



September 2002

Goals, Objectives and Activities: Comparative Analysis of FY 2001 Systems Change Grantees

Wayne Anderson, Ph.D.
Janet O'Keeffe, Dr.P.H.

Submitted to

Mary Fran Laverdure
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-14-26
Baltimore, MD 21244-1850

Submitted by

Janet O'Keeffe, Project Director
RTI
Health, Social, and Economics Research
Research Triangle Park, NC 27709

Contract Number 500-00-0044, Task Order 2
RTI Project Number 7959.002

Contents

Acronym List	vii
Executive Summary	ES-1
ES.1 Introduction	ES-1
ES.2 Data and Analytic Approach.....	ES-2
ES.3 Findings.....	ES-3
ES.3.1 LTC System Strengths	ES-3
ES.3.2 Barriers and Challenges	ES-3
ES.3.3 Goals	ES-4
ES.4 Next Steps.....	ES-5
1. Introduction	1-1
1.1 Background	1-1
1.2 Context for the Report.....	1-2
1.3 Purpose of the Report	1-2
1.4 Organization of the Report.....	1-2
2. Data and Methods	2-1
2.1 Data Sources	2-1
2.2 Analytic Approach	2-2
2.3 Limitations of the Analysis.....	2-3
3. Organization of Findings	3-1

4.	Real Choice Systems Change Grants	4-1
4.1	LTC System Strengths	4-1
4.2	Challenges and Barriers.....	4-2
4.3	Goals, Objectives and Activities.....	4-3
4.3.1	Information, Referral, Assessment and Outreach.....	4-3
4.3.2	Education and Advocacy	4-4
4.3.3	Workforce Recruitment, Retention and Training	4-5
4.3.4	Personal Assistance Services and Supports.....	4-6
4.3.5	Consumer Direction, Choice and Control.....	4-7
4.3.6	Nursing Facility Transitions and Diversions	4-7
4.3.7	Policy, Planning and Management.....	4-8
4.3.8	Quality Assurance and Improvement	4-8
4.3.9	Housing	4-9
4.3.10	Person-Centered Planning	4-10
4.3.11	Interagency Coordination	4-11
4.3.12	Assistive Technology.....	4-11
4.3.13	Research	4-12
4.3.14	Waiver Program Improvement and Additional Waivers.....	4-12
5.	Nursing Facility Transition Grants	5-1
5.1	LTC System Strengths	5-2
5.2	Challenges and Barriers.....	5-2
5.3	Goals, Objectives and Activities.....	5-3
5.3.1	Information, Referral, Assessment and Outreach.....	5-3
5.3.2	Education and Advocacy	5-4
5.3.3	Workforce Recruitment, Retention and Training	5-4
5.3.4	Personal Assistance Services and Supports.....	5-5
5.3.5	Policy, Planning and Management.....	5-5
5.3.6	Housing	5-6
5.3.7	Person-Centered Planning	5-6
5.3.8	Interagency Coordination	5-7
5.3.9	Assistive Technology.....	5-7
5.3.10	Research	5-7

5.3.11	Waiver Program Improvement and Additional Waivers.....	5-8
6.	Community-Integrated Personal Assistance Services and Supports Grants	6-1
6.1	LTC System Strengths	6-1
6.2	Challenges and Barriers.....	6-2
6.3	Goals, Objectives and Activities.....	6-3
6.3.1	Information, Referral, Assessment and Outreach.....	6-3
6.3.2	Education and Advocacy	6-3
6.3.3	Workforce Recruitment, Retention and Training	6-3
6.3.4	Personal Assistance Services and Supports.....	6-4
6.3.5	Consumer Direction, Choice and Control.....	6-5
6.3.6	Policy, Planning and Management.....	6-6
6.3.7	Quality Assurance and Improvement	6-6
6.3.8	Interagency Coordination	6-7
6.3.9	Assistive Technology.....	6-7
7.	Next Steps	7-1
	Endnotes	E-1
	Appendix	A-1

Exhibit

Exhibit 3-1. Distribution of Grantees by Type of Grant and
Issues to be Addressed by Grant Activities.....3-3

Acronym List

AAA	Area Agencies on Aging
AT	assistive technology
CIL	Center for Independent Living
CIPS	consumer-initiated partnership and support
CMS	Centers for Medicare and Medicaid Services
CPASS	Community-Integrated Personal Assistance Services and Supports
FY	fiscal year
HCBS	home and community-based services
HUD	Housing and Urban Development
I&R	information and referral
ILC	Independent Living Center
ILP	Independent Living Partnership
LTC	long-term care
NFT	Nursing Facility Transition
PAS	personal assistance services
RC	Real Choice
SHS	Seniors Helping Seniors
SP	State Program

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.

The purpose of this initial report is to compare and contrast the fiscal year (FY) 2001 Systems Change Grantees' goals and planned activities as identified in their Grant applications submitted to CMS. This initial report provides a summary of the goals of the 52 FY 2001 Systems Change Grantees and representative examples of the various activities they plan to implement to help them achieve these goals. In addition, the report includes a summary of States' views of the strengths of, and challenges and barriers in, their LTC systems. In essence, the report provides a cross-sectional snapshot of what the initial 52 Systems Change Grants projects are attempting to achieve.

ES.2 DATA AND ANALYTIC APPROACH

Our principal source of data was the narrative sections of the Systems Change Grant applications for the 52 Grantees. Due to the overwhelming response CMS received to the solicitation (161 applications requesting \$240 million in funding from 48 States, the District of Columbia and Guam), all of the Grantees received less funding than originally requested. Each Grantee was then requested to revise the scope of their Grant projects 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 description of their activities and other information about their Grants. These six- to eight-page Grant summaries approved by the Grantees became the primary source of data for our analysis.

The information in the summaries that we used for this report are as follows: the LTC system strengths and challenges identified by each Grantee and Grantees' goals, objectives and related activities. We synthesized the information in these categories across the three types of Grants (RC, NFT and CPASS). We reviewed all of the goals and objectives listed in the summaries and identified 14 issues that the Grantees plan to address. For each issue identified, we then listed the major activities that Grantees will undertake relative to the issue. Due to space

limitations, we did not include every activity listed by every Grantee, but we did include a range of representative activities.

ES.3 FINDINGS

ES.3.1 LTC System Strengths

The Grantees identified a variety of strengths in their State LTC systems, many of which will support or enable Grant activities. Almost all Grantees identified multiple Medicaid waiver programs serving a range of people with disabilities. A large number identified strong, active participation in advocacy activities by disability-specific organizations, consumers and their families. Often, Grantees identified a commitment to or movement towards reducing the number of persons with disabilities served in institutional settings. Some also noted having consumer-directed personal assistance services (PAS) programs or programs that support the principle of person-centered planning. Some of the Grantees have previous experience with de-institutionalization programs.

ES.3.2 Barriers and Challenges

The Grantees also identified the barriers and challenges they face in their attempts to help people with disabilities live more independent lives. Many of the same problems were reported across all States and disability populations. The barriers include all those problems faced by consumers in nursing facilities who want to transition to the community as well as the barriers to remaining in the community once transitioned. Consumers face a lack of options for choosing, planning and directing their services and an institutional bias in service funding. Consumers and providers also need education and training about consumer direction and self-advocacy.

Frequently noted barriers were the critical shortage of accessible, affordable housing and problems with recruiting, retaining and training personal care assistants. Other challenges noted were a lack of accountability in service provision and the need for quality assurance systems. Some Grantees also noted that consumers in their States had not previously been given direct opportunities

to become leaders in designing, developing or evaluating policies and programs.

ES.3.3 Goals

Most Grantees specified goals to address several challenges and barriers. CMS asked Grantees to develop goals and objectives that focused on four areas: access to, availability of, quality of and value of services. CMS, in the *Coordinated Invitation to Apply for Systems Change Grants for Community Living*, defined these areas as follows:¹

- Z *Access*: To what extent are long-term support systems simple, understandable, comprehensive, flexible and fair and provide the right information, timely access and community participation?
- Z *Availability/Adequacy*: To what extent can we ensure that services are adequate in terms of the amount available, the type and scope of services and the time period or frequency of services?
- Z *Quality*: To what extent can one ensure that services achieve the outcomes desired and are provided in a manner that meets with the consumer's expectations and preferences? To what extent can we ensure that there exists an effective quality assurance and improvement system?
- Z *Value*: To what extent can we ensure that investments in services yield the highest value in terms of the service, individual and community?

Most of the Grantees chose goals addressing access to and availability of services, while fewer Grantees chose goals related to quality or value.

The 14 issues we identified when reviewing all Grantee goals are listed below, followed by the number of Grantees focusing on them.

- Z Information, Referral, Assessment and Outreach (27)
- Z Education and Advocacy (22)
- Z Workforce Recruitment, Retention and Training (20)
- Z Personal Assistance Services and Supports (19)
- Z Consumer Direction, Choice and Control (18)
- Z Nursing Facility Transitions and Diversions (18)
- Z Policy, Planning and Management (17)

- Z Quality Assurance and Improvement (17)
- Z Housing (16)
- Z Person-Centered Planning (13)
- Z Interagency Coordination (12)
- Z Assistive Technology (AT) (7)
- Z Research (7)
- Z Home and Community-Based Services (HCBS)² Waiver Program Improvement and Development of Additional Waivers (6).

States considering the issue of Personal Assistance Services and Supports above did not explicitly mention Consumer Direction, Choice and Control as part of their focus, so these two groups were separated so that this specific element was tracked in our analysis. Person-Centered Planning is conducted by State agencies or other organizations, as opposed to being conducted by consumers.

All three types of Grantees are addressing many of the issues, but the number of Grantees focusing on each issue varies across the types of Grants, due in part to the focus specified in CMS's solicitation document. For example, primarily only NFT Grantees focus on activities related to Nursing Facility Transitions and Diversions. Grantees are employing many different activities to address these issues, but there are some commonalities in approaches as well.

ES.4 NEXT STEPS

This is the first 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' semi-annual 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

a particular issue and will present case studies illustrating 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.

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 the same month.

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 conjunction 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.

The first step in an implementation evaluation is to clearly describe the goals and activities that will be used to determine progress and accomplishments. While this information is needed to determine the progress of individual Grantees, it is also desirable to have summary information for all of the Grants together to obtain a larger picture of what the entire Grants project is attempting to achieve. This report provides such a summary.

1.3 PURPOSE OF THE REPORT

The purpose of this report is to compare and contrast the fiscal year (FY) 2001 Systems Change Grantees' goals and planned activities.

1.4 ORGANIZATION OF THE REPORT

Section 2 describes our data sources and our analytic approach. Section 3 discusses how our findings are organized. Sections 4, 5 and 6 present the findings for each of the three types of Grant. Section 7 discusses next steps in the implementation evaluation.

Data and Methods

2.1 DATA SOURCES

Our original source of data was the narrative sections of the Systems Change for Community Living Grant applications for the 52 Grantees. In fiscal year (FY) 2001, CMS made a decision based upon an overwhelming response to the solicitation to fund more Grants than originally anticipated. Therefore, when the Grant awards were made, all but one of the Grantees received a lower amount of funding than they had originally requested. CMS required the Grantees to make any necessary changes to the original proposed scope of work (described in terms of goals, objectives and activities) to match the amount of the Grant award and to submit a revised budget.

An additional source of information we used about Grantees' goals and objectives was the *Compendium of Systems Change Grants for Community Living*.³ The *Compendium* includes a list of key goals and activities and a brief abstract that describes the project. The *Compendium* was prepared after the awards were made and contained more current information about goals and activities than did the original applications. However, because the *Compendium* contained limited information on each Grant, a more comprehensive source of information was needed.

Consequently, to assure that we had the most current and complete information for the analysis, we extracted information about goals and activities from the original applications, compared it to the information in the *Compendium*, noted discrepancies and

had each Grantee confirm the accuracy of our summary description of their activities and other information about their Grant. These Grant summaries approved by the Grantees are the primary source of data for our analysis.

2.2 ANALYTIC APPROACH

As a first step, we briefly reviewed each Grant application to determine the primary issues that the Grantees planned to address. After identifying an initial set of issues that had sufficient variance to identify distinct groups of Grantees for analytic purposes, Grantees were divided among the research team for follow up into eight groups of approximately six to eight Grantees.⁴

For each of these groups, we reviewed and summarized the information in the original application and the *Compendium*. The primary purpose for preparing the summaries was to reduce the large volume of information about each Grantee to a more concise and manageable form for analysis.

We developed a master template with 17 information categories to guide our review and the preparation of a six- to eight-page summary of each Grant application. We used information from the following categories to develop this report:

- Z the long-term care (LTC) system strengths identified by each Grantee;
- Z the LTC system barriers identified by each Grantee;
- Z the goals and objectives of each Grant; and
- Z related Grant activities.⁵

After completing summaries for each Grant, we sent them to the lead contact for each Grant for review. We included questions in the summaries that asked Grantees to clarify specific information in their applications. Grantees were also asked to review the content and make changes as needed to ensure accuracy and completeness. Grantees' comments and edits were then incorporated into the final Grant summaries.

We then synthesized the information in the categories that this report examines across the identified issue groups. We next drew from this synthesis to list the LTC system strengths, challenges and barriers identified by Grantees for each of the three types of

Systems Change Grants (i.e., Real Choice [RC], Nursing Facility Transition [NFT] and Community-Integrated Personal Assistance Services and Supports [CPASS]).

For the next step, all goals listed in each synthesis were read through serially and a heading was created for each new issue that was identified, for a total of 14 distinct issues. We then coded all the goals/objectives listed in the synthesis according to the 14 issues (See Exhibit 3-1).

For each issue identified, we then listed the major activities that Grantees plan to initiate to achieve their goals. Due to space limitations, we did not include every activity listed by every Grantee, but we did include a range of representative activities.

2.3 LIMITATIONS OF THE ANALYSIS

Our intent in this report is to compare and contrast all of the Grantees' goals and activities. Our analysis is subject to the limitations of the data and the analytic methods used. Some of the specific limitations in this analysis are as follows:

- Z The accuracy of the data we used is dependent on the thoroughness of each Grantee's review of the Grant summaries we prepared.
- Z The abstraction process we used to reduce the large volume of information about each Grantee to a more concise and manageable form, of necessity, reduced the amount of detail provided in the original applications. The issues we identified may not cover all activities mentioned by Grantees.
- Z In each step of the abstraction process, we exercised judgment to determine the key points to include. Consequently, our analysis may not contain some information that Grantees consider important.
- Z In particular cases, we exercised judgment in deciding the goals, objectives and activities that were linked to particular issues.

Organization of Findings

3

The next three sections will present our findings, one for each type of Grant: Real Choice Systems Change (RC); Nursing Facility Transition (NFT), both NFT-State Program (SP) and NFT-Independent Living Partnership (ILP); and Community-Integrated Personal Assistance Services and Supports (CPASS). In each section, findings are presented under the following three headings:

- Z Long-Term Care (LTC) System Strengths
- Z Challenges and Barriers
- Z Goals, Objectives and Activities
 1. Information, Referral, Assessment and Outreach
 2. Education and Advocacy
 3. Workforce Recruitment, Retention and Training
 4. Personal Assistance Services and Supports
 5. Consumer Direction, Choice and Control
 6. Nursing Facility Transitions and Diversions
 7. Policy, Planning and Management
 8. Quality Assurance and Improvement
 9. Housing
 10. Person-Centered Planning
 11. Interagency Coordination
 12. Assistive Technology (AT)
 13. Research
 14. Home and Community-Based Services (HCBS) Waiver Program Improvement and Development of Additional Waivers

Exhibit 3-1 presents the 14 issues that Grantees are planning to address, broken down by the type of Grant. The focus on each issue varies across the types of Grants, due in part to the focus specified in CMS's Grant solicitation document. For example, only NFT Grantees focus primarily on activities related to Nursing Facility Transitions and Diversions. However, as Exhibit 3-1 clearly demonstrates, all of the Grantees are addressing many of the same issues, regardless of the type of Grant.

Exhibit 3-1. Distribution of Grantees by Type of Grant and Issues to be Addressed by Grant Activities

Topic / Issue	Total	RC	NFT-SP	NFT-ILP	CPASS
Information, referral, assessment and outreach	27	AL, DE, FL, HI, IA, MA, MD, MI, MN, MO, NH, SC, VA, VT	AK, CO, CT, IN, MI, NH, WI, WV	AL, GA, MD	MT, NV
Education of consumers, providers, agency personnel; advocacy with the general public on general or specific disability issues.	22	AL, DE, HI, IA, ID, MO, NE, NJ, OR, TN	CT, MA, WA, WV	AL, GA, MD, TX	AK, MI, MT, RI
Workforce recruitment, retention and training	20	AR, FL, GU, KY, MD, ME, NC, NJ, OR, VT	AK, GA, WI		AK, AR, MI, MN, MT, NH, NV
Personal assistance services and supports	19	FL, IA, ME, MO, NE	AK, CO, CT, MA, MI, MD, NH, WA, WI	GA, MD, WI	MN, NV
Consumer direction, choice and control (individualized budgeting, development of fiscal intermediaries or other supports for consumers)	18	AR, IA, ME, MI, NC, NE, NH, NJ, SC, VA, VT			AK, AR, GU, NH, NV, OK, RI
Nursing facility transitions and diversions	18	IL	AK, CO, CT, GA, IN, MA, MI, MD, NH, WA, WV, WI	AL, GA, MD, TX, WI	
Policy, planning and management (legislative/regulatory actions to improve LTC system; consumer participation in planning/management)	17	AL, IL, MA, MI, MN, MO, NH, NJ, VT	GA, MA, WV	TX	AR, NH, OK, RI
Quality assurance and improvement	17	AR, HI, KY, MA, MD, ME, MI, MN, NE, NH, NJ, VA			GU, MI, NV, OK, RI
Housing	16	FL, IL, KY, NJ, OR, TN	AK, CO, CT, MA, MD, MI, NH, WA, WI	WI	
Person-centered planning	13	AL, GU, IL, OR	CO, GA, IN, MA, MI, WV	AL, GA, WI	
Interagency coordination	12	MA, ME, MO, NC	AK, IN, MD, MA	MD, WI	AR, MI
Assistive technology	7	DE, FL, IL, MI, NH	WA		NV
Research on effectiveness, costs and related issues	7	AR, ID, MO	CT, IN, MI, WA		
Waiver program improvement and additional waivers	6	FL, ME, NJ, VT	NH	GA	

Real Choice Systems Change Grants

4

4.1 LTC SYSTEM STRENGTHS

The 25 Real Choice Systems Change (RC) Grantees reported an array of strengths in their long-term care (LTC) systems. Several strengths cut across multiple disability groups in need of LTC services (e.g., children, elderly persons, people with severe mental illness, and people with mental retardation and other developmental disabilities) and were frequently mentioned by Grantees. For example, almost all identified multiple Medicaid waiver programs serving a range of persons with disabilities or chronic illnesses. A large number identified strong, active participation in advocacy activities by disability-specific organizations and consumers and their families, in keeping with the purpose of the Grants. Often, Grantees identified a commitment to, or movement towards, reducing the number of persons with disabilities served in institutional settings. Many also noted having consumer-directed personal assistant service programs or supporting the principles of person-centered planning.

Other strengths were more State-specific, focusing on distinct initiatives or abilities, including (1) the ability to show the cost benefit of transitioning persons who are institutionalized back into the community, (2) use of Section 8 housing vouchers to help consumers who are leaving nursing facilities find affordable housing,⁶ (3) working relationships with other States, which help them identify potential solutions to problems, (4) strong provider networks, (5) programs that have increased access to information

Strengths most commonly identified included a diverse range of HCBS programs, including Medicaid waiver programs, strong and active consumer participation in advocacy activities, and commitments to reduce institutionalization and increase person-centered planning.

about home and community-based services (HCBS), (6) development of common standards for key services funded by multiple public funding streams, (7) a State-level focus on the housing needs of persons with severe mental illness, and (8) a recent increase in State-funded wages for personal assistants.

4.2 CHALLENGES AND BARRIERS

RC Grantees identified numerous challenges and significant barriers for consumers and their families seeking LTC services in the community. Many of the same problems were reported across all States and disability groups. The most common challenges or barriers identified were the lack of options for consumers to plan and direct their services and an institutional bias in service funding. Although most Grantees stated a belief in or a commitment to consumer-directed services and self-advocacy, few States have programs or activities that allow consumers or their families to plan or manage their services. There is also a widespread need for education and training about consumer direction and self-advocacy, both for consumers and service providers.

Common challenges and barriers identified by RC Grantees included a lack of consumer direction and self-advocacy, need for a centralized information source, and a shortage of well-trained and adequately compensated personal assistance workers.

Other challenges commonly cited include (1) lack of an accurate, centralized source of information for supports and services; (2) variation in the availability of services and eligibility for services across funding streams and programs; and (3) the lack of accurate and complete information about HCBS, which are often provided by different agencies.

A major barrier to serving people with disabilities in HCBS settings identified by most Grantees is a shortage of personal assistance workers and worker turnover.⁷ This problem was cited by many as seriously hampering access to services as well as the continuity and quality of service delivery. There is widespread recognition that these workers lack adequate compensation and benefits, as well as proper training, all of which contribute to high job turnover and low job satisfaction.

Grantees also described the lack of transition programs, the lack of funding for them and the lack of affordable, accessible housing. Together, these problems keep consumers from leaving institutions. Some Grantees specifically noted that funding does

not follow the consumer through the LTC system and that funding across different programs cannot easily be combined to meet individual needs.

Finally, many Grantees stated a need for greater consumer involvement in program design, quality monitoring and the development and evaluation of HCBS services.

4.3 GOALS, OBJECTIVES AND ACTIVITIES

Though Grantees often identified similar barriers and challenges in their LTC systems, the goals and objectives in their Grant applications are more diverse. The RC Grant solicitation allowed Grantees “exceptional flexibility in selecting the type of investment that they judge will yield the most significant improvement in the State’s community-integrated service system.”⁸ RC Grant applicants were instructed that proposed enduring systems change activities should result in improvements in at least one of the four following areas: (1) access to services, (2) service availability, (3) the quality of services, and (4) the value of services. In designating goals and activities to achieve those goals, Grantees customized their approaches to meet their particular needs. While many RC Grantees focus on several issues, a few focus on a single issue (e.g., Delaware on access to assistive technology (AT) and Tennessee on access to housing for persons with mental illness).

Tennessee is focusing on access to housing for persons with mental illness.

As discussed in the previous section, we grouped Grantees’ diverse goals and objectives into 14 issue areas to facilitate analysis and discussion (see Exhibit 3-1). The remainder of this section will discuss RC Grantees’ goals, objectives and activities related to these 14 issue areas.

4.3.1 Information, Referral, Assessment and Outreach

Fourteen RC Grantees have goals associated with information and referral (I&R), assessment and outreach issues. These goals generally involve providing information to consumers in a more effective and efficient manner, developing single-point-of-entry LTC systems or developing a centralized information source for information about available services. Some Grantees plan to

develop an I&R function for LTC services or streamline their assessment and eligibility system.

Grantees plan to use a range of media to provide information to consumers and providers, including print materials, introductory videos and interactive Websites. Some plan to develop a comprehensive Statewide I&R system, create a comprehensive database of providers and services accessible from multiple points and train staff to become Information Resource Specialists.

Grantees vary in their approaches to developing single-point-of-entry systems for their LTC services. Arkansas plans to train workers, develop a central information resource, create a toll-free number, and develop I&R and assessment models. Florida will conduct a Statewide educational campaign using a toll-free number and Website to advertise a single-point-of-entry system. Other activities to be conducted include development of referral procedures and consumer feedback mechanisms for single-point-of-entry systems and studies to determine the costs and benefits of a Statewide automated benefits screening program. Missouri will develop a standardized application form and an automated referral system.

Missouri plans to educate judges and public administrators about guardianship options for persons with disabilities.

4.3.2 Education and Advocacy

Ten RC Grantees have a variety of goals and objectives aimed at educating consumers, providers and agency personnel about HCBS and related issues. Several Grantees have goals to educate the general public about disabilities in general and mental illness in particular. Grantees stated some of these goals in quite general terms, such as expanding resources for HCBS through planning, advocacy and education. Other goals were more specific, such as reducing the stigma of disabilities (particularly psychiatric disabilities) to provide a more welcoming community environment for persons with disabilities.

Grantees are planning to implement education and advocacy-oriented activities, including developing informational materials, for a variety of purposes. Missouri plans to educate judges and other public administrators involved with guardianship about guardianship issues and options for persons with disabilities. Vermont plans to expand the Statewide availability of recovery

education designed to encourage self-help activities, develop a recovery education curriculum and develop a specialized curriculum and related supports for individuals subject to involuntary treatment. Idaho plans to implement a mass media campaign for the general public in order to reduce the stigma often associated with disabilities.

4.3.3 Workforce Recruitment, Retention and Training

Ten RC Grantees have workforce recruitment, retention and training goals. These goals are aimed at improving the size and quality of the LTC personal assistant workforce to address the critical shortage of personal assistance workers in all States. The goals listed were general in nature and did not quantify the number of additional workers sought, though the activities associated with these goals were more specific.

In general, these Grantees are planning to develop strategies to recruit and retain personal assistance workers, including the provision of training and benefits and the development of worker registries and associations. They identified numerous activities to be carried out, including conducting studies and/or surveys with subsequent development of a plan for Statewide implementation. Several plan to implement a range of marketing initiatives to attract job seekers, including the development of a public awareness or marketing campaign with public service announcements and the development of other media strategies. Some Grantees plan to host job fairs and create worker registries and associations.

In order to retain workers, several Grantees plan to examine options for making health insurance coverage more accessible through group insurance or other means. Another retention activity is to develop strategies for competency-based wage incentives. Maine and Vermont plan to create a personal assistance worker association or worker guild. Others plan to develop a career ladder for personal assistance workers.

Some Grantees plan to study or modify the structure of the jobs performed by personal assistance workers. New Jersey plans to change State policies to increase the ability of personal assistance workers to perform specific nursing tasks. Other Grantees plan to

Kentucky plans to develop a training system for academic credit linked to the State's technical and community college system, including the use of virtual classrooms.

conduct pilot studies to determine needed competencies and functional skills for personal assistance workers and modify State licensing laws to increase the number of specific nursing tasks that personal assistance workers can perform. Training-related activities include materials development for presentation using both traditional and online media, internship and mentoring programs and the development of standards for training around job-related competencies. For example, Kentucky plans to develop a training system for academic credit linked to the State's technical and community college system, including the use of virtual classrooms.

Some RC Grantees are planning infrastructure improvements to improve the quality of services delivered by personal assistance workers. Others will create an emergency backup system for personal assistance workers, classify current job categories, develop a Website on workforce issues and make improvements in data capability to track the personal assistance workforce over time and to inform workforce policies and programs.

Some Grantees will create an emergency backup system for personal assistance workers.

4.3.4 Personal Assistance Services and Supports

Five RC Grantees have goals to identify persons who want to transition to the community or to provide services and supports to transition consumers from institutions to the community (or in some cases, to prevent institutionalization). Grantees plan to either establish a framework or develop a system for successful long-term community supports for persons who transition (or who want to remain in the community but are at risk for institutionalization). Iowa plans to develop and implement a Statewide coordinated system of crisis prevention and intervention services to prevent institutionalization.

Several Grantees will implement training activities to help consumers learn how to obtain or use resources, such as AT, needed for community living. Some States (Illinois and New Hampshire) plan training activities to help consumers understand guardianship issues as they relate to persons with disabilities. (Guardianship rules in most States are so strong that they do not allow persons with disabilities enough freedom in decision making. New Hampshire will investigate the possibility of using mentors instead of guardians). Grantees will also create service resource

tools, develop and support community options or provide start-up grants to consumers. For example, Florida is creating LTC Resource Networks to increase local capacity to support community choices, developing an outreach and referral strategy to link consumers most at risk of institutionalization with resources and information, and implementing a Help for the Caregiver Initiative to recruit and place volunteers to provide support services for people with disabilities and long-term illnesses and/or their caregivers.

Other Grantees are conducting pilot projects to transition persons back to the community. Missouri plans to conduct a case-by-case analysis of persons who have remained in institutional settings longer than anticipated to determine if transitioning is appropriate.

4.3.5 Consumer Direction, Choice and Control

Eleven RC Grantees will work on personal assistance services and supports with a particular focus on consumer direction, choice and control as one of their goals. These Grantees seek to increase knowledge about and support for consumer direction across the systems that serve people with disabilities and to maximize options for consumer choice and control. For example, Maine will address policy barriers to, and develop a methodology for, allowing consumers to pool service dollars across programs and purchase services of their choice.

Maine will develop methods to allow consumers to pool service dollars across programs.

Grantees plan to conduct a variety of activities to achieve consumer direction goals. Some will develop a consumer-directed care model and implement it. New Jersey plans to develop and implement a training and marketing program around consumer direction targeted at county agency staff as well as potential and enrolled beneficiaries. Oklahoma plans to develop fiscal intermediaries or business agents that will provide consumers with the administrative support needed to exercise choice and control over their services. Vermont plans to develop a design for direct consumer funding, while Guam is planning to develop an individualized budgeting program. Other Grantees plan to analyze current service coordination across several systems, evaluate existing policies, and design and develop a customized system for their consumers.

4.3.6 Nursing Facility Transitions and Diversions

Only one RC Grantee, Illinois, plans to transition consumers from nursing facilities to the community. This Grantee plans to provide start-up grants to approximately 50 consumers in Rockford or Southern Illinois to help them make the transition to the community.

4.3.7 Policy, Planning and Management

Nine RC Grantees have goals to change State policies or regulations, affect State planning for services designed for people with disabilities or encourage consumer involvement in the management of community-integrated programs or services. Some Grantees have formal policy-oriented goals directed to improving the broad LTC system, while others focus on specific State systems issues. In many cases, to ensure that the results are consumer driven, consumers will participate in activities to achieve policy, planning and management goals. In general, consumers will participate as part of a work group that is addressing a specific issue or a task force that is overseeing all of the Grant's activities.⁹

Consumers in Michigan will help in publishing a newsletter about Medicaid changes affecting persons with disabilities.

New Hampshire plans to establish a Policy Resource Center to issue reports on HCBS legislative and regulatory issues, compare targeted issues of interest within LTC service systems and document trends and outcomes.

Beyond general goals of making LTC systems more consumer oriented, some Grantees are planning legislative or regulatory action on specific issues. New Jersey has a goal to amend its Nurse Practice Act to allow persons without professional clinical training, such as personal assistants, to perform certain nursing tasks. Other topics for legislative or regulatory action include direct funding for consumers (Vermont), development of housing resources (Illinois) and adding consumer-directed service coordination options (Minnesota).

Consumers will be involved in various advisory groups, governing councils and cooperatives to help develop language for legislation and program guidelines to ensure that consumer preferences and needs will be met in the provision of supports and services. In Michigan, consumers will be involved in publishing a newsletter

with information about changes in the Medicaid system, including new State laws and regulations affecting persons with disabilities.

4.3.8 Quality Assurance and Improvement

Twelve RC Grantees have goals and objectives related to quality assurance or improvement. The goals often involve conducting studies to document the effectiveness of or satisfaction with services, finding what works best, creating a model and implementing it Statewide. Some Grantees plan to develop a consumer-oriented quality assurance system. New Hampshire will develop a model for consumer-designed and -driven quality assurance and improvement functions.

Activities in Minnesota include recruiting a commission to oversee quality design teams and developing a consumer feedback system. Idaho proposes to conduct an effectiveness study and develop a plan for Statewide implementation. Missouri plans to coordinate quality assurance measures, measure demographics of people on waiting lists and track their movement and develop parameters for a provider agency listing/profile outlining services offered by provider agencies and make it available for consumers. Other Grantees plan to develop consumer satisfaction surveys, design an ongoing assessment approach to obtain feedback about services and improve quality or develop quality indicators for use across LTC settings.

Quality improvement activities include developing consumer satisfaction surveys and quality indicators for use across LTC settings.

4.3.9 Housing

Six RC Grantees have housing initiatives. Tennessee's entire RC project involves the design and implementation of an effective, consumer-directed, accessible housing resource system for persons with mental illness. Tennessee plans to hire consumer housing specialists in four target communities, create a comprehensive Housing Resource Website, hold an annual one-week "Housing Academy" for stakeholders, conduct a longitudinal evaluation and establish a "Housing Hotline" to improve the housing situation for persons with mental illness.

Other Grantees with housing initiatives are attempting to create more effective strategies for locating, developing and maintaining affordable, accessible community housing. Several Grantees have initiatives to help consumers obtain housing. These

Housing activities include analyzing the costs and benefits of covering initial transition expenses, developing flexible rental assistance, sources of wraparound funding and transitional case management services. 4-9

activities include analyzing the costs and benefits of covering initial transition expenses (e.g., rental security deposits) and developing flexible rental assistance, sources of wraparound funding and transitional case management services to assist consumers in securing community housing. New Jersey plans to develop incentives for builders to reserve some housing units for persons with disabilities.

Grantees cited many nonfinancial activities designed to help in securing housing. For example, Kentucky plans to develop a protocol on housing options and preferences for use in LTC facilities to help residents make choices on where to reside upon transition to the community. Oregon plans to increase coordination of services for persons with disabilities who are homeless. Other activities identified by Grantees include the following:

Consumer direction activities include implementing a new system to allow the pooling of service dollars across programs and allowing consumers to purchase their own services.

- Z developing lists to match subsidized housing vacancies with consumers (New Jersey),
- Z developing strategies to recruit and retain landlords (Illinois),
- Z working with local housing agencies to ensure universal design principles are incorporated (Kentucky),
- Z developing an accessible housing-specific Website and toll-free number (New Jersey),
- Z developing a training package and other education materials (e.g., videos and brochures) for consumers (Kentucky),
- Z developing a toolkit of best practices on housing issues (Kentucky),
- Z conducting housing demonstration projects (Maine), and
- Z developing a user-friendly application process for obtaining home modifications (Kentucky).

4.3.10 Person-Centered Planning

Four RC Grantees have goals concerning person-centered planning. Person-centered planning is a process that develops service plans around the needs of an individual instead of the service provider. Most of the goals proposed by Grantees regarding person-centered planning center on designing and changing systems to respond to consumers' rather than providers' needs.

Some Grantees did mention specific activities that would result in products for use by consumers and/or providers. For example, Alabama plans to develop a person-centered assessment tool for senior services and Illinois will develop a model person-centered assessment plan.

Other activities include developing a training curriculum for service providers, service coordinators, medical professionals and policy-makers on person-centered service delivery.

4.3.11 Interagency Coordination

Four RC Grantees seek to improve interagency coordination and planning. Responsibility for HCBS is often held by many agencies in a State and coordination of responsibilities and activities is needed. Grantees are planning to form interagency task forces to address the need for standardized regulations and policies to ensure efficient and effective service delivery.

To achieve these ends, Florida and Missouri will each create an interdepartmental systems change team. North Carolina will standardize policies across departmental divisions and Missouri will standardize regulations and forms. Maine plans to develop a shared data system among agencies and Massachusetts will conduct policy studies across agencies.

AT goals range from increasing awareness and providing education about AT to identification of funding sources to improve access to AT.

4.3.12 Assistive Technology

Five RC Grantees have goals and activities pertaining to AT. These goals range from increasing awareness and providing education about AT to identification of funding sources to improve access to AT. Delaware's entire project pertains to AT, while the other four Grantees are conducting AT activities as a part of their larger efforts.

Several Grantees plan to educate and inform consumers to increase awareness and knowledge of AT and how to gain access to it and to inform local providers about options for its use.

Delaware plans to conduct a needs analysis, launch a comprehensive awareness and training campaign and develop a Website to serve as the central repository for information.

Michigan plans to provide training and implement consumer feedback processes.

The five Grantees also plan to implement activities to help consumers obtain funding for AT. Delaware will help interagency work groups to clarify existing funding mechanisms and attempt to identify alternative financing. Illinois will develop an Internet-based manual on obtaining AT. Activities to improve access to AT include demonstration projects and equipment reuse/recycling in Delaware and the development of an AT assessment tool in Florida. Delaware will also conduct analyses of needs, equipment, expenditures and outcomes to improve access.

4.3.13 Research

All Grantees were required as part of their application to incorporate formative learning activities to monitor progress made over the Grant period and incorporate feedback into ongoing Grant activities. Many Grantees also plan to conduct informal studies or needs assessments to inform their activities.

Research studies to be conducted include evaluations of demonstration projects to identify best practices that can be replicated.

Three RC Grantees plan formal research efforts on specific topics, such as research and demonstration projects to identify best practices and projects that can be replicated. Missouri plans to conduct research on the cost effectiveness of services and Arkansas is conducting a study to develop recommendations for a voluntary Medicaid/Medicare integrated system. Idaho plans to increase or maintain the value of services by conducting an economic analysis of service and support utilization and to use the results of this analysis to develop a daily rate for services.

4.3.14 Waiver Program Improvement and Additional Waivers

Four RC Grantees plan activities associated with HCBS waiver programs. These Grantees will either apply for new waivers or work to identify recommendations for improvements in cost efficiency, consumer direction and effectiveness in existing waiver programs.

Vermont plans to develop a Section 1115 waiver to increase the use of HCBS.¹⁰ Maine will develop a waiver application to maximize options for consumer choice and control of personal assistance services (PAS). Florida will streamline selected Medicaid waiver programs and New Jersey will conduct an

analysis of its Medicaid waiver programs to improve efficiency and effectiveness.

Nursing Facility Transition Grants

5

In keeping with the focus of the Nursing Facility Transition (NFT) Grant solicitation, all NFT Grantees propose some type of nursing facility transitions and diversions goal or activity. Seven Grantees will establish diversion programs to help consumers avoid a nursing facility admission after a hospital stay. Not all Grantees identified a specific number of consumers to be transitioned (or diverted), but cumulatively, twelve Grantees plan to transition or divert more than 1,300 people to community settings. Only Indiana mentioned a specific number of consumers (20) to be *diverted* and those consumers will be diverted from hospital settings as they frequently serve as the last residence prior to nursing facility placement; the other eleven NFT Grantees that mention specific numbers of consumers have proposed programs to transition consumers from nursing facilities. The largest number of consumers that any single Grantee planned to help transition was the NFT-State Program (SP) Grantee in Wisconsin, which had the goal of transitioning 400 consumers.

Most Grantees stated that they will provide case management or support coordination to facilitate transitions for consumers who want to move to the community. Grantees will also coordinate community housing and services after transition. Grantees will compile and distribute lists of affordable, accessible community support services and help consumers understand, identify and obtain local community resources.

Cumulatively, twelve Grantees plan to transition or divert more than 1,300 people to the community.

5.1 LTC SYSTEM STRENGTHS

The 17 NFT Grantees (both the SP Grants and the Independent Living Partnership [ILP] Grants) identified as strengths an array of current or past programs or projects that have given them experience with a range of issues relevant to their goals. Many of these Grantees have prior experience with deinstitutionalization programs that inform their understanding and some have other related grants. They also frequently cited well-established Independent Living Centers (ILCs) that run smoothly and have other grant implementation experience. The effectiveness of the ILCs was particularly relevant for NFT Grantees, because most Grantees either are ILCs or are working in partnership with ILCs.

All of these Grantees' States have Medicaid waiver programs and some programs that aid consumers who do not qualify for Medicaid services. Some Grantees also have established outreach programs that share the values of consumer empowerment and advocacy. Some States have a single point of entry to a number of State agencies that can provide access to a wide array of long-term care (LTC) services.

Strengths identified by NFT Grantees included single-point-of-entry agencies, outreach programs and commitments from Housing Authorities to provide housing assistance.

NFT Grantees also identified other agencies or partners with whom they have relationships to help them implement Grant activities. For example, Directors of Housing Authorities are committed to providing housing assistance (through Housing and Urban Development [HUD] Section 8 vouchers or other means) as consumers attempt to transition from (or are diverted from) nursing facilities. Finally, some of these States have existing Olmstead Task Forces¹¹ that have provided the initiative and impetus for helping consumers live more independently in the community.

5.2 CHALLENGES AND BARRIERS

NFT Grantees identified numerous challenges and barriers in their States and framed their goals and activities to address a number of them. The barriers include problems faced by consumers in nursing facilities who want to transition to the community as well as the barriers to remaining in the community once transitioned.

Several Grantees noted that they did not have a consistent method to identify people residing in institutions who want to return to the community. They also cited a lack of case managers or service coordinators to assist consumers who wish to transition to the community and insufficient peer support resources to aid in transitioning activities. Additionally, flexible funds to support transition—including funding of basic housing-related needs such as furniture and household items—are in short supply.

According to most Grantees, services to aid independent living offered by State public agencies are not coordinated well. There is also a shortage of accessible, affordable housing. As is true for consumers of home and community-based services (HCBS) in general, consumers face problems with recruitment, retention and adequate training of personal assistants. Quality is difficult to measure, and there is a lack of accountability in service provision. Finally, Grantees believe that a disproportionate amount of funding is spent on institutional care.

Challenges and barriers cited by NFT Grantees include a critical shortage of accessible, affordable housing and problems with recruitment, retention and adequate training of personal care assistants.

5.3 GOALS, OBJECTIVES AND ACTIVITIES

We identified 11 issues that NFT Grantees are focusing on, as shown in Exhibit 3-1. The goals, objectives and activities of SP Grantees were similar to those of the ILP Grantees and most of the SP Grantees proposed to work in partnership with ILCs. Therefore, except as needed to distinguish between ILP and SP Grantees in the same State, we jointly discuss their goals, objectives and activities.

5.3.1 Information, Referral, Assessment and Outreach

Eleven NFT Grantees' proposed goals concern either the provision of information or outreach to, or assessment of, consumers in nursing facilities, hospitals or community settings. About half of these Grantees specifically mention outreach activities, while the remainder plan to provide information to consumers or to assess the potential for transition and referral to a community setting.

New Hampshire is planning to enhance its older adult outreach capacity. Wisconsin is planning to develop Statewide systematic

processes for ongoing identification of institutionalized residents or persons being discharged from hospitals who wish to transition to the community. An example of assessment or referral activities is West Virginia's plan to utilize, evaluate and modify as needed an assessment tool using person-centered planning to identify consumers' potential strengths and needs.

5.3.2 Education and Advocacy

Eight of the NFT Grantees propose to conduct activities to address education- and/or advocacy-related goals. Grantees plan to train consumers, service providers, State agency personnel and the general public on varying topics using traditional media approaches. For example, Alabama will develop transition manuals for staff training and Connecticut will provide training on independent living and self-determination to a variety of professional target audiences.

Workforce-related goals include hiring outreach or transition workers, and initiatives to increase community services and establish worker registries.

Massachusetts proposes to educate the greater Worcester community to build community capacities to engage individuals transitioning from nursing facilities. Washington will organize with independent living consultants to provide skills training and advocacy to consumers and Maryland's ILP Grantee will develop a curriculum to empower individuals with disabilities to advocate for themselves. Texas plans to coordinate annual conferences for Centers for Independent Living (CILs) staff, State agency staff and other partners focusing on best practices and barriers in outreach activities. ILCs in Alabama will hire a Community Transition Advocate to specialize in assisting transitions, and recruit and train ten Peer Outreach Advocates.

5.3.3 Workforce Recruitment, Retention and Training

Three NFT Grantees have workforce recruitment and retention goals. Grantees' goals include initiatives to hire outreach or transition workers, increase community services and establish worker registries.

Wisconsin (SP) will hire a workforce planning analyst to develop local workforce development projects, work with adult educators to develop core curricula for training personal assistance workers, and develop and disseminate training for the managers and

supervisors of personal assistance workers to help them create positive work environments.

5.3.4 Personal Assistance Services and Supports

In addition to case management and support coordination, 12 NFT Grantees plan to pay for one-time expenditures for services and supports that help a consumer transition to the community. These one-time expenditures will be used for housing deposits, furniture, household items and other items consumers need to live in the community. NFT Grantees generally do not plan to provide personal assistance services (PAS) using Grant funds, but plan to facilitate consumers' access to PAS provided by other programs.

The most common form of support that Grantees plan to provide is peer support and counseling through community-dwelling consumer networks. ILCs will frequently be sources of peer counseling and support in both SP and ILP Grants.

Massachusetts will work with several advocacy groups for people with disabilities.

Grantees will also develop or arrange for community resources and support and coordinate services, referrals and follow-up. New Hampshire will develop and implement a "Wrap Around Services" program to assist individuals transitioning to the community. Other Grantees will compile and distribute lists of affordable, accessible community support services and help consumers understand, identify and obtain local community resources.

New Hampshire will develop and implement a "Wrap Around Services" program to help individuals transition to the community.

5.3.5 Policy, Planning and Management

Four NFT Grantees highlighted goals to change State policies or management procedures for HCBS. They are planning to create consumer advisory bodies that will provide input for policy and planning. Georgia will establish a Consumer/Provider Task Force to develop and prioritize strategies to overcome institutional bias in State policy. In part, this Task Force will identify existing policy barriers to the development of community support services.

Massachusetts plans to establish a local citizen advisory committee in Worcester, the only community served by the Grant. The committee, composed of a majority of individuals with disabilities and their family members, will promote the ability of

individuals to transition out of nursing facilities and provide direct advice to the project. West Virginia plans to develop a Consumer Oversight Commission that in part will monitor project activity through data on consumer satisfaction collected through surveys. Texas will evaluate State agency policy when implementing new programs to facilitate transition to the community and present specific recommendations for local, State and national policy changes.

5.3.6 Housing

Ten NFT Grantees focus on increasing nursing facility residents' access to affordable housing. Most of their goals focus on developing methods to obtain accessible, affordable housing for consumers transitioning to the community. Many of these NFT Grantees are only starting to develop the relationships essential to promote access to housing opportunities. They plan to collaborate with State and local housing authorities and private organizations to identify housing options. For example, Massachusetts and Michigan identified pledges for HUD Section 8 housing vouchers from their housing authorities, and other Grantees (e.g., Alaska and Colorado) are going to pursue the use of housing vouchers. New Hampshire plans to hire a housing specialist to pursue available and affordable housing through the use of State and federal housing benefits, while Wisconsin will fund local projects to systematically address the housing issues of individuals with disabilities.

The Wisconsin NFT-SP Grantee will fund local projects to systematically address housing issues and New Hampshire will hire a housing specialist to pursue affordable housing through the use of State and federal housing benefits.

5.3.7 Person-Centered Planning

Nine NFT Grantees explicitly stated that they plan to use person-centered planning. Additional Grantees may also use person-centered planning, since the Grantees varied in the level of detail used in describing the support planning process.

Four Grantees plan to develop or revise tools to facilitate person-centered planning or to increase consumers' involvement in choosing the supports they receive. For example, Alabama plans to create a person-centered model for NFTs. Colorado plans to develop an approach to enable people with developmental disabilities, cognitive impairments and situations or conditions that make communication difficult to give informed consent for NFT.

Other Grantees plan to develop a self-assessment and a guide to the transition process for consumers (Connecticut) and adapt a person-centered assessment tool designed for NFTs and diversions (West Virginia).

5.3.8 Interagency Coordination

Six NFT Grantees have goals that emphasize collaboration with other agencies and organizations. Massachusetts will establish an interagency, interdisciplinary case management team to assist individuals transitioning to the community. Indiana plans to enhance collaboration with nursing facilities, associations, housing partners and assisted living facilities to develop more timely methods to identify persons who can return to their communities after a hospitalization, rather than being transferred to a nursing facility.

Maryland's NFT ILP Grantee will work with existing SPs to ensure that the transition process is successful and consumer-controlled. Maryland's NFT SP Grantee will develop and sustain working relationships with public housing authorities and other housing resources in all Maryland jurisdictions. Wisconsin's NFT ILP Grantee proposes to develop new public and private partnerships to create permanent funding for transition expenses.

Research studies to be conducted by NFT Grantees include identifying best NFT practices and comparing the cost effectiveness of community versus nursing facility living.

5.3.9 Assistive Technology

Washington is the only NFT Grantee that has a goal concerning assistive technology (AT). The Grantee plans to increase the provision of AT services necessary to live in the community. The Grantee plans to provide AT for transitioning consumers, work with the Washington Assistive Technology Fund to make low-interest loans for AT available and conduct a study of the State's durable medical equipment program.

5.3.10 Research

Four NFT Grantees have formal research goals beyond those required for all NFT Grantees. The two largest research efforts focus on identifying best practices in NFTs (Connecticut) and comparing the cost-effectiveness of community versus nursing facility living (Michigan). Two Grantees have smaller research

projects: Indiana will evaluate a model NFT demonstration and Washington will evaluate a durable medical equipment program.

Connecticut will research, evaluate and implement best practices in NFTs. After gathering and analyzing national and State-specific data on successful transition practices, it will evaluate key indicators of success both in terms of efficiency and effective use of resources and in terms of “successful” transitions. A final document will be distributed to the State’s Grantee agencies and the CILs for implementation.

5.3.11 Waiver Program Improvement and Additional Waivers

Two NFT Grantees plan activities to change their Medicaid HCBS waivers or add additional waivers. Georgia’s NFT ILP Grantee will work with the State to address current problems with its waivers through two activities. It will first solicit consumer input through surveys and other methods and then host waiver improvement sessions with consumers, agency and CMS personnel and experts from cutting-edge programs. New Hampshire will develop a mental health HCBS waiver application to ensure continuation of the NFT project activities.

Community-Integrated Personal Assistance Services and Supports Grants

6

6.1 LTC SYSTEM STRENGTHS

The ten Community-Integrated Personal Assistance Services and Supports (CPASS) Grantees identified strengths in their programs, policies and partnerships that will support their Grant project activities. Many of the Grantees cited numerous waiver and other programs that provided personal assistance services (PAS) to consumers, some with sliding fee scales so that non-Medicaid eligible persons could receive services. Nevada cited recently enacted legislation mandating the identification of consumers with severe disabilities in need of PAS and the provision of services to them. In addition, the legislation mandated the formation of a consumer-majority PAS planning group.

Several Grantees cited recent reorganizations of State agencies around PAS programs, improved collaboration among agencies that provide PAS and good partnerships with external organizations on selected issues such as information systems. Nevada cited increased State funding so that PAS workers are now paid approximately \$9 per hour, which helps to address recruitment and retention issues, and Michigan has obtained some funding for PAS from the State's tobacco settlement funds.

Many Grantees cited participation by consumers in planning and more opportunities for consumer-directed PAS as project goals

Strengths cited include legislation mandating the identification of consumers with severe disabilities in need of PAS and the provision of services to them.

and objectives. Some use person-centered planning in the delivery of PAS and some plan to develop person-centered planning initiatives. A number of Grantees stated that there are currently some options for consumer direction or some level of consumer control in a number of State PAS programs. Others have initiatives under way to demonstrate how to increase consumer direction, control and satisfaction.

6.2 CHALLENGES AND BARRIERS

The CPASS Grantees identified many challenges and barriers. Despite the option for consumer direction in some programs, all Grantees identified the need to make significant improvements in this area by noting the following:

- Z Consumers usually have no control over the hiring, payment, training or termination of direct support staff and individuals cannot direct their workers in all settings.
- Z State systems often lack qualified employer agents or fiscal intermediaries.

Additionally, in the past consumers have held advisory roles but have not had opportunities to become leaders in designing, developing or evaluating PAS policies and programs.

Grantees cited infrastructure weaknesses that prevented widespread adoption of consumer direction, including the following: (1) a focus on treatment instead of prevention and a lack of a single point of entry for services; (2) person-centered planning is not consistently implemented across programs; (3) direct-pay consumers usually cannot hire and manage their own assistants and ensure payment of their taxes, insurance and benefits; (4) assessment and care planning tools are often not compatible across programs; (5) children and persons of color in some States are underserved; and (6) consumers and providers need training on various topics.

Grantees also cited problems recruiting and retaining qualified and well-trained staff. Workforce-related problems often translate into inconsistent service delivery and poor quality.

Challenges cited by CPASS Grantees include assessment and care planning tools that are often not compatible across programs.

6.3 GOALS, OBJECTIVES AND ACTIVITIES

Given the more specific focus of the CPASS Grant solicitation, Grantees are addressing 9 of the 14 issues, as shown in Exhibit 3-1. Many CPASS Grantees are focusing on some aspect of consumer direction to address identified program weaknesses and satisfy Grant requirements for a more consumer-driven system.

6.3.1 Information, Referral, Assessment and Outreach

Two of the CPASS Grantees have goals and activities concerning information, referral, assessment and outreach. Montana seeks to address consumers' need for knowledge and information about maximizing the use of PAS. Nevada is planning to develop referral agreements needed to ensure access to PAS for persons not meeting Medicaid eligibility standards and those on waiting lists for waiver services. Nevada is also planning to develop and implement a central database to ensure that persons who need PAS are served as soon as possible by the most appropriate program.

6.3.2 Education and Advocacy

Four CPASS Grantees have goals concerning education and advocacy. For example, Rhode Island plans to develop specialized training modules about its CPASS project targeted respectively to children, providers, brokers/fiscal intermediaries and agency personnel. In addition to training activities on consumer direction, Montana plans to conduct public education activities to increase the visibility and positive perception of its PAS program.

6.3.3 Workforce Recruitment, Retention and Training

Seven CPASS Grantees plan to address workforce issues through a variety of activities. The lack of qualified personnel affects PAS continuity and quality and these Grantees view recruitment and retention of workers as a major goal. While most Grantees planning workforce activities are focusing on recruiting potential workers or current workers, New Hampshire plans to develop and implement models for retaining backup personal care coverage.

To improve recruitment efforts, Grantees will develop advertising campaigns and recruitment materials (Arkansas); establish a provider registry detailing the policies, wage scales, benefits and training packages of available providers (Nevada); and implement activities to enhance the image of personal assistants' work (Alaska).

Several activities will focus on improving benefits for workers. Grantees will assess worker interest in credit unions, pooled health insurance products, low interest loans, educational incentives for career advancement and worker-owned cooperatives (New Hampshire). They will also identify facilitating practices and collaborations that will lessen liability and lower workers' compensation costs (Nevada).

To address retention issues, some Grantees plan to establish a career path and a professional association for personal assistants (Alaska). Others plan to identify a methodology for establishing provider rates that are consistent across programs and sufficient to attract reliable high-quality personnel (Nevada).

Workforce-related activities include assessing worker interest in credit unions, pooled health insurance products, low interest loans, educational incentives for career advancement and worker-owned cooperatives.

Grantees will also try to develop and implement backup personal care coverage models by developing effective mechanisms for providing backup coverage when scheduled workers fail to show up. New Hampshire plans to develop a pooled insurance model for backup coverage, worker cooperatives to supply backup coverage, pools of college and graduate students in social service fields to serve as backups and models of backup coverage using faith-based and other community organizations.

Two Grantees are attempting to expand the worker base supply to try to alleviate the shortage of workers. Montana plans to partner with Area Agencies on Aging (AAA) to develop, implement, evaluate and replicate a Seniors Helping Seniors (SHS) pilot program, designed to attract, train and place older workers in the PAS program. Nevada plans to develop, implement and evaluate a demonstration program that trains and employs adults with mental retardation as personal assistants using a supported employment model.

6.3.4 Personal Assistance Services and Supports

All of the CPASS Grantees have goals and activities focusing on services and supports that are consumer-directed or offer maximum individual control. We identified two Grantees that have less common activities designed to improve access to services and supports. Minnesota plans to develop a model of service delivery to provide a forum for people to learn how to utilize consumer-directed PAS and to come together to share natural support networks. These consumer-initiated partnership and support networks (CIPS) are composed of friends, family and acquaintances of consumers, who may be shared among a group of consumers to meet specific needs on an ongoing basis. Nevada plans to identify incentives or service innovations that can increase access to PAS in rural areas and develop planning for implementation of those models.

6.3.5 Consumer Direction, Choice and Control

Seven CPASS Grantees will work on personal assistance services and supports with a particular focus on consumer direction, choice and control. The specific focus of these goals varies across these Grantees depending on their current State long-term care (LTC) systems and the potential in their States for implementing consumer-directed services. Goals include exploration of new options for service delivery, expansion of consumer-directed personal assistance services and supports, work with providers to ensure consumer direction in service delivery, enhancement of consumer self-advocacy, and training of consumers and providers on numerous consumer direction topics.

New options in service delivery being considered to meet these goals include creating a commission in Arkansas to study and develop a service brokerage system (a “one-stop shopping” model), developing a database to track individual budgets (Guam) and developing a system of fiscal intermediaries (Oklahoma). New Hampshire plans to provide assistance for issues related to taxes, withholding and other employer issues.

Given the lack of understanding of consumer direction principles among consumers, agency personnel and providers, Grantees are planning numerous training activities targeted to these groups. Activities include (1) sharing information through Websites and

Consumer direction goals include enhancement of consumer self-advocacy, incorporation of consumer control in service delivery and training of consumers and providers on numerous consumer direction topics.

handbooks for consumers and families (Arkansas), (2) provision of skills and advocacy training for eligible consumers or their representatives (New Hampshire), (3) preparation and dissemination of a manual for the start-up and operation of a consumer-directed program (New Hampshire), and (4) design and presentation of a training curriculum for agency providers (Minnesota).

6.3.6 Policy, Planning and Management

Four CPASS Grantees are planning initiatives related to policy, planning and management. Activities include designing consumer-directed PAS programs, optimizing current funding sources for an individualized budgeting program and recommending changes to the Nurse Practice Act to support appropriate delegation of nursing tasks to unlicensed personal assistants.

Rhode Island will collaborate with consumers, advocates and providers to guide the design of key components of a PAS program. Guam plans to develop a Creative Funding Task Force to identify and research various funding alternatives for a comprehensive consumer-directed service delivery system. Oklahoma will evaluate and recommend modifications to its Nurse Practice Act to ensure that nursing tasks can be appropriately delegated to personal assistants, including family and friends.

6.3.7 Quality Assurance and Improvement

Five CPASS Grantees have goals and activities related to quality assurance or improvement. Grantees will direct their efforts toward creating measures of systems improvement and consumer satisfaction. Rhode Island plans to implement a quality assurance and PAS program evaluation system. Rhode Island, Guam and Nevada are planning to measure aspects of personal satisfaction with services.

To meet their quality goals, Grantees are planning to develop criteria or standards to measure provider performance and service quality. They will collect data through surveys, site visits and administrative data reviews to monitor utilization and satisfaction and use this information to improve system performance and service delivery. Nevada will develop procedures for handling

complaints, appealing adverse actions (e.g., denial, reduction or termination of services) and incorporating suggestions for improvement.

6.3.8 Interagency Coordination

Two CPASS Grantees have goals pertaining to interagency coordination. Arkansas proposes to increase and promote coordination among public and private agencies and organizations and other interested parties. Michigan plans to develop coordinated information systems based on an overall service delivery analysis that it will perform.

6.3.9 Assistive Technology

Only Nevada has a goal focused on assistive technology (AT). The Grantee seeks to demonstrate and document the efficacy of PAS that provide access to AT and other independent living services as an integral part of service planning. The Grantee plans to (1) develop and disseminate information for PAS consumers about the availability and benefits of AT, (2) provide quarterly demonstrations of AT to PAS recipients at centralized locations through the State, (3) assess PAS recipients for their independent living and AT needs during initial intake and at annual consumer evaluations, and (4) develop a Statewide cadre of volunteer sponsors through the Centers for Independent Living (CILs) to assist consumers in acquiring independent living services, advocacy and AT.

Next Steps

7

This is the first in a series of reports that we will prepare as part of a CMS-funded implementation evaluation of the Systems Change Grants for Community Living. As stated in the Introduction to this report, an implementation evaluation is designed to document the progress of projects and assist Grantees in identifying solutions to problems encountered during project implementation.

Among the reports we will prepare are annual reports based on Grantees' semi-annual and annual reports to CMS, describing their Grant activities during each year of the Grant. 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 enduring long-term care (LTC) systems change. We will also identify any barriers Grantees are encountering in the implementation of specific objectives.

In addition to annual reports, we will also prepare a series of topic papers that focus on specific issues that Grantees are addressing, such as workforce recruitment and retention. These topic papers will provide a more in-depth analysis of activities that Grantees have undertaken during the Grant period to address a particular issue and will present case studies illustrating effective approaches.

Appendix

Grantees by Grant
Type and State

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)

ENDNOTES

¹ See <http://www.cms.hhs.gov/systemschange/backgrnd.asp> and Federal Register notice – 66 Federal Register 28183-23187.

² See *Understanding Medicaid Home and Community Services: A Primer* (U. S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, October 2000) pg. 13 for information about these waivers.

³ RTI prepared the *Compendium of Systems Change Grants for Community Living* under contract to CMS. We developed a template, which we sent to all Grantees for them to complete.

⁴ There was little variation in the goals and activities addressed by the different types of Grants. NFT Grants and CPASS Grants in particular had very similar goals and objectives. RC Grants had more variation, but because each Grant typically had multiple goals and activities, it was not possible to group Grantees according to specific activities. Consequently, we decided to keep the three types of Grants as distinct groups and divided them into smaller groups based on whether the Grant was going to address workforce issues and/or fiscal intermediary issues.

⁵ Six categories dealt with partnership activities, which are the subject of a companion report. The other 13 categories contained in each summary were (1) primary focus of Grant activities, (2) overall goal, (3) key activities and products, (4) consumer partners and consumer involvement in planning activities, (5) consumer partners and consumer involvement in implementation activities, (6) public partners, (7) private partners and subcontractors, (8) public and private partnership involvement in the planning phase, (9) public and private partnership involvement in the implementation phase, (10) existing partnerships that will be utilized to leverage or support project activities, (11) oversight/advisory committee, (12) formative learning and evaluation activities and (13) evidence of enduring change/sustainability.

⁶ HUD Section 8 housing vouchers aid people with disabilities and other persons who meet specified eligibility criteria to rent private housing by limiting the amount of rent paid by qualifying persons or families. HUD pays the remaining balance.

⁷ Some Grantees use the term “direct care workers.” Throughout this report, we use the term “personal assistance workers.”

⁸ *Coordinated Invitation to Apply for Systems Change Grants for Community Living*, p. 34, May 21, 2001.

⁹ See the companion report entitled “Partnership Development Activities: Comparative Analysis of Systems Change Grantees,” for additional information on oversight activities.

¹⁰ Section 1115 demonstrations are the broadest Medicaid waiver authority available to States that wish to test innovative approaches to financing and delivering medical and supportive services to Medicaid beneficiaries. See *Understanding Medicaid Home and Community*

Services: A Primer (U. S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, October 2000) pg. 13 for information about these waivers.

¹¹ Many States have responded to the Supreme Court's Olmstead decision by setting up Olmstead Advisory or Planning Groups, or Task Forces. The general purpose of these entities is to develop comprehensive plans for placing qualified individuals in the least restrictive setting.