, while others qualified their statements of satisfaction with remarks such as “[there was] probably not optimal representation from persons with severe mental illness, but [it was] definitely adequate.” One consumer described a lot of “give and take” between the State and task force members. He and other task force members provided significant feedback.

Four of the consumers felt that there was not enough input from consumers, although one conceded that “for the kind of population [the Grant] wanted to serve, I guess it was [adequate].” One consumer vehemently stated, “Absolutely not! Because their idea of making it available was to put it on their Website... as far as the Grant goes, it wasn’t available to us at all.” Others were less outspoken but had concerns that the voices of consumers, particularly current residents of nursing facilities and seniors, were not heard or adequately represented during the planning process.

Public and Private Partner Respondents. Nearly all of the respondents agreed with the lead agency respondents that consumers were very involved and well-represented and had a considerable impact on goals and activities. One partner noted that the consumers’ input was of tantamount importance, overriding even that of the government agencies. However, while

some of the respondents felt that everyone's voice was heard, a few noted concerns about equal representation among various consumer groups and differing interests. As one partner pointed out, "the aging, those with physical disabilities, developmental disabilities and mental health disabilities are all separate cohorts with their own sets of needs... all competing for a finite set of resources." Another complained that there was "very little new blood" during the process because the same consumers who are involved in many other activities worked on the Grant application.

Although some of the public and private partner respondents did not feel that consumer involvement made the planning process easier, most of those involved did agree that it made it better because it legitimized the process, made the Grants more relevant and empowered consumers. Those partners who mentioned difficulties generally cited logistical problems, funding and resource issues, the need to inform consumers about the Grant application process, gaining consensus among a broad range of interests and bridging the gap between knowing *what* consumers want and *how* to make it happen. Those public and private partners who stated that consumer involvement made the process infinitely easier indicated that consumer experience and perspectives provided the foundation upon which to build the Grant applications and consumer continuous feedback and participation significantly contributed to further the application process.

All lead agency respondents felt that consumers and their representatives were satisfied with the planning process and the opportunities that they were given to participate.

3.6.2 Consumer Satisfaction with the Planning Process

Lead Agency Respondents. In general, all lead agency respondents felt that consumers and their representatives were satisfied with the planning process and the opportunities that consumers and their representatives were given to participate. As one respondent noted, "everyone who participated was grateful for being invited. I got a lot of thanks and they really appreciated the opportunity to be involved." However, she also added that, due to time constraints, the all-day meetings were "long and hard," particularly for those consumers who were new to the process and for those with severe disabilities.

The lead agency respondent in Oklahoma conceded that consumers were not initially satisfied with the process and had

considered writing their own Grant. When the consumers realized that there was insufficient time to do so and that they could not reach consensus among themselves regarding goals and activities, they joined forces with the lead agency. As reported earlier, the lead agency respondent in Nevada (CPASS) commented that all of the consumers were satisfied, except for one who resigned from the process because the other consumers did not agree with his view that all PAS in the State should be consumer directed.

In general, there was consensus among the lead agency respondents that the consumers were satisfied with the process and their role in it. As one respondent stated, the consumers “gave incredibly positive feedback.”

When asked what they would do differently to ensure consumer input if they had to do it again, more than half of the respondents recommended expanding input from more diverse sources. However, two respondents felt that lack of time prevented them from obtaining more broad-based stakeholder input, while another felt that inadequate planning on the agency’s part prevented them from obtaining a greater amount of consumer input.

There was no consensus among other recommendations, which ranged from including consumers on the Grant application writing team to “meet[ing] those with cognitive impairments on their own turf.” One respondent said that they would do nothing differently. Other suggestions included getting fast-track approval from their Governor, using interpreters in the field and convening smaller, consumer-only groups to ensure that consumers are given opportunities to fully express themselves.

Consumer Respondents. Of the 12 consumer respondents across the eight Grantees, 10 were satisfied with their opportunities to participate in the planning process. One consumer was “extremely satisfied” with the process because she felt people truly listened to her at the task force meetings and she felt like a real collaborator. Another felt that consumers were given excellent reference materials and plenty of lead time to provide input and feedback. He was able to assist with initial drafts and worked on the final application. He rated the group “high” in process development. Others valued the chance to

Of the 12 consumer respondents across the eight Grantees, 10 were satisfied with their opportunities to participate in the planning process.

become acquainted with more consumer groups and advocates and to work in cooperation with them. As one consumer stated, “it is critical for [his organization] to network more with other disability groups and this was a great opportunity to do so.”

In contrast, one consumer respondent noted that although consumers had been allowed to participate in Grant application writing in previous efforts, the lead agency representative informed consumer volunteers that time was too limited for them to take part in the actual writing of the Grant application. Another consumer reported that her only real participation was to write a letter of support for the lead agency. She further noted that only consumers employed by the ILC were directly involved in the NFT-SP development process. One consumer respondent added that the process can be frustrating due to the challenge of working with a government bureaucracy.

Many of the consumers felt that their input was largely incorporated into the Grants’ goals and activities. Most were unequivocal in their assertions that consumers were highly influential, but one consumer indicated that only group voices rather than individual voices were heard and that she did not believe that her input was used in making decisions about goals and activities. Another consumer from the same State pointed out that she was not personally very vocal. However, she noted that she “was not upset with the end product.” Many others were much more enthusiastic. For example, one consumer from a different State felt that her input was “undoubtedly used in deciding goals and activities...all of the collaborative input of everyone involved was included.”

Eight of the 12 consumer respondents were satisfied with the final goals and activities.

Eight of the 12 consumer respondents were satisfied with the final goals and activities, although one noted that she would have been more satisfied if the provision of mental health services could have been included in the application. Of those consumers who were dissatisfied with the goals and activities, one would have liked more “teeth” in the Grant, saying “...How are we going to help people?” Another consumer noted that she had “no idea” what the final product was and felt unable to comment, and another consumer stated that she had been unable to attend the last few meetings because she had lost interest in the process due to its lack of applicability to her own disability.

When asked for recommendations for the lead agency if the planning process were to be repeated, nearly half responded that the State should “spread the net wider” and increase the number of participants to include, for example, service providers (“not administrators”), other State agencies, more seniors, those with all types of developmental disabilities and consumers (“not administrators”) from consumer organizations. Four other respondents stated that the methods employed to ensure consumer participation were quite successful and that their three Grantees should continue soliciting as much consumer input as possible and serve as an example to other Grantees.

Other recommendations were more specific. One consumer noted that the State “needs to be more straightforward in communication” and allow for 30 days of public comment on proposed goals and objectives. He felt that the Grant applications were due too soon after they were announced, thus preventing the agencies from learning what people really wanted. Another consumer respondent wanted consumers’ comments regarding Grant applications, including dissenting opinions and justification for why such opinions were overridden, published. One consumer stated that more focus groups might have been beneficial because “many of the interviews were done by phone... but I would have preferred more face-to-face [contact and participation].”

3.7 PUBLIC AND PRIVATE PARTNERSHIP FORMATION

3.7.1 Selection of Public and Private Partners

Lead Agency Respondents. The majority of respondents reported that their agencies approached other public agencies, primarily State agencies that had expertise in various areas of LTC and disability populations and existing relationships with the lead agency. For example, in Nevada, the lead agency preparing the CPASS Grant application approached three other public agencies that operate PAS programs. In Minnesota, the lead agency respondent noted that the State invited all 87 counties to be involved.

For the most part, lead agency approaches to selecting quasi-governmental entities (e.g., governors' councils) and other private entities followed the same pattern as approaching public agencies—primarily seeking out and involving those with expertise and existing relationships. For example, the lead agency in Nevada approached the University of Nevada as a primary partner because of their past work and experience with people with disabilities: “They’ve done a lot of work in the area of services to children with autism and serious behavioral disorders and in life transitioning.”

As reported earlier, the lead agency in West Virginia chose to partner with West Virginia University through an existing agreement to write the application and administer the Grant. The Tennessee respondent said that the lead agency identified key public and private leaders across the State and sent them letters from the Commissioner of the Department of Mental Health and Developmental Disabilities that invited them to participate in outreach activities, educational meetings and regional task force meetings. However, she noted that “public and private entities involved in the planning and implementation phases were ultimately self-selected for partnership by their expressed interest in the issue/cause.”

Respondents from smaller States said that it was easy to get partners because they already know everyone who is working on LTC issues. For example, the West Virginia respondent felt that because the State was small, reaching out to every disability group in the State was not too much of a challenge. “It wasn’t difficult to decide who would be involved, because practically everyone in the field knew about the Grants.” In other States, a more formal process was followed to ensure representation by all stakeholders. The Georgia respondent said that the State increased involvement of nursing home providers as partners after State agency representatives, consumers and disability organizations reflected on representation in the planning process and asked themselves, “Who’s not here at the table?”

Several respondents felt that while their lead agency was active in the planning process, they were initially encouraged to apply for the Grant by private entities. In Alaska, the ILC “courted and pushed and helped [the lead agency] ... to do the Grant.” In

Respondents from smaller States said it was easy to get partners because they already know everyone who is working on LTC issues.

Colorado, one of the lead private partners, an ILC and a Medicaid provider of home care services, approached the State about submitting an NFT-SP Grant. “[The organization] volunteered to become the lead partner on the NFT-SP Grant, and the State was more than happy for them to assume responsibility for both the Grant application and major tasks under the NFT-SP Grant, if awarded.”

Public and Private Partners. Similar to lead agency respondents, most public and private partner respondents felt that their expertise and existing relationships led to their selection as partners in the planning process. However, several partners described approaching the lead agency about the Grant and actively pursuing involvement, rather than reacting to the lead agency’s overture.

The State increased involvement of nursing home providers as partners after State agency representatives, consumers and disability organizations reflected on representation in the planning process and asked themselves, “Who’s not here at the table?”

In Colorado, a respondent with a public agency said that his agency worked with the lead agency on another housing project and that discussing the Systems Change Grant seemed logical, “like a natural progression to our common goals.” In Tennessee, a respondent also with a public agency reported that the lead agency and his agency ultimately report to the same commissioner and have a memorandum of understanding to facilitate collaboration. When the Notice of Funding Availability was announced, both agencies were aware of it and willing to collaborate “in whatever ways possible.” One respondent with a county agency in Minnesota said that she had probably heard about the Grant through a mailing list, but that a county committee effort in 1997 had already made recommendations related to systems change.

A respondent with the Alaska Governor’s Council on Developmental Disabilities said that this organization received the Starter Grant and served as the lead agency’s designee for developing the Grant application. In Nevada, a respondent with the Center for Independent Living felt that the State relied on the organization’s expertise. “We had just held public hearings and given legislative testimony on PAS issues, so working on the Grant was like the next step.” In Oklahoma, the respondent from a private agency said that her organization provides case-management services for a waiver and has had a long-standing relationship with the State.

Several partners, both public and private, described approaching their respective lead State agencies and encouraging them to submit Grant applications.

As reported by the lead agency respondents, several partners, both public and private, described approaching their respective lead State agencies and encouraging them to submit Grant applications. For example, a private partner in West Virginia said that she encouraged the State to respond to the request for applications. In Oklahoma, a respondent with the Long Term Care Authority encouraged the Aging Services Division to apply for the CPASS Grant. Other agencies were also quite active and informed the States about the available Grant opportunities, encouraged them to apply and made it known that they wished to be active partners. As one respondent noted, these partners would have become quite vocal if the State had not responded to the Notice of Funding Availability.

3.7.2 Public and Private Partner Involvement in Planning

Lead Agency Respondents. Lead agency respondents described public and private partner involvement in the planning process through a variety of mechanisms, including participation in Consumer Task Force meetings and proceedings, other informal and formal meetings and as reported earlier, Grant application writing services. In Minnesota, the State hosted large planning meetings and then held smaller meetings of State staff to work on specific issues.

In Colorado, the lead agency worked very closely with the State Housing Agency to devise a memorandum of understanding to guide the commitment and allocation of 40 Housing and Urban Development (HUD) Section 8 vouchers for use under the NFT-SP Grant. The lead agency also relied on a leading ILC to work with the State's grant writing consultant to prepare the application. In Iowa, the State did hold several meetings with public and private partners, but primarily relied on their feedback from an existing document, the Iowa Plan for Community Development, developed through Iowa's *Olmstead* planning process.

In two States, the lead agencies reported that they tried to ensure that public and private partner voices did not compete with the consumer input process. In Alaska, the State purposefully limited the numbers of public agency staff at Consumer Task Force meetings focused on obtaining consumer input. However, the lead agency circulated drafts for review and held separate

In two States, the lead agencies reported that they tried to ensure that public and private partner voices did not compete with the consumer input process.

informal meetings for both private and public partners to obtain additional input. In Tennessee, attempts to get input from public and private partners were reported to be less extensive than were attempts to get input directly from consumers.

Public and Private Partner Respondents. Nearly all of the respondents indicated that they had provided input in some form or another during the planning process, based on their areas of expertise. However, there was extensive variation in their level of involvement. For example, two respondents indicated that their agencies were not involved at all in the planning process beyond providing assistance regarding Section 8 vouchers. Another stated that his own time constraints prevented him from being directly involved, but that he was given all of the meetings' minutes and encouraged to provide feedback. His agency also supplied a letter of support, as did others for other grants. Many of the respondents noted that their agencies had a long history of collaboration with the lead agencies.

Some States reported barriers to public and private participation in the planning process, citing difficulty scheduling meetings, and the threat of a government shutdown due to budget shortfalls.

The Governor's Council in Alaska, although not the lead agency for the Systems Change Grant, was the lead agency for the Starter Grant. In this capacity, the Council was responsible for convening a community task force, soliciting input about goals and objectives, providing travel money and PAS for Consumer Task Force members and obtaining Grant application writing assistance from the University of Alaska Center on Developmental Disabilities. Some of the respondents also wrote substantial portions of the Grant applications.

3.8 BARRIERS TO PUBLIC AND PRIVATE PARTNER PARTICIPATION IN PLANNING

Lead Agency Respondents. Four of the eight respondents reported no barriers or difficulties in obtaining input from and participation by public and private entities.¹¹ The respondent in Nevada said that "everyone was really interested in giving as much input as possible and in seeing the project move forward." In the remaining four States, respondents reported barriers that ranged from time constraints caused by Grant application deadlines, to difficulties in scheduling meetings that all public and private representatives could attend, to the threat of a State

government shutdown due to budget shortfalls. The Tennessee respondent reported that the only barrier to public and private involvement related to a lack of a common understanding of terminology and language surrounding mental illness, mental health and disability. To overcome this barrier, the State helped arrange consumer testimony and showed an educational video at the initial task force meeting and at each of the direct outreach meetings.

Public and Private Partner Respondents. More than one-fourth of the 20 public and private partner respondents unequivocally stated that there were no barriers or difficulties in establishing a public-private partnership with the lead agency. As one respondent in Georgia noted, “this was an unusually easy process. The State was very willing to come forward and partner with us. Logistics-wise, it was very easy to... schedule meetings.” Another respondent from Georgia stated that “there is a history of conflict between some of the consumer organizations... (but)... this was probably the FIRST time anything productive came from these parties working together.” Some reported that the partners have worked together in the past, and one noted that these Grant applications were viewed as a “real opportunity.”

In general, among those who indicated that there were a few difficulties in developing partnerships, the most common barriers cited were lack of time, lack of funds, the need for education and adding another layer to the process. According to a small number of respondents, other barriers included competing perspectives and priorities, lack of support for consumers to enable participation, questionable leadership, consumer distrust and skepticism and difficulty obtaining buy-in from other agencies. One respondent noted that, unbeknownst to the division that was ultimately awarded the Grant, another division in the same State agency was preparing a competing application and, upon discovery, refused to coordinate their efforts or collaborate in any way.

3.9 PARTNERSHIP FUNCTIONING

3.9.1 Disagreement among Public and Private Partners in the Planning Process

Lead Agency Respondents. Four of the eight respondents reported no disagreements regarding goals, objectives and activities during the application development process.¹² In Nevada, the lead agency respondent reported few disagreements during the planning process, noting that there had been more disagreements among public and private agencies during the past few years around PAS legislation than during the planning process. The lead agency respondent in Oklahoma reported no disagreements: “We made some modifications, but we really didn’t deviate from the original direction.”

The other four respondents reported varying levels of disagreements about both the process and the content of the Grant applications. One respondent reported that there was a “healthy discussion” about differences of opinions. She also noted that some differences remained due to the problems with the LTC system. “We did not always resolve issues because they reflect problems we have with the system.”

In Colorado, the respondent reported that to avoid any potential disagreements, the agency insisted that the Center on Independent Living, which helped write the NFT-SP Grant, target not only persons with physical disabilities in nursing homes (the organization’s own primary focus) but also people with mental retardation and other developmental disabilities, and people with serious mental illness.

One respondent noted that there were some disagreements among public agencies about who would take the lead for a particular type of Grant. She felt that the consumers actually helped mediate an agreement among competing agencies. Another respondent reported a moderate level of disagreement over what types of activities should be emphasized and how funding should be directed. He felt a quick resolution was reached because the agency emphasized that the partners consider systems change from the perspective of the consumer with “a shift of focus from their own interests to those voiced by consumers.”

Nearly three-quarters of the public and private partner respondents stated that no, or only minor, disagreements arose involving the State and its public and private partners regarding goals, objectives, and activities in the planning process.

Public and Private Partners. Nearly three-fourths of the public and private partner respondents stated that no, or only minor, disagreements arose involving the State and its public and private partners regarding goals, objectives and activities in the planning process.¹³ A few of those respondents explained that some concerns were expressed, and clarification and critical thinking were sometimes required, but that “the process was pretty smooth.”

Others were more critical of the decision-making process, especially with regard to State agency perspectives. One respondent noted that the lead agency had difficulty obtaining buy-in from another State agency and that there was an apparent misunderstanding within that agency about the infrastructure focus of the CPASS Grant application. The issues were resolved at a large meeting, during which there was much feedback and at which all participants agreed, by a hand-vote, to the concepts and goals presented in the Grant application. Another respondent stated that there is much conflict between those who would like to see the LTC system evolve and become more consumer-directed and those who favor an institutional approach.

One respondent complained that the State was more interested in planning than acting but that “they came to a consensus and a workplan that they could all live with was developed. They felt that something was better than nothing.” In one State, “the biggest disagreement was the timeline.” Consumers urged the State to act more quickly and actively than it normally does; in turn, the State educated consumers about the bureaucracy and feasibility of objectives. Eventually, a compromise was reached.

3.9.2 Decision Making on Grant Goals and Activities

Lead Agency Respondents. Four of the nine respondents reported that final decisions regarding the application’s goals, objectives and activities were primarily based on a consensus of the lead agency, consumers and public and private entities or agencies.

In Minnesota, consensus decision-making became possible after stakeholders broadened their perspective: “Folks had to step away from their silos and specific needs and projects to think

In Georgia, the time constraints actually enabled consensus because timely submission of the Grant required it: a time constraint “forces people to move ahead with difficult issues.”

about broad infrastructure change.” In Georgia, the time constraints actually enabled consensus because timely submission of the Grant required it: a time constraint “forces people to move ahead with difficult issues.”

In the remaining five States, the respondents indicated that the lead agency had the final decision-making authority. Even so, in Colorado, Tennessee and West Virginia, respondents felt it was pro forma, given all the discussion and input by stakeholders. For example, in West Virginia, the respondent stated that while the lead agency had the final say, the members had the opportunity to review the changes and give feedback as the agency made changes to the drafts that resulted from task force meetings. In Alaska, the respondent reported that respective program managers reviewed the Grant application to ensure that the goals and activities were practical or “doable”—a process that led to several compromises at the State level.

Public and Private Partners. Concurring with lead agency respondents, many of the public and private partner respondents stated that final decisions regarding the Grant’s goals, objectives and activities were made based on consensus and thoughtful compromise between the lead agencies, consumer partners and the public and private partners. Roughly half of the respondents described consensus-building processes that resulted in general approval for the Grant applications, although some also noted that the final sign-off was made by the lead agencies. However, as a private partner in Tennessee stated, “All were interested in the common good and understood that making sacrifices was necessary.”

Three respondents indicated that they did not know how final decisions were reached among some or all of the stakeholders. In Iowa, “the goals identified by the Consumer Task Force were the ones included in the final application.” In Minnesota, it was noted that the Minnesota Associated Centers for Independent Living “wrote the application and the [RC] Grant writer from the State reviewed and commented on it.” Other respondents commented that although the State made the ultimate decisions, there was so much feedback and input from all of the partners throughout the process that “everyone had a good sense of what the final product would look like before it was written.”

3.10 PERCEPTIONS OF PARTNERSHIP FORMATION AND FUNCTIONING

3.10.1 Influence of Public and Private Partners in the Planning Process

Lead Agencies. While one of the lead agency respondents stated that the agency relied primarily on consumers rather than public and private partners in developing the Grant goals and activities, the remainder of the interviewees indicated that the public and private partners had a great deal of influence. For example, as reported earlier, in Colorado, an ILC took the lead in putting together the NFT-SP Grant, the only Systems Change application that was awarded to that State. In many other States, public and private partners were used as sounding boards for application ideas.

Public and private partners had a great deal of influence in the planning process.

There was no consensus among the lead agency respondents in regard to whether working with other public and private organizations made the Grant development process easier or more difficult. In addition, three responses were vague and lacked specificity,

despite probing. Some lead agency representatives felt that their participation made the process much easier because they shared the workload and provided a broader perspective and more expertise. Two of the interviewees stated that public and private partner involvement made some tasks difficult and others easier. Their rationale was that it took more time and energy to bring everyone together but that the sharing of ideas and perspectives led to a more productive, involved and informed team. The one respondent who found the participation of the public and private partners to be cumbersome noted the logistical problems associated with convening meetings involving all of the many partners and the difficulty in keeping interest levels high.

Public and private partners made the process much easier because they shared the workload and provided a broader perspective and more expertise.

Public and Private Partners. Three-fourths of the public and private partner respondents believed that they influenced the Grant's goals, objectives and planned activities. Of those who did not perceive themselves or their organizations as being influential, it was indicated that although they share similar philosophies with

the lead agencies, they did not play a large part in the planning process. Many judged the level of their influence by whether their recommendations were used in the final Grant application. Others, such as a private partner in Iowa who conducted the public meetings, affected the process by acting as a facilitator between the consumers and the State agency representatives.

About half of the public and private partner respondents thought that their involvement made the Grant development process easier. Of these, a few noted that their participation signified buy-in, provided input and expertise, lessened the workload for each entity involved and lent “an element of support and legitimacy to the whole process.” As one respondent in Alaska commented, “including [partners] meant no surprises. We had consensus.”

Approximately one-fourth of the respondents cited specific difficulties that such partnerships created. One noted that it made the Grant development process more time consuming and “wasn’t always a feel-good situation.” Another challenge was educating everyone about the process itself as well as trying to reach agreement across many diverse views.

A large majority of the public and private partner respondents were satisfied with their role in the planning process.

A large majority of the public and private partner respondents were satisfied with their role in the planning process. Many stated that they could not have had a larger role, either because their participation was already so great or because they did not have the time to do more. As a public partner in Nevada stated, “I think we were involved as much as we wanted and needed to be.” Of the two respondents who felt that their roles were not large enough, one stated that he has “no regrets because I think (the Grant application) encompasses good services and is in the right spirit.” The other thought her involvement was appropriate even if it did not satisfy her desire to participate more.

3.10.2 Public and Private Partner Satisfaction with the Planning Process

Lead Agency Respondents. When asked what they would do differently if they had to repeat the planning process, respondents had diverse views. Five stated that they would try to get more input from consumers and other stakeholders. One lead agency respondent specifically noted that the State should “probably go out more to the rural areas.” Other suggestions included

improving Grant application support and improving coordination with and involvement of other government agencies. One respondent said that the State would not do anything differently.

Public and Private Partners. All of the public and private partners who were involved in the planning process were satisfied with their opportunities to provide input and be involved. As one private partner noted, "...the lead agency was very open to ideas from the whole team and the community." This opinion was echoed by a few other respondents. About one-fourth of the respondents stated that their own time constraints, rather than lack of opportunities provided by the lead agency, prevented them from being as involved as much as they may have liked.

When asked for recommendations for the lead agency if the planning process were repeated, more than one-fourth of the public and private partner respondents had none. Many respondents felt that applying for a Grant can be an extremely difficult process, especially with so many partners, but that the lead agencies had done a good job.

Two other public and private partner respondents stated that a professional facilitator is needed with so many diverse constituencies at the table. One suggested that this be "someone who could skillfully help all those people stay at the table until the end," and another said that it should be "someone outside of government... someone from the corporate world with conflict resolution experience." Two respondents in Iowa noted that partnership development should be an ongoing activity and "shouldn't just be done for projects." Other public and private respondent recommendations include the following:

- Z allowing more lead time so that everyone has the opportunity to participate;
- Z viewing the partners as "experts" and using their knowledge, as well as involving the partners more in Grant implementation;
- Z facilitating greater involvement by holding meetings in various regions of the State;
- Z involving providers more but balancing their perspectives with consumer viewpoints; and
- Z going outside of the disability community for partners and collaborating more with existing systems.

Many respondents felt that applying for a Grant can be an extremely difficult process, especially with so many partners, but that the lead agencies had done a good job.

Next Steps

4

This is the second in a series of reports that we will prepare as part of a CMS-funded implementation evaluation. As stated in the Introduction section of this report, an implementation evaluation is designed to document the progress of projects and help Grantees to identify solutions to problems encountered during project implementation.

Among the reports we prepare will be annual reports based on Grantees' semiannual and annual reports, which will describe Grantee activities during each year of the Grant period. Based on the Grantees' reports, we will determine whether there are State-specific factors that present barriers to, or a favorable environment for, bringing about systems change. In the case of barriers, we will identify areas where technical assistance may be indicated to help overcome the barriers.

In addition to annual reports, we will also prepare topic papers that focus on specific issues that Grantees are addressing, such as workforce recruitment and retention. The topic papers will provide an overview of activities that Grantees have undertaken during the Grant period to address specific issues and present case studies illustrating effective approaches.

Appendix

Grantees by Grant Type
and State

Communication with
Grantees and
Their Partners

List of States with 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	NEBRASKA
ARKANSAS	NEW HAMPSHIRE
DELAWARE	NEW JERSEY
FLORIDA	NORTH CAROLINA
GUAM	OREGON
HAWAII	SOUTH CAROLINA
IDAHO	TENNESSEE
ILLINOIS	VERMONT
IOWA	VIRGINIA
KENTUCKY	
MAINE	
MARYLAND	
MASSACHUSETTS	
MICHIGAN	
MINNESOTA	
MISSOURI	

List of States with Grants, in Alphabetical Order

ALABAMA (NFT-ILP)
ALABAMA (RC)
ALASKA (C-PASS)
ALASKA (NFT-SP)
ARKANSAS (C-PASS)
ARKANSAS (RC)
COLORADO (NFT-SP)
CONNECTICUT (NFT-SP)
DELAWARE (RC)
FLORIDA (RC)
GEORGIA (NFT-ILP)
GEORGIA (NFT-SP)
GUAM (C-PASS)
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 (C-PASS)
MICHIGAN (RC)
MINNESOTA (C-PASS)
MINNESOTA (RC)
MISSOURI (RC)
MONTANA (C-PASS)
NEBRASKA (RC)
NEVADA (C-PASS)
NEW HAMPSHIRE (C-PASS)
NEW HAMPSHIRE (NFT-SP)
NEW HAMPSHIRE (RC)
NEW JERSEY (RC)
NORTH CAROLINA (RC)
OKLAHOMA (C-PASS)
OREGON (RC)
RHODE ISLAND (C-PASS)
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)

Script (Including Informed Consent Information) for Telephone Interviews with Consumers

(Staff will introduce themselves at the beginning of the phone interview.)

Thank you for talking with us today about the role you (or your organization) played in preparing your state's Systems Change grant application. Before we begin, I would like to share with you some information about the interviews we are conducting and how the resulting information will be used.

These interviews are part of RTI's effort to help CMS identify the role that you played in writing your state's Systems Change grant application. Our purpose today is to explore that role using the questions we sent you earlier as a guide, so that we can understand the ways you found to work together with the state on this proposal effort. We plan to use the information we obtain to develop a report for CMS on the different levels of participation that consumers and public and private organizations experienced in preparing these applications.

We have scheduled about 5 interviews over the next month with consumers and organizations in your state that helped develop the state's application. We will be conducting almost 50 interviews across 5 states to complete our report. You have been identified by the person in charge of the Systems Change grant at the state office as someone whose viewpoints of how the application was developed are important to understand.

This interview should take about an hour. Your participation in this interview is purely voluntary, and your responses will be kept strictly confidential. If you want to stop the interview at any time, just let me know. In addition, you are free to decline to answer any questions during the interview. Your decision to participate will not affect any benefits to which you are entitled, nor will it affect any relationship you have with the state.

The information that you provide will be combined with the data collected in interviews with numerous other individuals. CMS will share the results of our interviews with all the interviewees and the general public by posting our report on a website that contains information on Systems Change activities in all states.

If you have any questions about the research study after we have completed our interview, feel free to contact the project's data collection task leader, Dr. Wayne Anderson, at 800-647-9657. If you have any questions about your rights as a study participant, you can call RTI's Office of Research Protection at 1-866-214-2043 (a toll-free number).

Do you have any questions before we start?

Discussion Guide for Study of Partnership Development

Lead Agency (Interviewer) Protocol

1. Did you receive a CMS \$50,000 Real Choice starter grant or a Robert Wood Johnson Olmstead planning grant?
2. [If yes] How was the money used? Would you please furnish us with a copy of the report you submitted to CMS (final or interim)?

Consumer Participation

The first set of questions relate only to consumer participation.

3. What methods did you use to enable consumers and their representatives to participate in the proposal development process? [*Probe: Subcommittee of existing Olmstead group? A new consumer task force or advisory board? Public Hearings? Focus groups?*]
4. Why did you choose these methods? [*Probe: Method used for establishing Olmstead group?*]
5. How did you assure that a broad range of consumers with different types of disabilities or long-term illnesses (and their representatives) participated in the proposal development process? [*Probe: Base decision on demographic information? Experience with population? Referrals?*]
6. What methods of obtaining their participation worked particularly well? [*Probe: Round table discussions? Informal communication? Liaison from lead agency appointed to work with consumers?*]
7. What resources or accommodations, if any, did you provide to ensure their input? [*Probe: Funds for transportation expenses; sign language interpreters; personal care assistants; honorarium?*]
8. Were there any barriers or difficulties you encountered in seeking and obtaining their participation? [*Probe: For example, not understanding the structure of the LTC system or its limitations.*]
9. What disagreements, if any, among consumers and their representatives arose regarding the selection of goals and activities, and how were they resolved?
10. To what extent did their input influence the proposal's goals and activities?
11. Do you feel that having consumers and their representatives participate made the proposal development process easier or more difficult? Both? In what way?

12. Do you believe that the consumers and their representatives were satisfied with the process and the opportunities they were given to participate? [*Probe: Positive feedback? Good rapport established?*]
13. Do you think consumers and their representatives should have had a larger role in the proposal development process?
14. If you had to repeat the process again, what would you do differently to assure or increase the participation of consumers and their representatives? [*Probe: Involve consumers earlier? Appoint liaison to work with consumer group? Use different methods to identify consumers to work with?*]

Private and Public Partnerships

The next set of questions relates only to public and private entities and organizations.

15. What process was used to determine which public and private entities would partner with the lead agency in the planning and proposal development work, as well as during the implementation phase? [*Probe: Prior working/collaborative relationship established?*]
16. What methods for working with these entities in the proposal development process were selected? [*Probe: Formal work groups? Informal communications Formal review process?*]
17. What methods worked particularly well?
18. Were there any barriers or difficulties in obtaining input from and participation by public and private entities? [*Probe: Scheduling conflicts? Differing organizational mission/philosophy?*]
19. What disagreements, if any, regarding goals, objectives, and activities arose during the proposal development process and how were they resolved ?
20. To what extent did their input influence the proposal's goals and activities?
21. How were final decisions made regarding the proposal's goals, objectives and activities? [*Probe: Majority? Consensus? Approval by lead agency?*]
22. Do you think that working with other public and private organizations made the proposal development process easier or more difficult? Both? In what way?
23. If you had to repeat the process again, what would you do differently to develop and maintain partnerships with public and private entities?

Discussion Guide for Study of Partnership Development

Public / Private Partner Protocol

1. How was your agency/organization involved in the proposal development process?
[Probe: participated in one-on-one meetings, open-forums, round table discussion?]
2. How was your agency/organization solicited by the lead agency for participation in the proposal development process?
3. Were there any barriers or difficulties in establishing a private/public partnership with the state? *[Probe: Scheduling conflicts? Differing organizational mission/philosophy?]*
4. What disagreements, if any, arose involving the state and its public/private partners regarding goals, objectives and activities in the proposal development process, and how were they resolved?
5. How were final decisions made regarding the proposal's goals, objectives and activities?
[Probe: Majority? Consensus? Approval by lead agency?]
6. Were you satisfied with your opportunities to provide input and be involved in the proposal development process? If not, why not?
7. To what extent do you believe that you influenced the proposal's goals, objectives and planned activities?
8. To what extent do you believe *consumers'* input influenced the proposal's goals, objectives and planned activities?
9. Do you think that involving public/private partners made the proposal development process easier or more difficult? Both? In what way?
10. Do you feel that obtaining input from consumers and involving consumers made the proposal development process easier or more difficult? Both? In what way?
11. Do you think you should have had a larger role in the proposal development process?
12. If you had to repeat the process again, what recommendations would you give the lead agency regarding establishing public/private partnerships and working with public/private partners?

Discussion Guide for Study of Partnership Development

Consumer Protocol

1. How did you participate in the proposal development process? [*Probe: participated in open-forums, round table discussion, task force member?*]
2. Were there any barriers or difficulties you encountered when participating in the process? [*Probe: New to the process? Unable to attend meetings?*]
3. Were you given any accommodations or other resources that helped you to participate? [*Probe: Funds for transportation expenses; sign language interpreters; personal care attendant; honorarium?*]
4. Were you satisfied with your opportunities to participate in the proposal development process? If not, why not?
5. Do you feel that there was adequate input from consumers in the target population(s) to be served by the grant? [*Probe: People with severe mental or physical disabilities represented?*]
6. What disagreements arose among consumers (if any) about grant goals and activities, and how were they resolved?
7. How were final decisions made regarding the proposal's goals and activities? [*Probe: Majority? Consensus? Approval by lead agency?*]
8. Do you think your input was used in deciding the goals and activities?
9. Were you satisfied with the final goals and activities?
10. If the state were to go through the same process again, what recommendations would you give them for assuring consumer participation?

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-14-26
Baltimore, Maryland 21244-1850



Center for Medicaid and State Operations
Disabled and Elderly Health Programs Group (DEHPG)

March 20, 2002

Dear _____:

As you know, formative research is an integral component of the Systems Change Grant Project. Our Research Contractor, RTI, will be preparing several reports for CMS throughout the three-year grant period, the first of which will be due shortly after the Systems Change Conference.

This first report will present a comparative analysis of the 52 Systems Change Grantees. In addition, it will provide a description of consumer and stakeholder involvement in the development of the grant application process and the implementation of grant activities.

To perform the comparative analysis, RTI has summarized key information from each Grantee's application and the two-page Compendium form you recently completed. Because many Grantees revised their original scope of work once the awards were made, some of the activities proposed in the original applications may no longer be included in the final scope of work. ***Because the information in RTI's grant summaries will be used as baseline data for the initial comparative analysis and all future research activities, it is essential that you review the summary of your grant to assure its accuracy and completeness.***

Sometime in the next few days, RTI will send you a 5-6 page summary of your grant, with a request that you carefully review it to assure that it is accurate and complete. You will also be asked to clarify RTI's description of the grant's key activities as well as your partnerships with consumers, and private and public entities. In a few instances, you may be asked to supply additional information in order to clarify or complete the summary.

We appreciate your timely participation in helping RTI prepare an accurate and valuable report. When published, later this summer, the report will be available on the CMS Systems Change website and RTI's website.

Thank you again for your cooperation and continued endeavors to make lasting improvements in the delivery of long term care services and supports.

Yours truly,

Thomas E. Hamilton
Director

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-14-26
Baltimore, Maryland 21244-1850



Center for Medicaid and State Operations
Disabled and Elderly Health Programs Group (DEHPG)

March 15, 2002

Dear _____:

As you are aware, CMS has contracted with RTI to assist us in conducting formative research on the Systems Change Grants for Community Living. The RTI Research Team for the Systems Change Grants is currently in the process of preparing a report for CMS, Systems Change Grantees and other interested parties on Consumer and Stakeholder participation in the Systems Change Grants.

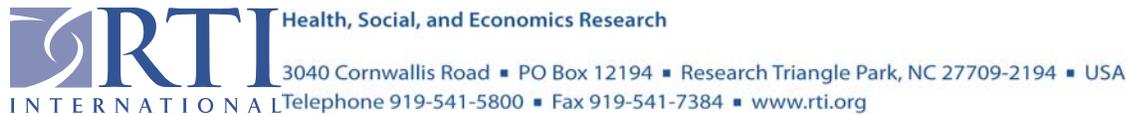
RTI has reviewed all of the applications from the 52 Systems Change for Community Living Grantees to identify those who used unique or exemplary practices to assure consumer input and involvement in the application development process. Your state is one of nine states that has been selected for this effort. Therefore, we have asked RTI to gather more in-depth information about your consumer and stakeholder involvement process to include in this report.

Someone from RTI will be contacting you the week of March 18th to set up a convenient time to conduct a telephone interview, and to obtain your assistance in identifying three partners (consumers, private partners and public partners) to be interviewed about their involvement in the development of your application.

The RTI Report is due to CMS in April, so your timely participation is much appreciated. Your fellow Grantees and others are looking forward to RTI's report to learn more about your consumer and stakeholder involvement activities. When published this summer, the report will be available on RTI's and CMS' web site.

Yours truly,

Thomas E. Hamilton
Director



Dear _____,

The Centers for Medicare and Medicaid Services is sponsoring a project to study the partnership development process used by grantees to prepare their proposals for a Systems Change grant. The grantee in **STATE** gave us your name as someone who would have firsthand knowledge of the proposal preparation process for your state. The purpose of this letter is to request your participation in an interview about your experiences with the process.

Staff from RTI, a non-profit research organization in North Carolina, will conduct the interview by phone and will contact you shortly to schedule an interview. The interviewer will ask questions about your role in setting goals and objectives for the grant, whether you were involved in the process in ways that allowed you the amount of participation you wanted, whether you feel you were able to influence the development of goals and activities, and whether there is a role for you in the actual project implementation phase. A copy of the interview questions is included with this letter. Participation in the interview will last about an hour.

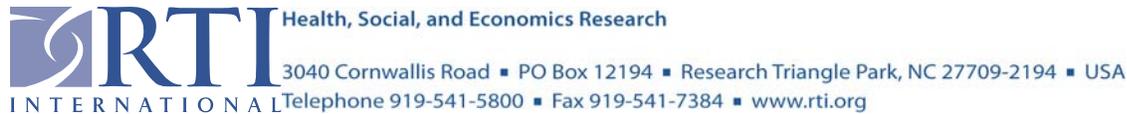
We will summarize the information we collect and prepare a report of our findings. We will identify the findings only by state. Your name will not be specifically linked to anything that you tell us. All information you and the other participants provide is protected by the Privacy Act, and will be kept strictly confidential.

Please call **800-XXX-XXXX and press X** for the interviewer assigned to your state. We will set up a time to talk that works best for you.

If you have any questions about the study, please call Dr. Wayne Anderson of RTI at 1-800-647-9657 or Ms. Mary Fran Laverdure of CMS (1-410-786-0119). If you have any questions about your rights as a study participant, you can call RTI's Office of Research Protection at 1-866-214-2043 (a toll-free number). Thank you for your cooperation.

Sincerely,

Janet O'Keeffe



Dear **INSERT NAME**:

The Centers for Medicare and Medicaid Services is sponsoring a project to study the partnership development process used by grantees to prepare their proposals for a Systems Change grant. The grantee in **STATE** gave us your name as someone who would have firsthand knowledge of the proposal preparation process for your state. The purpose of this letter is to request your participation in an interview about your experiences with the process.

Staff from RTI, a non-profit research organization in North Carolina, will conduct the interview by phone and will contact you shortly to schedule an interview. The interviewer will ask questions about your role in setting goals and objectives for the grant, whether you were involved in the process in ways that allowed you the amount of participation you wanted, whether you feel you were able to influence the development of goals and activities, and whether there is a role for you in the actual project implementation phase. A copy of the interview questions is included with this letter. Participation in the interview will last about an hour.

You do not have to participate in this study and you do not have to give us the name of anyone else to interview. Your decision to participate will not have any effect on any benefits or services for which you are entitled, nor will it affect your employment status. We will summarize the information we collect and prepare a report of our findings. We will identify the findings only by state. Your name will not be specifically linked to anything that you tell us. All information you and the other participants provide is protected by the Privacy Act, and will be kept strictly confidential.

If you would like to participate in our study, please call **800-XXX-XXXX and press X** for the interviewer assigned to your state. We will set up a time to talk that works best for you. If you do *not* want to be interviewed, we would appreciate your calling us to let us know, and to suggest other people who were involved in the grant preparation process who might be interested in talking with us.

If you have any questions about the study, please call Dr. Wayne Anderson of RTI at 1-800-647-9657 or Ms. Mary Fran Laverdure of CMS (1-410-786-0119). If you have any questions about your rights as a study participant, you can call RTI's Office of Research Protection at 1-866-214-2043 (a toll-free number). Thank you for your cooperation.

Sincerely,

Janet O'Keeffe

ENDNOTES

¹CMS State Medicaid Director Letter (SMDL #01-007), New Tools for States, January 10, 2001.

²Detailed information about each Grantee, including partnership involvement in planning activities, was provided to CMS in a separate document.

³In 1999, the Supreme Court ruled in the *Olmstead* decision that it is a violation of the Americans with Disabilities Act for States to discriminate against people with disabilities by providing services in institutions when the individual could be served more appropriately in a community setting. Many States have responded to this decision by setting up *Olmstead* advisory or planning groups, or task forces. The general purpose of these entities is to develop comprehensive plans to allow individuals to receive services in the least restrictive setting.

⁴A few States indicated in their application narrative that consumers wrote letters of support. However, because letters of support were included in an appendix to some Grant applications, other States might also have had letters of support from consumers but not stated so in the narrative section of their applications.

⁵More than half (56 percent) of Area Agencies on Aging function as public agencies on the local government level, while 44 percent function as private nonprofits (Source: National Association of Area Agencies on Aging, personal communication with K.J. Hertz). In this paper, we include them as public partners.

⁶Personal assistance workers are also referred to as direct care workers. In this report, we use the former term.

⁷The Institute is an independent, nonpartisan research and policy institute that studies current issues involving the overlap of health care, social supports and the law in New Hampshire.

⁸To help ensure a 100 percent response rate, CMS Director of the Disabled and Elderly Health Programs Group, Thomas Hamilton, sent a letter to each of the nine Grantees explaining the importance of the research effort and encouraging their participation.

⁹Staff conducted one additional interview using the lead agency protocol. This additional interview was conducted because the current lead agency contact in Georgia had not participated in the lead agency's planning activities. Therefore, the lead agency contact recommended that we interview the person who had led the agency's planning process, which we did, and we included those responses in our analysis and findings for this report.

¹⁰Three of the nine Grantees did not indicate how the funds were spent.

¹¹One respondent did not answer this question.

¹²One respondent did not answer this question.

¹³One respondent did not answer this question.