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System and Impact Research and Technical Assistance for CMS FY2005, FY2006, and FY2007 RCSC Grants

Person-Centered Planning Implementation Grants 18-Month Summary Report

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Contents

List of Exhibits

List of Acronyms

ADA	Americans with Disabilities Act (Pub. L. 101-336)
ARP	Automated Recovery Plan
CMS	Centers for Medicare and Medicaid Services
CNA	Caregivers Need Assessment
CAFAS	Children and Adolescent Functional Assessment Scale
CFT	Child Family Team
CPOC	Comprehensive Plan of Care
DD	Developmental Disabilities
ELP	Essential Lifestyle Planning
FY	Fiscal Year
HCBS	Home and Community-Based Services
ICF/MR	Intermediate Care Facility for the Mentally Retarded
IEP	Individual Education Plan
IMR	Illness Management and Recovery
ISP	Individual Service Plan
ICAT	Informal Caregiver Assessment Tool
IFP	Initial Futures Planning
LOC	Level of Care
LTC	Long-term Care
MH	Mental Health
MR	Mental Retardation
MR/DD	Mental Retardation/Developmental Disabilities
MAPS	McGill Action Planning System
NASDDS	National Association of State Directors of Developmental Disabilities

NOC	Network of Care
NF	Nursing Facility
PATH	Planning Alternative Tomorrows with Hope
PES	Participant Experience Survey
PCP	Person-Centered Planning
PCT	Person-Centered Thinking
PFP	Personal Futures Planning
POM	Personal Outcomes Measures
QM	Quality Management
RCSC	Real Choice Systems Change
ROSI	Recovery Oriented Systems Indicator
SA	Substance Abuse
SAMHSA	Substance Abuse and Mental Health Services Administration
SPOE	System Point of Entry
ST	Systems Transformation
TPM	Team Performance Model
WFI-4	Wraparound Fidelity Index (version 4)
WRAP	Wellness Recovery Action Planning
WLP	Whole Life Planning

Introduction

On September 30, 2007, the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS) awarded $13.9 million in grants under its Real Choice Systems Change (RCSC) Grants for Community Living Program. The purpose of the program is to support States and territories in enabling individuals with disabilities or long-term illnesses to reside in their homes and participate fully in their communities.

The FY07 Grants were awarded in two categories for a three-year period:

- Person-Centered Planning (PCP) Implementation Grants ($9.1 million); and
- State Profile Tool Grants (SPT) ($4.8 million).

Eighteen PCP Implementation Grants were awarded to 13 states, three instrumentalities of states and one territory. Grantees include:

- Alaska Department of Health and Social Services (DHSS)
- Arkansas Department of Human Service, Division of Medical Services (DHS/DMS)
- Arizona Department of Employment Security, Division of Developmental Disabilities (DES/DDD)
- Connecticut Department of Mental Health and Addiction Services (DMHAS)
- Florida Agency for Persons with Disabilities (APD)
- Guam Department of Integrated Services for Individuals with Disabilities (DISID)
- Idaho Dept of Health and Welfare (DPW), Council on Developmental Disabilities (CDD)
- Louisiana Department of Health and Hospitals, Office of Aging and Adult Services (DHH/OAAS)
- Louisiana Department of Health and Hospitals, Office of Mental Health (DHH/OMH)
- Massachusetts Executive Office of Health and Human Services/Department of Mental Retardation (EOHHS/DMR)[1]
- Missouri Department of Mental Health, Comprehensive Psychiatric Services (DMH/CPS)
- North Carolina Department of Health and Human Services, Office of Long-Term Services and Supports (DHHS/OLTS)
- Tennessee Department of Health and Developmental Disabilities (DHDD)
- University of New Hampshire, Institute on Disability (UNH/IOD), College of Health and Human Services
- University of Southern Mississippi Institute for Disability Services (USM/IDS)
- Virginia Commonwealth University (VCU)[2]
- Washington Department of Health and Social Services (DHSS)
- Wisconsin Department of Health and Family Services (DHFS) Division of Mental Health and Substance Abuse Services (DMHSAS)

[1] Since the award of the Grant, the name of the MA Department of Mental Retardation has changed to the Department of Developmental Services.

[2] This project includes six states working collaboratively, GA, NC, OR, SD, TN and VA.

Three grantees are instrumentalities of a state: (1) University of Southern Mississippi Institute for Disability Service (USM IDS), (2) University of New Hampshire, Institute on Disability (UNH IOD), and (3) Virginia Commonwealth University (VCU). The first two are university institutes on disability services. The USM IDS is working with the Mississippi Department of Rehabilitation Services and UNH IOD is working with the New Hampshire Department of Health and Human Services to accomplish their grant objectives. Virginia Commonwealth University, on the other hand, submitted a grant application on behalf of a six state consortium (Georgia, North Carolina, Oregon, South Dakota, Tennessee and Virginia). The purpose of the VCU grant is to assist state developmental disabilities agencies in incorporating PCP into the infrastructure of their service delivery systems at three levels: (1) day-to-day practice; (2) provider agency management; and (3) service delivery system infrastructure. Additionally, VCU is assisting the states in the consortium to establish a multi-state system change collaborative. Two states in the consortium (North Carolina and Tennessee) also submitted and were awarded a stand-alone PCP grant in addition to the VCU grant.

The purpose of the FY'07 PCP Implementation Grants is twofold: (1) to change the basic model of care planning from one that is directed by the needs of institutions and provider agencies to one that responds to the needs of the individual, and (2) to assist states and territories in developing ways to identify the strengths, capacities, preferences, needs and desired health and quality of life outcomes of the person who needs assistance. PCP Implementation Grants focus on:

- Strengthening and expanding the use of current PCP models in the state or territory;
- Assuring the PCP process systematically incorporates informal support and community network assessment tools;
- Training of professionals (including hospital discharge planners) working in critical pathways to long-term supports and services on new community network and assessment tools; and
- Developing new interventions to support caregivers and build ongoing ties for the individual to their community network of organizations and friendships.

The purpose of this report is to present to CMS:

- the status of progress across the 18 grantees as of March 31, 2009 (the first 18 months of the PCP Implementation Grant),
- the factors that facilitated and/or impeded grantees' progress, and
- how stakeholders, in particular consumers and their families, were included in the development and implementation of grantees' PCP models and processes.

Mandatory Requirements and Components

Each PCP Implementation Grant was required to address three Mandatory Components:

- A distinct PCP model is selected, refined, and/or expanded on, including a systematic "informal" support assessment and intervention process for individuals' informal support caregivers;

- An "informal community network" assessment and intervention process for the individual to create enduring and meaningful ties to organizations in his/her community; and
- A proposed evaluation of quantifiable outcomes that includes three CMS-required outcome questions.

As minimum requirements, each grantee had to describe (1) their PCP Vision including the target population(s), (2) geographic reach, (3) who and which organizations will participate in the grant process to meet the vision, and (4) which Optional Components, if any, will be implemented. Grantees also had to describe (1) the PCP model to be implemented/expanded, (2) how consumer preferences will be elicited and customized choice developed, (3) who will be trained on the PCP model, (4) the informal caregiver assessment tool (ICAT) to be used, (5) the ICAT training that will be provided and to whom, (6) how the informal caregiver assessment tool will be sustained, (7) how customized interventions based on the assessment will be developed for consumer's informal supports, and (8) the time intervals and criteria for reassessment.

Optional Components

In addition to the Mandatory Components and requirements, each Grantee could choose to design and implement one or more Optional Components. The six Optional Components include:

- Self-direction,
- Comprehensive Community-based Resource Directory (web-based)
- Comprehensive Risk Management Strategy,
- Web-based Care Planning Tool,
- Evidence-based Practices, and
- Planning for Youth with Co-occurring Disorders (MH/DD/SA)

The number of Optional Components selected by PCP Implementation grantees ranged from none to three. No grantee selected the Comprehensive Risk Management Strategy Optional Component. The two grantees from Louisiana and the grantees from Florida, USM Institute for Disability Services, North Carolina, Washington State and Wisconsin chose not to design and implement an Optional Component. This is indicated by dashes in Table 1 below, which depicts the Optional Components selected across grantees.

Table 1. Optional Components Selected by PCP Implementation Grantees

Grantee	Self-Direction	Comprehensive Community-based Resource Directory (web-based)	Comprehensive Risk Management Strategy	Web-based Care Planning Tool	Evidence –based Planning Tool	Planning for Youth with Co-occurring Disorders (MH/DD/SA)
Alaska	--	--	--	--	--	X
Arizona	--	--	--	--	--	X
Arkansas	--	X	--	--	--	--
Connecticut	--	X	--	X	X	--
Florida	--	--	--	--	--	--
Guam	X	X	--	X	--	--
Idaho	X	X	--	--	--	--
Louisiana (Aging and Adults w/ Disabilities)	--	--	--	--	--	--
Louisiana (Mental Health)	--	--	--	--	--	--
Massachusetts		X	--	--	--	--
Missouri	X	--	--	--	--	--
North Carolina	--	--	--	--	--	--
USM Institute for Disability Services	--	--	--	--	--	--
UNH Institute on Disability	--	--	--	X	--	--
Tennessee	**--**	X	--	--	X	--
VCU	X	--	--	--	--	--
Washington	--	--	--	--	--	--
Wisconsin	--	--	--	--	--	--

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews

Target Populations Selected by Grantees

Table 2 describes the target populations identified by the grantees. Although individuals (children, youth and/or adults) with mental retardation, development disabilities or mental illness were primarily targeted by grantees:

- seven grantees (38.9%) reported targeting youth transitioning from school to adult life (AK, AZ, GU, ID, MA, MO and USM/IDS),
- six grantees (33.3%) reported targeting adults with physical disabilities (GU, LA/OAAS, MA, USM/IDS, NC, and NH),
- six grantees (33.3%) reported targeting adults with mental illness and /or emotional disturbances (CT, LA/OMH, MO, TN, USM/IDS, and WI) with seven (38.9 %) targeting children/youth with mental illness and/or emotional disturbances (AK, AZ, AR, MA, MO and USM/IDS, and WI),
- three grantees (16.7%) reported targeting elders with physical disabilities (LA OAAS, MA, and NC),
- six grantees (33.3%) reported targeting elders with mental retardation and developmental disabilities (FL, ID, MA, MO, UNH/IOD, VCU),
- three grantees (16.7%) reported targeting elders with mental illness (LA OAAS, UNH, and WI),
- seven grantees (38.9%) reported targeting children/youth with mental retardation and developmental disabilities (AZ, FL, GU, ID, MO, USM/IDS and VCU) and six grantees (33.3%) reported targeting adults with mental retardation and developmental disabilities (FL, GU, ID, MO, USM/IDS and VCU),
- two grantees (11.1%) reported targeting individuals with sensory disabilities (MA and NC),
- one grantee (5.6%) reported targeting children with special health care needs (GU),
- four grantees (22.2%) reported targeting children and/or youth with co-occurring disorders (AK, AZ, USM/IDS, and WI), with (AZ, and WI) focusing on substance abuse disorders.

Table 2. Target Population(s) by Grantee

Grantee	Target Population(s)
Alaska DHHS	Children/Youth (Age 0-21) with mental illness Youth in transition to adult status Youth (Age 14-21) with co-occurring disorders transitioning from institutional or out-of-home settings to the community

Grantee	Target Population(s)
Arizona DES/DDD	Children and youth (Age 0-21) with physical and mental retardation and developmental disabilities and mental illness Youth in transition to adult status Children and youth co-occurring developmental disabilities and emotional/substance abuse
Arkansas DHS/DMS	Children and youth (Age 0-21) with severe mental illness and emotional disturbances and their families
Connecticut DHMAS	Adults (Age 22-64) with serious mental illness including those whose condition may be compounded by other socio-economic and psychosocial ailments (i.e., homelessness and unemployment) who are served by DMHAS
Florida APD	Children/youth (Age 0-21), adults (Age 22-64) and elderly (Age 65 and older) with developmental disabilities
Guam DISID	Children, youth and adults with physical and mental retardation/ developmental disabilities including those whose condition may be compounded by other socio-economic and psychosocial ailments (i.e., homelessness and unemployment) Youth in transition to adult status Children with Special Health Care Needs (Age 0-21) and Their Families
Idaho DHW/CDD	Children/youth (Age 0-21), adults (Age 22-64) and elders (Age 65 and older) with mental retardation/developmental disabilities Youth in transition to adult status
Louisiana DHH/OAAS	Adults (Age 22-64) and elders (Age 65 and older) with physical disabilities
Louisiana DHH/OMH	Adults (Age 22-63) with mental illness
Massachusetts EOHHS/DMR	Adults (Age 22-64) and elders (Age 65 and older) with physical, mental retardation/developmental disabilities and mental illness including those whose condition may be compounded by other socio-economic and psychosocial ailments (i.e., homelessness and unemployment) Children and youth with mental illness Youth in transition to adult status Individuals who are deaf and hard-of-hearing
Missouri DMH/CPS	Children/youth (Age 0-21), adults (Age 22-64) and elders (Age 65 and older) with mental retardation/developmental disabilities Children/youth (Age 0-21), adults (Age 22-64) and elders (Age 65 and older) with mental illness Youth in transition to adult status
North Carolina DHHS/OLTS	Adults (Age 22-64) and elders (Age 65 and older) with physical disabilities Adults who are aging and have special needs or who have physical/sensory disabilities

Grantee	Target Population(s)
USM Institute for Disability Services	Medicaid-eligible South Mississippi college-bound high school students and college students with physical, mental retardation/developmental disabilities and mental illness Youth in transition to adult status Children with special health care needs (Age 0-21) and their families Youth with co-occurring developmental disabilities and emotional/substance disorders if in secondary or postsecondary education
UNH Institute on Disability	Adults (Age 22-64) and elders (Age 65 and older) with physical disabilities Elders (Age 65 and older) with mental retardation/developmental disabilities or mental illness
Tennessee DHDD	Adults (Age 22-64) who have been diagnosed with serious and persistent mental illness
VCU	Children/youth (Age 0-21), adults (Age 22-64) and elders (Age 65 and older) with mental retardation/developmental disabilities receiving Medicaid home and community based services in each of the six participating states (GA, NC, OR, SD, TN, VA) Oregon, South Dakota, Tennessee and VA are focusing mainly on adults with mental retardation/developmental disabilities.
Washington DHSS	36 adults (Age 22-64) with significant developmental disabilities who are employed, Medicaid eligible, have varied levels of need, resources, and informal supports and are recruited from three counties
Wisconsin DHFS	Children/youth (Age 0-21), adults (Age 22-64) and elders (Age 65 and older) with mental illness Children and adults with mental health and co-occurring substance abuse disorders

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

Geographic Reach

PCP Implementation Grants were implemented statewide and by region (See Table 3). Fourteen grantees (77.8%) reported implementing their grants statewide (AK, AR, CT, FL, GU, ID, LA OAAS, LA OMH, MO, NC, UNH/IOD, TN, VCU and WI), however, in at least one case it was reported to be a goal (VCU). Four states that reported implementing their grants on a regional basis (AZ, MA, USM/IDS and WA). One grantee (MA) reported two reasons for using this approach: (1) the current state budget crisis, and (2) piloting the PCP models selected by the six line agencies would allow the Executive Offices of Health and Human Services and Elder Affairs to review the model's effectiveness and any implementation issues and then make adjustments to the models, tools and processes, as necessary, before implementing them statewide.

Table 3. Geographic Reach by Grantee

Grantee	Statewide	Regional	Comments
Alaska DHHS	X		The PCP Grant recruits participants statewide.
Arizona DES/DDD		X	PCP Grant implemented throughout most of Southern AZ (Pima, Cochise, Graham, Greenlee, Santa Cruz and Pinal counties) with the expectation that by the end of Year 3 of the Grant the PCP model will be recommended for statewide replication.
Arkansas DHS/DMS	X		Statewideness will be accomplished by piloting training academies in the Fall of 2009 in two AR System of Care Demonstration sites (Batesville and Hot Springs, AR). The remainder of the training academies will be implemented during the Spring of 2009 through out the 14 mental health catchment areas in the State.
Connecticut DHMAS	X		
Florida APD	X		
Guam DISID	X		
Idaho DHW/CDD	X		
Louisiana DHH/OAAS	X		
Louisiana DHH/OMH	X		PCP start up in some locations has been better than in others.
Massachusetts EOHHS/DMR		X	Community building activities are being undertaken in three (3) geographic areas: Lawrence, Holyoke and Greater Boston, MA.
Missouri DMH/CPS	X		Statewide with pilot projects focusing on people transitioning from habilitation centers through training initiatives - Learning Collaboratives organized in the Western and Central regions of State with involvement with selected St Louis state facilities.
North Carolina DHHS/OLTS	X		
USM Institute for Disability Services		X	PCP Grant covers 15 high schools in 13 school districts in six (6) So MS counties (Forrest, Jefferson Davis, Hancock, Lamar, Marion and Pearl River).
UNH Institute on Disability	X		
Tennessee DHDD	X		
VCU (applies to all state in the collaborative)	X		The goal is for all states in the collaborative to have implemented PCP statewide.

Grantee	Statewide	Regional	Comments
Washington DHSS		X	PCP Grant established in three (3) counties, Snohomish, Clark and Chelan/Douglas, WA.
Wisconsin DHFS	X		All 72 of WI counties have been invited to participate in PCP and related training

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

Types PCP Models Selected by Grantees

Table 4 briefly describes the PCP models selected by grantees. Grantees used a variety of PCP models to implement Person-centered Planning in their states.

- Fourteen grantees (77.8%) reported working with one or more existing PCP models, deconstructing/refining them and/or incorporating key elements and tools to reflect the unique characteristics of the state and/or the target population (AK, AR, FL, GU, ID, LA OAAS, LA OMH, MO, NC, USM/IDS, UNH/IOD, TN, VCU and WA).
- Four grantees (22.2%) reported developing their own PCP model (not using/modifying one or more existing PCP model(s)) (AZ, CT, MA and WI). However, the only grantee that truly accomplished this was the Connecticut grantee by developing the "Person-Centered Care Questionnaire."
- The other three grantees (AZ, MA and WI) used one or more existing PCP models to craft the PCP model(s) they would use (See Table 4 below).

The majority of grantees used the PCP model to develop and implement person-centered care/service plans for their target populations. However, grantees also implemented PCP models in different ways. For example, one grantee (LA OMH) implemented WRAP plans for persons in recovery to assist them managing their recovery in addition to their treatment/service plans. The grantee reported "the WRAP process is truly self-directed and 'owned' by persons in recovery. It's the person in recovery who decides if he/she wants a WRAP plan, who will be involved in developing and facilitating the plan, what is included in the plan, if his/her supporter(s) (informal caregivers) will complete the self-assessment tool and how their information will be incorporated in the plan; and when a WRAP should be updated." Under the PCP model, WRAP facilitators are persons in recovery who have been trained to perform the WRAP process. LA OMH grant staff reported an important next step for implementing WRAP in their state is to get professionals to (1) recognize the WRAP process and its value to a person's recovery, (2) suggest WRAP to their clients, and (3) use/incorporate the WRAP plan in the treatment of their clients.

Another grantee (CT) is using the PCP model selected (Person-Centered Care Questionnaire or PCCQ) as a guide to persons in recovery and their treatment planning team (composed of a psychiatrist, rehabilitation staff and a social worker) in preparing person-centered plans and as a monitoring tool for Department of Mental Health and Addiction Services (DMHAS) staff to determine whether individuals' treatment plans are being developed using person-centered principles. The 31-item PCCQ has a clinician and a person in recovery version, each of which includes a list of questions that the person in recovery and the clinician can review prior to the person's treatment planning meeting. In addition, DMHAS staff responsible for quality assurance activities will use the PCCQ to review individuals' treatment plans to determine if they were developed in a person-centered manner. The grantee reported that their

subcontractor, Yale University Program for Recovery and Community Health, also has developed and posted on their web site a "tool kit" of PCP models and tools that both persons in recovery and their treatment planning teams can use to customize the treatment planning process to meet the needs and preferences of the person in recovery.

Initially, one grantee (MA) thought they would be developing one PCP model, informal caregiver assessment tool (ICAT) and training curriculum; and customized intervention process and interventions to be used across the six human service agencies operating under the Executive Offices of Health and Human Services/Elder Affairs. In researching PCP models and ICATs, MA Project staff found that the various target populations had different characteristics and needs related to person-centered planning (e.g., PCP models and tools used for people with intellectual and developmental disabilities did not work as well for persons in recovery). As a result, it was decided that each of the six human service agencies would determine the PCP model and related processes and tools that would be implemented for their target population. In addition, it was reported that a PCP Tool Kit is being developed and will be posted on the appropriate web sites. This Tool Kit will include the PCP models and tools selected by the six line agencies to assist consumers and planning staff in developing and implementing person-centered plans. The grantee reported that using this new approach has increased the complexity of the MA PCP Project and has presented a challenge for them to complete their grant within the prescribed, three-year grant period.

As grantees began to train on and implement their PCP models, many reported receiving valuable feed-back from stakeholders (e.g., consumers, families and planning-related staff) that, in some cases, resulted in their PCP models and tools being further refined. In one case, a grantee (GU) started using a well known PCP model (PATH) and conducted some internal training with internal staff, including social workers, on its use. Social workers, the individuals identified to facilitate and person-centered planning process, reported the logistics of doing PATH as "daunting." "The PATH plans require drawings – it's intimidating. Trying to pull together a group with a facilitator, especially a graphic artist, is hard." Currently, Guam is trying to determine if PATH can be revised to address the concerns of social workers or if another PCP model needs to be identified, putting the grantee at risk of not being able to complete their grant in the three-year grant period.

Table 4. PCP Models Selected by Grantee

Grantee	State Developed Its Own PCP Model	PCP Models Used
Alaska DHHS	No	The Planning for Alternative Tomorrows with Hope (PATH) has been adapted to include the principles of wraparound. During the telephone interview, AK reported although PATH works well with a large portion of the target population, facilitators also will be trained in Essential Lifestyle Planning (ELP), McGill Action Planning System (MAPS), and Personal Futures Planning in order to best meet individuals' needs.
Arizona DES/DDD	Yes	Essential Life Style Planning (ELP) is being used as the core PCP model but the grantee is grafting specific components related to vision and community relationships from other PCP tools. Grantee reported this to be the development of a "new" PCP model.
Arkansas DHS/DMS	No	Customized a Wraparound Care Planning PCP model (based on work done by National Wraparound Initiative and includes four phases) that has been used by the AR Child and Adolescences Service System Program. This PCP model was developed specifically in and for Arkansas.
Connecticut DHMAS	Yes	Developed a new PCP model, "Person-Centered Care Questionnaire" (PCCQ) (Tondora & Miller 2009).
Florida APD	No	Using Personal Outcome Measures developed by the Council on Quality and Leadership (CQL).
Guam DISID	No	Initially planned to use Planning Alternative Tomorrows with Hope (PATH) but received feed-back from social workers about the process being "daunting." Project staff is looking at the feasibility of either modifying PATH or finding another PCP model to address social workers' concerns.
Idaho DHW/CDD	No	Building on the existing PCP component currently in place as part of Idaho's *My Voice My Choice* self-directed service option and existing state-approved online support broker training curriculum by adding elements of Essential Lifestyle Planning (ELP), McGill Action Planning System (MAPS), and Planning Alternative Tomorrow's with Hope (PATH). PCP Specialists will be encouraged to use components of these PCP models to individualize the best PCP process for each individual situation.
Louisiana DHH/OAAS	No	Using the PCP model developed by UNH/IOD based on the Team Performance Model (Drexler and Sibbett 1999). It defines predictable stages of the group planning process and offers a comprehensive framework for customizing PCP tools and decision-making approaches.
Louisiana DHH/OMH	No	Using Wellness and Recovery Plan (WRAP).

Grantee	State Developed Its Own PCP Model	PCP Models Used
Massachusetts EOHHS/DMR	Yes	Developing a PCP Toolkit for the six line agencies (reported as "new" PCP model) that includes Essential Lifestyle Planning (ELP), McGill Action Planning System (MAPS) and Planning Alternative Tomorrows with Hope (PATH), Personal Futures Planning (PFP), Whole Life Planning (WLP).
Missouri DMH/CPS	No	Refining and updating basic Person-Centered Planning Guidelines (Adams and Grieder) and encouraging use of existing tools such as Essential Lifestyle Planning (ELP), McGill Action Planning System (MAPS), Community Asset Mapping and Life Books. The Division of Comprehensive Psychiatric Services (CPS) will use Wellness Recovery Action Planning (WRAP) with the help of Peer Support Specialists.
North Carolina DHHS/OLTS	No	Using person-centered thinking and Planning which has evolved from Essential Lifestyle Planning (ELP). The Learning Community for Person-Centered Practices owns the intellectual rights to the curricula and tools.
USM Institute for Disability Services	No	Using a PCP model based on several models (Individual Service Design, Personal Futures Planning, McGill Action Planning System (MAPS) and Essential Lifestyle Planning (ELP)) in which individuals are viewed by their history, current life and what he or she would like in the future.
UNH Institute on Disability	No	Revising the PCP model and visual tools used in developmental services to address the planning and learning needs of older adults and their families. The model is adapted from Drexler/Sibbert's Team Performance Model (TPM) (1999). It defines predictable stages of the group planning process and offers a comprehensive framework for customizing PCP tools and decision-making approaches.
Tennessee DHDD	No	Wellness Recovery Action Plan (WRAP) is being used.
VCU	No	Essential Lifestyle Planning (ELP) is being used by all six states, however, states may deconstruct the PCP model to customize for state use.
Washington DHSS	No	Personal Futures Planning (PFP) and Planning Alternative Tomorrows with Hope (PATH) PCP models has been selected for refinement.
Wisconsin DHFS	Yes and No	Developing a new PCP model that focuses on the participant's perspective based on important aspects of "Trauma Informed Care." This PCP model will be used with individuals with mental health and/or substance abuse issues who are enrolled in the Comprehensive Community Service Program and Community Support Program. The grantee also selected the PCP model, "Person-Centered Approaches to Planning," developed by Adams and Grieder, that will focus on service providers implementing person-centered plans.

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

PCP Implementation Grant 18- Month Progress Report, Follow-up Telephone Interviews and Evaluation Report

Abt Associates staff prepared a Person-Centered Planning (PCP) Implementation Grant 18-month Progress Report template. Each grantee then prepared and submitted an 18-month Progress Report using the report template by April 30, 2009. Ascellon and Abt Associates staff reviewed each of the grantees' 18-month Progress Reports and Ascellon staff provided feed-back to each Grantee. Grantees then were asked to revise their 18-month Progress Reports, as needed, and resubmit them to Ascellon by July 17, 2009.

Abt Associates staff prepared a telephone interview protocol structured around the PCP Grant 18-month Progress Report template. This interview protocol was used to conduct a two-hour phone interview with each Grant Project Director to gain a better understanding of the grantee's implementation efforts, their progress to date and the status of them successfully meeting their grant goals and objectives; and to clarify any information provided in their 18-month Progress Report. The telephone interviews were conducted in June 2009.

A number of grantees reported that the telephone interviews were helpful and provided them with an opportunity to step back and reflect on their project goals, objectives and progress to date and to review the approach they plan to use to complete their grants, including the evaluation component. For example, one grantee realized although they had collected their baseline data for their evaluation, their next data round of data collection (that would be compared to the baseline information), would not occur until after the end of the three-year Grant period. Although the grantee reported a no-cost extension of their grant would provide them with the time they needed to conduct the next round of data collection and complete their evaluation, they might not have any funds to extend based on their grant funds spending to date. So the grantee reported they would have to re-think how they would complete the evaluation component of their grant.

As previously noted, the purpose of this report is to present to CMS:

- the status of progress across the 18 grantees as of March 31, 2009 (the first 18 months of the PCP Implementation Grant),
- the factors that facilitated and/or impeded grantees' progress, and
- how stakeholders, in particular consumers and their families, were included in the development and implementation of grantees' PCP models and processes.

The information contained in this PCP Grant 18-month Summary Report is based on the information provided in the Grantees' revised 18-month reports and the information gathered during the two hour telephone interviews with each of the Grant Project Directors. Throughout the report, grantees are identified to highlight specific efforts that may be particularly informative to CMS and other grantees. In addition, in some cases, quotes are included and designated in italics to provide first-hand accounts of actual grantee experiences. The quotes are not attributed to any specific grantee.

Grantee Experience and Factors That Influenced PCP Grant Efforts

Grantee Experience Level with PCP Compared to Grant Progress and Spending

Grantees were asked what their experience level was with Person-Centered Planning (PCP) at the beginning of their PCP Grant (See Table 5).

- Three grantees (13%)[3] reported their experience was at the "beginner" level (AR and TN under the VCU Project and WI).
- Four grantees (17.4%) reported their experience was at the "beginner/intermediate" level (MO, TN, and GA and VA under the VCU Project).
- Seven grantees (30.4%) reported their experience was at the "intermediate" level (FL, GU, LA OAAS, LA OMH, MA, NC, and SD under the VCU Project).
- One grantee (4.3%) reported their experience was at the "intermediate to advanced" level (OR under the VCU Project), and
- Seven grantees (30.4%) reported their experience was at the "advanced" level (AK, AZ, CT, ID, USM/ISD, UNH Institute on Disability and WA).

Three grantees (AK, ID and USM Institute for Disability Services) noted that their PCP experience level varied among state agency staff and between themselves and their subcontractors. It was found in some cases, grantees' self-reported level of experience with PCP was a good predictor of their level of progress in completing the mandatory and optional components and/or of grant spending as of 18-month mark of the PCP Grant.

Grantee PCP Experience Compared to Grant Progress

There are four activities related to the mandatory components that one would expect grantees to have either completed or nearly completed by the 18-month mark of the PCP Grant. These include (1) selecting, refining and/or expanding their PCP model, (2) developing their informal caregiver assessment tool (ICAT), (3) developing their customized intervention process and interventions, and (4) developing their ICAT training curriculum (See Tables 7-10).

Of the seven grantees that reported having an "advanced" level of experience with PCP at the beginning of the Grant (AK, AZ, LA OMH, ID, USM/IDS, UNH/IOD and WA), three grantees (42.8%) reported completing the selection, refinement and/or expansion of their PCP model (AK, AZ, UNH/IOD), three (42.8%) reported the activity >75 percent complete (CT, USM IDS and WA), and one (14.3%) reported it being 51-75 percent complete (ID).

Of these same seven grantees, four grantees (57.1%) reported they had completed the selection/ development of their ICAT (AK, AZ, ID and UNH/IOD). The remaining three (42.8%) reported the activity 26-50 percent complete (CT, USM/IDS, and WA).

[3] The denominator for the percentages in the bulleted list is 23 to account for the six individual states in the VCU consortium.

Of the seven grantees that reported having an "advanced" level of experience with PCP at the beginning of the Grant, none reported completing the development of their customized intervention process and interventions. Two grantees (28.6%) reported the activity being 51-75 percent complete (AZ and UNH/IOD) and 25-50 percent complete (USM IDS and WA); while three grantees (42.8%) reported the activity 1-25 percent complete (AK, CT and ID).

Finally, two of the seven grantees (28.6%) reported that their ICAT training curriculum was completed (AK and AZ). One grantee (14.3%) reported the activity being >75 percent (UNH/IOD) and 26-50 percent complete (WA). Three grantees (42.8%) reported the activity being 1-25 percent complete (CT, ID, and USM/ISD).

On average, only one grantee (14.3%) that reported having an "advanced" level of experience with PCP at the beginning of the Grant completed > 75 percent of all activities related to the mandatory components (including the development of their evaluation methodologies) (AZ). Of the remaining six grantees:

- two (28.6%) completed 51-75 percent of the activities (AK and UNH/IOD),
- three (42.8%) completed 26-50 percent of the activities (CT, USM/IDS and WA); and
- one grantee (ID) completed 1-25 percent of the activities related to the mandatory grant components (including the development of their evaluation methodologies).

It should be noted that, in the majority of cases, grantees had to be reminded that they needed to include the three CMS-required evaluation questions in their evaluation methodologies.

There were seven grantees (FL, GU, LA OAAS, LA OMH, MA, and NC and SD under the VCU grant) that reported having an "intermediate" level of experience with PCP at the beginning of the Grant. Of these only one (LA OMH) reported the selection, refinement and enhancement of its PCP model as complete. Two grantees (28.6%) reported the activity being > 75 percent complete (NC and SD under the VCU grant); one (12.5%) reported it being 51-75 percent complete (FL), and three (37.5%) reported the selection of their PCP model being 26-50 percent complete.

Of these seven grantees, one grantee (14.3%) reported the selection/development of their ICAT complete (FL) and one grantee (14.3%) reported the activity being >75 percent complete (LA OMH). In addition, two grantees (28.6%) reported the activity 51-75 percent complete (NC and SD under the VCU grant) and two grantees (28.6%) reported the activity 26-50 percent complete (GU and LA OAAS). Finally, one grantee (5.6%) reported the activity 1-25 percent complete (MA).

Of the seven grantees that reported having an "intermediate" level of experience with PCP at the beginning of the Grant, none reported completing the development of their customized intervention process and interventions. One grantee (14.3%) reported the activity >75 percent complete (LA OMH) and 26-50 percent complete (FL) and five (71.4%) reported the activity 1-25 percent complete (GU, LA OAAS, MA, NC, and SD under the VCU grant).

Of these seven grantees, only one grantee (14.3%) reported their ICAT training curriculum completed (FL). One grantee (14.3%) reported the activity 51-75 percent complete (SD under the VCU grant) and four grantees (57.1%) reported the activity 1-25 percent complete (GU, LA OAAS, MA, and NC).

One grantee (14.3%) developed an ICAT and instructions that they considered self-explanatory and did not develop an ICAT training curriculum or planned to conduct ICAT trainings (LA OMH). However, the grantee did report that if an individual needed face-to-face assistance in completing the ICAT assistance would be made available.

On average, no grantee that reported having an "intermediate" level of experience with PCP at the beginning of the Grant completed either >75 percent or 51-75 percent of all of the activities related to the mandatory components including the development of their evaluation methodologies. However, on average, LA OMH completed >75 percent of the activities it chose to complete (two fewer than the other grantees). Three grantees (42.8%) completed 26-50 percent of the activities (FL, NC, and SD under the VCU grant) and three (42.8%) completed 1-25 percent (GU, LA OAAS and MA) of the activities related to the mandatory components including the development of the evaluation methodologies. It should be noted that Guam did not report any progress associated with the development of their evaluation methodologies. In addition, the majority of the grantees had to be reminded that they needed to include the three CMS-required evaluation questions in their evaluation methodologies.

Finally, three grantees reported having a "beginner" level of experience with PCP at the beginning of the Grant (AR, TN under the VCU grant and WI). Of these grantees, none had completed selecting and refining and/or enhancing their PCP models. One grantee (33.3%) reported the activity >75 percent complete (TN under the VCU grant) and two grantees (66.7%) reported they were 51-75 percent complete in selecting and refining/enhancing their PCP model (AR and WI).

Of the three grantees, two (66.7%) reported being 51-75 percent complete (TN under the VCU grant and WI) and one (33.3%) reported being 26-50 percent complete in selecting/developing their ICAT (AR). In addition, of the three grantees that reported having a "beginner" level of experience with PCP at the beginning of the Grant, two (66.7%) reported being 26-50 percent complete (AR and TN under the VCU grant) and one (33.3%) reported being 1-25 percent complete (WI) developing their customized intervention process and interventions. Finally, of the three grantees, and one (33.3%) reported being 51-75 percent complete (TN under the VCU grant) and two (66.7%) reported being 26-50 percent complete with developing their ICAT curriculum (AR and WI).

On average, of the three grantees that reported having a "beginner" level of experience with PCP at the beginning of their Grant, all three (100%) had completed between 26-50 percent of the activities related to the mandatory components including the development of their evaluation methodologies. It should be noted that the grantees had to be reminded that they needed to include the three CMS-required evaluation questions in their evaluation methodologies.

Table 5. Level of Experience with PCP at Start of Grant by Grantee (Self Reported)

Grantee	Beginner	Beginner/ Intermediate	Intermediate	Intermediate/ Advanced	Advanced
Alaska[4]					X
Arizona					X
Arkansas	X				
Connecticut					X
Florida			X		
Guam			X		
Idaho[5]					X
Louisiana (Aging and Adults w/ Disabilities)			X		
Louisiana (Mental Health)			X		
Massachusetts			X		
Missouri		X			
North Carolina			X		
USM Institute for Disability Services[6]					X
UNH Institute on Disability					X
Tennessee		X			
VCU					
GA		X			
NC			X		
OR				X	
SD			X		
TN	X				
VA		X			
Washington					X
Wisconsin	X				

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

[4] AK reported Department of Health and Social Services staff being at the "beginner" level, while their subcontractor, the University of Alaska Anchorage Center for Human Development was at the "advanced" level.

[5] ID Project staff reported one project staff was a "beginner" while the other was "advanced" in their experience with PCP at the start of their Grant.

[6] MS project staff reported their staff as intermediate and advanced. "We've been doing PCP in housing and other programs for over 10 years but new staff may have less experience with PCP."

Grantee Experience with PCP Compared to Grant Spending

At the 18-month mark of the PCP Grant, one would expect grantees to have expended close to 50 percent of their grant funds unless one or more key activities were scheduled to be implemented towards the end of the grant. However, grantee spending overall for the first 18 months of the grant was low (See Table 6). Of the seven grantees who reported having an "advanced" level of experience with PCP at the beginning of their Grant, only two were close to spending 50 percent of their grant budget (USM/IDS and CT), at 48 percent and 40.7 percent, respectively**.** Alaska, Washington and UNH/IOD followed spending 36.7, 36.0 and 35.0 percent, respectively. The remaining two grantees who reported "advanced" experience with PCP at the beginning of the Grant (AZ and ID) spent less than 20 percent of their total grant budget at the 18-month mark, spending 19 percent and 17.4 percent, respectively.

Grant spending also varied significantly and was low for those grantees who reported being at the "intermediate/advanced" and "intermediate" levels of experience with PCP. Grantee spending for this group ranged from a low of 3.8 percent (GU) to a high of 52 percent (LA OMH) at the 18-month mark of the Grant. Spending for grantees who reported being at the "beginner" level of PCP experience was similar ranging from 3.9 percent (AR) to 30 percent (WI).

Grantees reported a number of reasons for low grant spending. In some cases where the grantee was an academic institution, it was reported that low spending was due in part to slowness in the academic institutions' administrative billing systems. Other grantees reported low spending was due part to the time it took to: (1) get the state approvals in place to use the federal grant funds, (2) prepare and issue Requests for Proposals (RFPs) and complete the RFP process; and (3) to make contract awards and get contracts in place with subcontractors; and (4) decisions to change the number and type of subcontractors that were to be used to implement the grant. Others grantees reported the current state budget crisis and hiring freezes negatively affected their ability to hire grant staff in a timely manner.

More than half of the grantees volunteered they would be interested in applying for a no-cost extension for their PCP project, with only one reporting the submission of a formal request for a no-cost extension, as of the 18-month mark of the grant.

Table 6. Grant Spending by Grantee

Grantee	Total Project Budget	Actual Expenditures for 18-Month Period (10/1/07-3/31/09)	Percent Total Budget Spent for 18-Month Period (10/1/07 – 3/31/09)
Alaska	$371,043	$136,170	36.7%
Arizona	$500,000	$97,971	19.0%
Arkansas	$499,807.13	$19,446.84	3.9%
Connecticut	$499,626	$237,873	48.0%
Florida	$478,190	$133,880.51	29.4%
Guam	$489,900	$18,250	3.8%
Idaho	$499,435	$86,870	17.4%

Grantee	Total Project Budget	Actual Expenditures for 18-Month Period (10/1/07-3/31/09)	Percent Total Budget Spent for 18-Month Period (10/1/07 – 3/31/09)
Louisiana (Aging and Adults w/ Disabilities)	$285,000	$54,227.83	19.0%
Louisiana (Mental Health)	$215,000	$111,838	52.0%
Massachusetts	$500,000	$149,806.62	30.0%
Missouri	$499,200	$135,642	27.2%
North Carolina[7]	$490,304	$138,551	18.1%
USM Institute for Disability Services	$274,117	$111,437	40.7%
UNH Institute on Disability	$499,413	$172,922.69	35.0%
Tennessee	$497,208	$101,120	20.0%
VCU	$2,154,474	$519,514.25	24.0%
Washington	$499,796	$181,607	36.0%
Wisconsin	$487,222	$144,265	30.0%

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

Externalities and Their Influence on Grantees' PCP Grant Efforts

Grantees reported a number of externalities that influenced their PCP Grant efforts both positively and negatively. The majority of grantees reported state administration and/or agency leadership as both positively and negatively influencing their PCP Grant efforts. The following summarizes these externalities and their influence on grantees' PCP Grant efforts.

Political/State Agency Leadership Support

Six grantees reported State Government Administration and/or program agency executive leadership to be very supportive and "champions" for their PCP grant activities (GU, CT, LA OAAS, MA NH, and TN). For example, it was reported that the Commissioner and Deputy Commissioners of the Connecticut Department of Mental have issued public letters and a policy directive in support of PCP and related grant activities. It was reported that the Assistant and Deputy Assistant Secretaries for the Louisiana Department of Health and Hospital's Office of Aging and Adult Services were very supportive of the grant, participated on the PCP Workgroup, and function as a "bridge" to other programs where PCP applies so that the PCP project director is included in those efforts to increase communication and collaboration.

The New Hampshire grantee reported that the Administrator of the Bureau of Elderly and Adult Services "has been a strong champion for PCP in public and private meetings and has encouraged agencies and

[7] North Carolina reported $88,550.88 in spending in the first 18 months of the Grant plus an additional $50,000 in spending through 3/31/09 that had not been reported through the system. The total amount ($138,551) has been reported here.

stakeholders to participant in planning and implementation activities." In addition, there has been a change in political leadership in New Hampshire primarily to a Democratic House, Senate and Executive Leadership; and the new Administrator for the Bureau of Behavioral Health, (hired in 2007), has been extremely supportive of PCP and has worked to transform home and community-based supports and services for New Hampshire citizens in recovery.

It was reported that the Administrator of the Wisconsin Division of Mental Health and Substance Abuse is very supportive of the PCP Grant. He is serving as the lead communicator to various state and county mental health entities, encouraging them to avail themselves of the PCP training and technical assistance provided through the grant according to grant staff.

Other grantees reported that the State Legislature, Administration and/or program agency executive leadership to be "neutral" at best towards their PCP grant activities (FL and ID). One grantee reported that their state program administrator could be supportive of the grant when a case could be made that implementing PCP would result in cost savings and streamlining the service delivery system, whereas, the Deputy Administrator see opportunities coming from the grant and implementing PCP and has become a champion within the Agency. Another grantee reported "the Governor's Office really didn't care what we were doing as long as there was an exit strategy that said how we were going to get out [of the grant] and we were not going to increase the number of state employees or cost the state any more money [as a result of implementing the grant]."

Some grantees reported getting local government to buy-in to PCP has been a challenge. For example, the One grantee reported that none of the 11 tribal governments were willing to participate in PCP trainings. Another grantee reported that most report local governments have a "we do things our way" attitude and some see PCP as an administrative (and sometimes financial) burden.

> *Towns/local governments have a lot of autonomy in our state and have not always been supportive of PCP. We have been talking with them about PCP for a long time.*

Federal Policy Issues

Grantees reported a number of federal policy related issues that could have an effect on their PCP grants either directly or indirectly. One grantee reported, "if the current moratorium on implementing changes to case management and other federal Medicaid rules (i.e., limiting habilitation services to rehabilitation services) is lifted, this could affect PCP related activities [negatively]."

Other grantees reported confusion about CMS policies related to the provision of and payment for person-centered planning and related quality monitoring procedures used by federal and state surveyors. Some grantees reported state program administrators, support coordination/case management staff and service providers often referenced federal Medicaid policy (correctly or in error) as reasons for not being able to implement PCP in the manner being proposed. One grantee reported that at a recent training conference for psychology professionals in Virginia, CMS Central office staff reported that the agency was still working on its policies related to PCP and that federal surveyors need additional training in PCP so that "everyone is on the same page." The grantee also reported there has been some concern and confusion in the field regarding CMS regulations and announcement as they relate to medical necessity/reimbursement of treatment plans and the need to distinguish between "active treatment" and "custodial care." Another

grantee found it helpful to have a CMS representative present at each training session to interpret CMS rules as they relate to PCP.

State Policy Issues

The LA OMH grantee reported that the state is moving to eliminate the regional office system which historically reported to Central Office of the Department of Health and Hospitals. They are converting them to local districts and authorities that will be self-governed with a Board of Directors. LA OMH staff reported there are some areas of excellence in the regions, but other areas do not have the infrastructure and expertise to make WRAPs happen even though they may embrace the philosophy of PCP.

Guam has been mandated through a court decision to pass legislation and merge their Department of Integrated Services for Individuals with Disabilities with their Department of Mental Health (see discussion under *Grant Issues* below). It was reported these activities will result in disruption due to moving the PCP grant and function to a new entity and the possible assignment of new staff to the grant and PCP implementation.

Due to the current state budget crisis, support coordinators in Florida, who are also responsible for the PCP function, must rebase 30,000 individuals' cost plans in the Fall of 2009 (see discussion under *Grant Issues* below). It was reported that this activity will result in delaying support coordinator training in the PCP model, tools and procedures until January 2010.

Stakeholder (Non Consumer/Family) Support, Involvement and Feedback

Overall, grantees reported stakeholders have been supportive of the PCP Grant and related activities, and in many cases, have actively sought out training and technical assistance through the grant. However, there have been some detractors. For example, one grantee reported that some clinicians appear to be afraid of losing power through the implementation of PCP. Another grantees reported that some providers are concerned about how they will be reimbursed for the time it take to perform their tasks related to PCP and how PCP activities will take up time that would otherwise be dedicated to the delivery of direct care services.

Some individuals and organizations responsible for conducting PCP (i.e., support coordinators and case managers) reported that doing PCP results in increased administrative burden for already overburdened staff. A number of grantees reported they have worked hard to show support coordinators, case management staff and service providers that PCP can be an efficient way to develop high quality service/care plans that are customized to individuals' needs and preferences but some resistance still exists.

In one case, (GU) case managers actively protested the use of PATH because it requires graphic artist skills, and it is complex and time consuming. This caused the grantee to review whether PATH could be amended or a new PCP model would need to be selected to address the social workers' concerns. This has resulted in a significant delay in implementing a PCP model and other grant activities in the territory.

Another grantee (MA) reported that the support coordinators are unionized. Although grantee staff reported that support coordinators generally they like PCP and the quality of care plans it produces, the

unions are not as supportive of PCP because they believe support coordinators already are overburdened with high case loads and PCP adds to their burden.

The majority of grantees have reported that stakeholders have and continue to provide significant feed-back on the design and implementation of their PCP grants. Grantees have reported that stakeholders have provided feedback through participation on PCP Grant Steering Committees and Advisory Groups, by field testing models, tools and websites; and attending focus groups, trainings and responding to surveys. An example of membership in a typical Grant Steering Committee (LA OMH) includes:

- Relevant DHH agency staff,
- Regional agency executive directors and managers,
- Directors of the State Hospital System,
- District and authority executive directors,
- Consumers and consumer advocates,
- Representatives from the Mental Health Rehabilitation System in LA,
- Representatives from the Clinic System in LA, and
- Directors of community provider and mental health organizations.

Consumer and Family Support, Involvement and Feed-back

Grantees reported consumers and family members overall have been supportive of PCP and the grant; and, in many cases, have contributed significant feed-back and guidance on how the grant has been designed and being implemented. It was reported that consumer/family involvement most often occurs through PCP Grant Steering Committees and Advisory Groups (the majority of grantees), consumer and family networks (AR), and community coalitions (MA). In some cases, grantees reported the involvement of advocacy groups more than individual consumers and family members and some reported recruiting elders and their families to be a challenge (LA OAAS and UNH/IOD). Grantees also reported that consumers and families have been providing significant feed-back by field-testing the PCP models, tools and web sites; and by participating in focus groups, trainings and responding to surveys. PCP grant staff are aware that consumer/family participation represents a significant time commitment and expense. As a result, it was reported they continue to try to refresh consumer and family member representation and have used grant funds to defray travel related costs.

Grant Integration

A number of grantees reported having one or more federal (CMS, SAMHSA, AoA) grants in addition to their PCP grant. Of those grantees, 67 percent (AK, CT, GU, LA OAAS, LA OMH, ID, MO, NC, WA and WI) reported engaging in ongoing collaboration with other grant staff on PCP-related issues and found the collaboration beneficial. As one grantee put it, “we are trying to incorporate PCP and person-centered thinking in everything we do.”

Collaboration was reported to occur in a number of ways. One grantee reported collaboration being informal in nature. A significant number reported that grant staff were members of each other’s Grant Steering Committee or Advisory Group. At least one grantee reported that the same state agency staff are involved in leading and/or working on multiple federal grants, thus creating a level of synergy and collaboration. In addition, at least one grantee reported the various federal grants shared a common

Stakeholder Advisory Group which enhanced communication and collaboration. Finally, a number of grantees reported they are using funding from multiple grants to achieve common objectives.

Grant- Specific Issues

Grantees reported a number of state-specific issues that were affecting the implementation of their PCP grants. One issue reported by the majority of grantees was the fiscal/budget crisis states currently are experiencing and that appears to be only getting worse over the next few years. Grantees reported significant reductions in state agency staff due to the implementation of hiring freezes, layoffs and early retirement programs. They also reported reductions in state general funds available to support program infrastructure. As a result, grantees are seeing increased caseloads and reduced funding available which is delaying work on anything but essential activities.

For example, one grantee reported a significant increase in state agency vacancies due to the implementation of an early retirement program and reported their agency's IT and ES budget had been "swept" in a recent round of state budget negotiations. However, the same grantee reported that the state agency vacancies might end up being an opportunity for them down the road in getting more peer specialists trained and hired to facilitate and expand the use of person-centered planning statewide when/if the state budget issues are resolved. Another grantee reported that due to budget issues and related legislative mandates, they have encountered constant conflicting priorities that have caused a delay in PCP grant implementation.

The Florida grantee reported that due to the state budget crisis, support coordinators, who will be trained in PCP under the grant and use person-centered planning practices, must rebase all participants cost plans (there are approximately 30,000 plans to be rebased) in the fall of 2009. This is the same time support coordinators were to be trained in PCP. As a result, support coordinator training on PCP must be postponed until January 2010.

Guam reported addressing a civil case against Department of Integrated Services for Individuals with Disabilities (DISID) as a result of the Olmstead decision as being a significant externality that is distracting state agency staff from the PCP grant. As a result of the court decision, DISID has to transition over 200 consumers into the community and they have been instructed to draft a bill in the Legislature to merge DISID and the Department of Mental Health. The grantee reported if the merger takes place, the PCP grant will be moved to the Department of Mental Health with potentially new staff assigned to manage the grant. If the merger does not take place, the court monitors may look at remanding the agencies to the US Marshall and to Federal receivership. In addition, in November 2008, the Governor issued an executive order transferring all group homes from DISID to the Department of Mental Health.

LA OAAS grant staff reported they continue to have to address competing priorities related to hurricane recovery as a result of Hurricanes Katrina and Rita and to the annual hurricane season in general. For example, they have to develop their PCP training schedule to avoid holding trainings in September and October, when hurricanes are likely to occur.

Grantees' Progress Related to Mandatory Component Activities

As noted in the Introduction of this report, each PCP Implementation Grant was required to address three Mandatory Components:

- A distinct PCP model is selected, refined, and/or expanded on, including a systematic "informal" support assessment and intervention process for individuals' informal support caregivers;
- An "informal community network" assessment and intervention process for the individual to create enduring and meaningful ties to organizations in his/her community; and
- A proposed evaluation of quantifiable outcomes including three CMS-related outcome measures.

As minimum requirements, each grantee had to (1) describe their PCP Vision including the target population(s), (2) geographic reach, (3) who and which organizations will participate in the grant process to meet the vision, and (4) which Optional Components, if any, will be implemented. Grantees also had to describe (1) the PCP model to be implemented/expanded, (2) how consumer preferences will be elicited and customized choice developed, (3) who will be trained on the PCP model, (4) the informal caregiver assessment tool to be used, (5) the training that will be provided and to whom, (6) how the informal caregiver assessment tool will be sustained, (7) how customized interventions based on the assessment will be developed for consumer's informal supports, and (8) the time intervals and criteria for reassessment.

From the grantee requirements and mandatory components, nine activities were identified and grantees' progress was reviewed. Activities include:

- Selecting, refining and/or expanding a PCP model(s),
- Developing/selecting of informal caregiver assessment tool (ICAT),
- Developing customized intervention process and interventions related to the ICAT,
- Developing of ICAT training curriculum,
- Conducting ICAT training,
- Developing statewide policies and procedures,
- Developing of informal community network assessment and intervention process,
- Incorporating connections to the community and "friendships" into PCP, and
- Developing evaluation methodologies including the incorporation of three CMS-required outcome questions.

The following provides a summary of grantees (1) PCP Vision, (2) progress as of March 31, 2009 for each of the activities; (3) issues specific to the activity; (4) the factors that facilitated and impeded

grantees progress in completing the activities; (5) how stakeholders, including consumers and family members were included in the design and implementation of each activity; and (6) any promising practices that appear to be emerging.

PCP Vision

Grantees were required to describe their PCP Vision in the 18-month PCP Progress Report template. In addition, they had to indicate how their PCP Vision will:

- strengthen and expand the use of PCP models in the state;
- assure that PCP systematically incorporates informal support and community network assessment tools;
- assure that professionals (including hospital discharge planners) working in critical pathways to long-term care supports and services receive training on the new assessment; and
- develop new interventions to support caregivers and builds ongoing ties for consumers to their consumers to their community network organizations and friendships.

Seven grantees (38.9%) clearly articulated their PCP Vision and indicated how their PCP Vision would address the four elements bulleted above (AR, CT, FL, ID, LA OAAS, VCU, and WI). Some grantees reported their PCP Vision was incorporated into larger statewide LTC Reform initiatives and other federal grant opportunities. For example, North Carolina reported that all PCP Grant activities and other federal grants are built around the vision and mission adopted by the Long Term Services and Supports Cabinet of the North Carolina Department of Health and Human Services in 2007. Arkansas reported their PCP grant activities were included in the state's *System of Care* reform initiative. Connecticut reported some of their PCP Vision comes from their SAMHSA Mental Health Transformation Grant work. New Hampshire reported it has legislation that mandates that all planning activities be person-centered.

Two grantees (LA OMH and MO) chose not to complete one or more of the mandatory requirements. LA OMH reported their informal caregiver assessment tool (ICAT) and instructions are self-explanatory and, therefore, training is not necessary (so they did not prepare an ICAT training curriculum or conduct ICAT training). Missouri has not planned to implement an ICAT, ICAT curriculum or training and does not plan to develop a customized intervention process and interventions for the ICAT. North Carolina reported they are trying to spread person-centered thinking (PCT) throughout the state and the ICAT requirements do not fit well with their PCP Vision. They would rather not develop a specific ICAT, ICAT training curriculum, training and a customized intervention process and interventions (although they reported progress on all four activities in their 18-month PCP Grant Progress Report).

Selection, Refinement and/or Expansion of the PCP Model and PCP Process

As mentioned earlier in this report, one activity that grantees should be close to completing by the 18-month mark of the PCP Grant is selecting refining and/or expanding their PCP model. Table 7 below describes the progress grantees have made in selecting, refining and/or expanding their PCP model and their PCP process as of the 18-month mark of the grant.

Table 7. PCP Model Selected, Refined and/or Expanded - Percent Complete by Grantee

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Alaska					X
Arizona					X
Arkansas			X		
Connecticut				X	
Florida			X		
Guam		X			
Idaho			X		
Louisiana (Aging and Adults w/ Disabilities)		X			
Louisiana (Mental Health)					X
Massachusetts		X			
Missouri		X			
North Carolina				X	
USM Institute for Disability Services				X	
UNH Institute on Disability					X
Tennessee		X			
VCU (applies to all states in collaborative)				X	
Washington				X	
Wisconsin			X		

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

Grantee progress related to completing this activity varied by grantee and tended to track with their level of experience with PCP at the beginning of their grants. As of the 18-month mark of the PCP grant, only half (9) of the grantees were >75 percent or more complete with selecting, refining and/or expanding their PCP model (AK, AZ, CT, LA OMH, NC, USM/ISD, UNH/IOD, VCU (all collaborative states) and WA), seven of which reported having an "advanced" level of experience with PCP at the beginning of the Grant.

Issues Related to PCP Models Selection, Refinement and/or Enhancement and the PCP Process

A number of issues were identified related to PCP model selection, refinement and/or expansion and the PCP process grantees are implementing.

1. In many cases, grantees reported that some stakeholders in their states believed they were doing PCP already. However, when grantees dug deeper, they found it really was not happening and had to convince stakeholders of this and get their buy-in to develop and implement *real* person-centered planning. One grantee reported,

> *I was told PCP was being done already and why did we have to change the current process. When I asked how it was being done, I was told 'the consumer gets to sign his/her plan.' This is not PCP.*

2. A number of grantees chose to use more than one PCP model and/or related tool to implement PCP (See Table 4). One reason given for using this approach was to ensure that assessment and planning staff have the PCP models and tools available to customize service plans to meet the needs and preferences of consumers and families. Grantee staff did not want assessment and planning staff to fall back into creating service plans using a "cookie-cutter" approach that resulted in plans that were "one size fits all." Another reason given by grantees for using one or more PCP models and tools was to provide consumers and their families with the models and tools they felt comfortable using and most met their needs and preference.

   However, using multiple PCP models and tools can raise the complexity of implementing PCP and monitoring its implementation by state quality assurance agency staff. If PCP models, tools and procedures are not implemented in a consistent manner, it can result in "systems equity issues" where access to and implemented of PCP can be inconsistent across a state.

3. Grantees who selected and refined and/or enhanced, established, easy to understand PCP models often found it easier to get "buy-in" from individuals and organizations responsible for implementing person-centered planning; to implement their PCP model and tools; and make person-centered planning available to large numbers of consumers and facilitators system wide. For example, one grantee implementing WRAP for persons in recovery noted that the tool has a definite structure and process that is clear and easy to use by persons in recovery and WRAP facilitators and clinicians. This resulted in it being accepted, in large part, by these stakeholders.[8]

   Also, the ease of the PCP process often resulted in increased "buy-in" from stakeholders. For example, Tennessee's plan was to implement a "train the trainer" model related to the implementation of WRAP. As a result, they have trained 126 WRAP facilitators to date, and each of these facilitators has committed to training 15 consumers in using WRAP by the end of the grant. Similarly, North Carolina, using Person-Centered Thinking and Planning which has evolved from Essential Life Style Planning or ELP, has trained 400 persons in "person-centered thinking" principles. North Carolina plans to almost double that number by the end of the grant.

   Some grantees reported incorporating PCP elements and tools into the state's existing service planning process helped to streamline the planning process and reduce administrative burden,

[8] One grantee reported they are still working with mental health clinicians, in some instances, to recognize the value of WRAP, encourage their patients to consider developing WRAP plans, and include the WRAP plans in their treatment of persons in recovery.

often resulting in "buy-in" from stakeholders and overall sustainability. For example, Florida is amending its use of Personal Outcome Measures (POMs), which it uses in its service planning process, to include the enhanced person-centered planning elements. The refined POM tool allows the support coordinator to look comprehensively and plan for participants' needs and then, throughout the year, it allows them to update the plan, based on progress made, over time. Another grantee reported:

> *We are trying to meet clinicians and providers where they are and then have the PCP Champions talk with them about their experiences and the benefits of PC.*

By contrast, some grantees selected to implement more complex PCP models and processes. For example, Guam chose to implement PATH. When PATH was initially implemented, Guam received significant negative feed-back from social workers who are responsible for the service planning process. Feed-back from social workers highlighted the complexity of the tool and the need for graphic artist resources to "draw" the PATH plans. The Guam grant team now is in the process of determining whether it should revise PATH or find PCP model that will be more accepted by social workers. This has significantly delayed the implementation of Guam's PCP model and resulted in them scaling back their implementation plan from facilitating 300 PATH plans to 100 by the end of the grant period.

4. Some grantees noted that, often when a plan is developed, it is difficult to get it through the approval process in "one piece." One grantee reported:

> *Support coordinators are strong advocates for PCP. However, they are caught in a system that requires a pre-service authorization process that is so onerous and bureaucratic that they can't do PCP and submit their plans for approval without them [the plans] being picked apart. It is a real struggle to keep support coordinators engaged in the person-centered approach with the people they serve."*

5. Some grantees raised the question, "Once a person-centered plan is created, are consumers' outcomes achieved and does a state have a process in place to monitor plan progress?" These grantees reported that unless consumers' outcomes are achieved, a person-centered plan, in itself, is not very valuable. Although many grantees thought it was important to have a process for reviewing how plan implementation is going and track whether consumers' outcomes are being achieved, the majority reported they were not at that stage yet because they were still in the process of implementing their PCP models and tools. One grantee had some interesting insight on this issue:

> *You can have a beautiful PCP but if there is no ongoing review of how things are going and if plan changes need to be made and different approaches taken to achieve the desired outcomes, and the outcomes are not achieved, the PCP is not valid and useful. A couple of a ways we are trying to monitor this on a value level is through the Participant Experience Survey (PES) so we can get an idea of some issues and trends. On an individual basis, this process is really up to the case manager. They are supposed to do at least a quarterly review of people's plans. But that tends not to happen and everyone gets back together a year later and says, "what happened? Why was the plan*

> *less than successful?' In our PCP model and process there are some analysis tools people can use when they "get stuck" to figure out what they should do* [to modify the plan to achieve the desired outcomes]. *My experience is you get a great plan, you figure out how to implement it, services are identified and we are on our way. Then two months later something happens and no one knows what to do, and typically the caregiver says, 'now what do I do?' I feel there needs to be a stronger feed-back loop once plans are implemented. I think it's a bigger issue with the developmental disability population (DD) than with the elderly because elders' situations and plans tend to change more often and have to readjust things all the time. With DD it could be almost a year before someone says, 'how come he/she didn't get that job?'*

During the telephone interviews, some grantees questioned the wisdom of raising the hopes of consumers through person-centered planning, only to tell them that the services they outlined in their plans are not, in fact, available. Washington State, an advanced, long-time user of PCP, chose to focus its grant entirely on elucidating the issues that prevent PCPs from being implemented among a group of 36 working-age developmentally disabled consumers in three counties. A county coordinator is working with consumers and their families in each county to remove obstacles to employment; the state plans to distill the lessons learned so that other counties can find ways to apply the lessons in a less cost-intensive, more sustainable way. Results from Washington State's study should be very valuable to other grantees as well.

6. Grantees also raised the importance of having a "risk free" environment available for planners, clinicians and providers to discuss why plans are not working or why certain services have not been provided without fear of penalty. This issue was raised by Michael Smull and colleagues at the meeting in Washington, DC in May 2009 with the six collaborating state agencies under the VCU grant. A concern raised by attendees was there is a disincentive to "tell all" for fear of being sanctioned through a state's quality assurance process. Another non VCU grantee reported,

> *This* [discussion of what is working and not working] *is supposed to happen during the quarterly review. The case manager is responsible for making sure the review happens and the process includes, at a minimum, the consumer, his/her case manager and the service provider(s). In a truly person-centered system it would be whoever the person includes in the process, but I don't think this is happening regularly.*

7. Several grantees used the web to post their PCP tools and resources, share their practice, and learn from communities of practice. However, in some states where traditional service planners were resistant to PCP, grantees turned to the web to directly connect to consumers with needed services and PCP tools. For example, when social workers in Guam expressed reluctance to use the PATH model, Guam focused most of its attention on developing a consumer interface for the Guam GetCare site, where consumers can book their own services "like travelocity, but for your services." Similarly, when Mississippi schools would not allow the grantee sufficient time in the schools to conduct in-person trainings, the grantee switched to a resource CD/online resource approach, combined with consumer trainings, to promote the use of PCP directly to students.

   Other states used the web as a networking tool to improve the practice of PCP, by posting curricula, new materials, and in some cases, PCP Toolkits, on one or more state approved web

sites. For example, North Carolina posts its curricula to the online *Learning Community for Person-Centered Practices,* a website that was created by practitioners of *Essential Life Planning (ELP).* When the PCP models and tools are complete, Massachusetts will prepare and post a PCP Toolkit that includes all of the PCP models and tools to be used by the six line agencies on the various agencies' web sites.

8. A final issue raised was how long it should take to implement PCP statewide for the target populations. Responses varied and many grantees reported they just did not know. One grantee reported it should take three to six months from when the PCP, ICAT and ICAT manual and other related tools are complete to implement PCP statewide. However, others reported taking at least three to five year to implement PCP statewide across all populations. One grantee reported:

> *I think to develop your PCP model and process it should not take more than 2-3 years. But to have it functioning in a way that is highly effective and gets PCP embedded and used by all service delivery systems – that could take some time.*

Another grantee reported:

> *What works for one target population (i.e., persons in recovery or adults with physical disabilities) may not work well for another (i.e., persons with developmental disabilities). So implementing PCP statewide across six different target populations is going to be an iterative process especially during a time of limited state resources when we have to get people thinking about using resources wisely.*

Finally, a grantee reported:

> *Part of the system wide implementation of PCP is the ability to be able to bill Medicaid for the activity. How long that is going to take is an open question because our state is in the middle of bringing on a new MMIS. This is a big initiative and we are about a year into the process. Once the MMIS transition is over we will have a much more flexible system. Another big issue that could effect implementation time is the regulatory issues related to providing PCP across target populations. There is a lot more analysis that needs to be done on this issue.*

Factors that Facilitated PCP Model Selection, Refinement and/or Enhancement and the PCP Process

Grantees reported a number of factors that facilitated PCP model selection, refinement and/or enhancement and the PCP process. They include:

- *We researched well know PCP models and then created a comparison chart that included all of the models, the populations they were designed for and any "success" information available. This was helpful.*
- *When implementing PCP for multiple target populations, we found a number of similarities across the populations related to PCP implementation.*

- *Attitude of key stakeholders (consumers/families, assessment and planning staff, state program agency staff, clinicians and service providers) towards PCP.*
- *Conducting community roundtables with stakeholders including professionals, advocates and parents was very helpful in making the decision to go with a Wraparound PCP model.*
- *Having a PCP process already used for a particular population was helpful.*
- *We* [subcontractor responsible for conducting PCP training] *were skilled facilitators.*
- *Our Commissioner and Deputy Commissioner have supported and facilitated the Grant. They have been Project Champions.*
- *Having our consultant subcontractor* [Copeland Center] *provide consultation on the PCP Grant activities was very helpful.*

Factors that Impeded PCP Model Selection Refinement and/or Enhancement and the PCP Process

Grantees reported a number of factors that impeded PCP model selection, refinement and/or enhancement and the PCP Process. They include:

- *The lack of information about PCP model "successes."*
- *Challenges and competing demands presented by current state budget issues.*
- *Attitude of key stakeholders (consumers/families, assessment and planning staff, state program agency staff, clinicians and service providers) towards PCP.*
- *Some believe you cannot bill for PCP.*
- *How do you reimburse service providers for doing PCP?*
- *There has been some concern/confusion regarding potential obstacles of fiscal and regulatory requirements (e.g., the perception of increasing pressure from CMS regarding the need to document the 'medical necessity' of service).*
- *The state had been doing some type of PCP but whether it was being done correctly and in a standard way was another question.*
- *Working out financing issues. Up until now wraparound was done in a "hit or miss' fashion.*
- *Wraparound is very family driven. Some professionals think this level of involvement is good while others feel families cannot do it at the level they are expected to do it.*
- *We are consistently hearing that the PCP process takes more time and it does to do it well.*
- *Implementing PCP under a Medicaid §1115 waiver and a managed care model (which is more acute care oriented) is challenging. A Notice of Action must be issued within a certain time period if a service is not provided. The service planning process was more flexible before the BBA – we could sit down with families and the managed care provider and construct a workable service plan.*

- *The complexity of the target population (youth age 14-21 with co-occurring disorders transitioning from institutional or out-of-home settings to the community).*
- *The target populations chosen for this grant involve many different funding streams, oversight agencies, politics and players. This creates complexities in how to approach implementing policy change, training and shifts in culture.*
- *The time available to develop and implement the PCP model, tools and other grant-related activities.*
- *How do you implement PCP in a very rural state and one that has a large Inuit population with their own unique culture and community?*
- *How do we determine that the individuals responsible for facilitating PCP in the state embrace PCP and the model selected to be implemented?*
- *Developing the electronic care plans that PCP will be embedded into.*
- *Obtaining feedback from all partners and stakeholders and meeting timelines was a challenge.*
- *Although the concepts of wellness and recovery are rapidly becoming integrated into our system of care, the readiness of implementing WRAP has varied by region/district. Some locations have had issues identifying self-sustaining options for implementation and have been slower to get people trained and groups started. This has been due in equal part to economic difficulties and the transitioning of our state system to local government entities.*
- *Negotiating the contract with the School of Social Work was more complicated than anticipated.*
- *We did not anticipate that the "Building a Person-Centered Organization" process would need more than one year per agency to complete.*

Stakeholder Involvement with PCP Model Selection, Refinement and/or Enhancement and Benefits

In general, grantees included stakeholders in PCP model selection, refinement and/or enhancement activities through membership in grant advisory/steering committees and workgroups. Some grantees also conducted special roundtables/focus groups and surveyed stakeholders to obtain feed-back on PCP Grant design, implementation and deliverables related deliverables (such as field testing websites, networks and informal caregiver assessment tools). When a target population is the elderly, grantees reported it is a challenge to recruit elders and their family members to participate as stakeholders for their PCP Grants.

The following describes some ways in which grantees included stakeholders (including consumers and family members) in PCP model selection, refinement and/or enhancement and some benefits for doing it.

- *Stakeholders were included through the Grant's Leadership Group and the Coordinating Council. Stakeholder input was helpful because it stressed that the PCP model(s) and process had to be understandable and user-friendly for consumers. "Imagining signing off on something you can not read."*

- *Stakeholders were brought in very early so they could help us understand the problems with our current treatment planning system including the lack of consumer involvement. They gave us lots of ideas about how to streamline the PCP process so it is not so burdensome for all involved. They have particularly supported the "peer" component.*
- *Stakeholders were included through the Behavioral Health Care Commission and the roundtables we conducted. We have gotten so much feed-back about the wraparound approach that we are going to use. Stakeholders have really stressed they want to make sure that the PCP model used results in the creation of individual processes and plans.*
- *We pulled together a group of people who we knew had a heart for PCP and were committed to it. There was great value in including them. Key issues discussed were how to do make sure the individuals facilitating PCP really embrace the philosophy and model selected; and how can we involve individuals in the process who are from the very rural parts of the state, where, in some cases, there are no roads in the winter?*
- *Stakeholders were included in our Project Steering Committee and other workgroups and they participated in 10 focus groups and training sessions at the two state psychiatric hospitals. They gave us a lot of ideas about streamlining the PCP process so it is not so burdensome for providers.*
- *Stakeholders completed surveys related to the PCP model and tools. They also were included in the PCP Workgroup. The value of including them is many of them work directly with participants throughout the state.*
- *Stakeholders have been included through the Project Steering Committee and survey feed-back from WRAP Groups. Over 50 percent of the Steering Committee is comprised of consumers, family members and community-based providers.*

Potential Promising Practices

For many grantees, it is too early to identify possible promising practices related to the selection, refinement and/or enhancement of their PCP processes. However, some examples have been identified as potential promising practices as a result of reviewing grantees' progress up through the 18-month mark.

The Connecticut grantee reported they have developed the concept of "Project Champions" related to its PCP grant effort. First, the Grant Steering Committee members determined they wanted to identify "Project Champions" from each of the nine sites where PCP training will occur. The Department of Mental Health and Addiction Services Deputy Commissioner, in collaboration with each regional DMHAS agency CEO, then identified individuals who were already on board and supportive of PCP. These individuals then were recruited to be "Project Champions", now attend the Grant Steering Committee meetings and are responsible for implementing PCP training and the other changes proposed under the grant in their region. The grantee also reported they want to move away from large group trainings and towards smaller groups using a "technical assistance" approach. For example, the Project Champions will be responsible for working with small groups in their regions to review consumers' person-centered plans, identify issues and provide feed-back to that particular site.

The Florida grantee also is developing a similar individual and function through the development and training of Area Quality Leaders (AQLs). A challenge reported with this approach is, due to competing

demands and scare resources, whether the AQLs' bosses will allow them to dedicate the time needed to be a successful AQL.

The Louisiana OMH grantee has implemented WRAP using a completely self-directed approach. The grantee reported "the WRAP process is truly self-directed and 'owned' by persons in recovery. It's the person in recovery who decides if he/she wants a WRAP plan, who will be involved in developing and facilitating the plan, what is included in the plan, if his/her supporter(s) (informal caregiver(s)) will complete the self-assessment tool and how their information will be incorporated in the plan; and when a WRAP should be updated." Under the PCP model, WRAP facilitators are persons in recovery who have been trained to perform the WRAP process. LA OMH grant staff reported an important next step for implementing WRAP in their state is to get mental health professionals to (1) recognize the WRAP process and its value to a person's recovery, (2) suggest WRAP to their clients, and (3) use/incorporate the WRAP plan in the treatment of their clients.

Development/Selection of an Informal Caregiver Assessment Tool (ICAT)

A second mandatory component activity for grantees that should have been close to complete by the 18-moth mark of the grant is developing/selecting an informal caregiver assessment tool (ICAT). Table 8 below describes grantee progress in developing/selecting an ICAT as of the 18-month mark of the grant.

Table 8. Development/Selection of an Informal Caregiver Assessment Tool (ICAT) - Percent Complete by Grantee

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Alaska[9]					X
Arizona					X
Arkansas		X			
Connecticut		X			
Florida					X
Guam		X			
Idaho					X
Louisiana (Aging and Adults w/ Disabilities)		X			
Louisiana (Mental Health)				X	
Massachusetts	X				
Missouri[10]	Not completed				

[9] This component was not included in Alaska's original, approved proposal. They are implementing it through the use of the National Wraparound Initiative Family Caregiver Assessment Tool.

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
North Carolina			X		
USM Institute for Disability Services		X			
UNH Institute on Disability					X
Tennessee					X
VCU (applies to all states in collaborative)			X		
Washington		X			
Wisconsin			X		

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

All grantees except for Missouri reported developing an ICAT, however, North Carolina was doing so reluctantly because they felt the ICAT requirements do not fit well with their PCP Vision and they would rather not develop a specific ICAT tool, ICAT training curriculum, training and a customized intervention process and interventions (although they reported progress on all four activities in their 18-month PCP Grant Progress Report).

As of the 18-month mark of the grant, one third of grantees (6) reported their ICAT was complete (AK, AZ, FL, ID, UNH/IOD and TN), one (5.6%) reported it being >75 percent complete (LA OMH) and three (16.7%) reported their ICAT 51-75 percent complete (NC, VCU-all collaborating states and WI). However, six grantees reported their ICAT 26-50 percent complete (AR, CT, GU, LA OAAS, USM/IDS and WA) and one (5.6%) reported being only 1-25 percent complete (MA).

[10] This activity was not included in Missouri's original, CMS approved proposal

Issues Related to the Development/Selection of an Informal Caregiver Assessment Tool

One issue raised by a grantee (related to the development/selection of an ICAT tool) was determining informal caregivers' needs and preferences, and then being able to deliver on their expectations of support. One grantee reported:

> *If we develop and implement an informal caregiver assessment tool, and obtain information from informal caregivers about their needs and preferences, does this mean we have to provide these supports even if they are not available or there is no funding available for them? What if we don't provide them?*

Another grantee reported that one way to address this issue is to identify any non-paid supports for the informal caregiver first and focus any customized interventions in that area. Then look to see if any paid supports may be available to address other needs that have been identified.

Factors That Facilitate the Development/Selection of an Informal Caregiver Assessment Tool

Grantees identified a number of factors that facilitated the development/selection of an ICAT tool. These include:

- *The expertise available from our Grant Steering Committee and our subcontractor has been very helpful.*
- *Technical assistance from our consultant subcontractor has been very helpful.*
- *Talking with people who are currently doing wraparound and looking at what is coming out of the Portland National WRAP Institute has been helpful.*
- *Receiving feed-back from the stakeholders (including persons in recovery and agency staff) through focus groups and training sessions (both opinions and perceptions) has been very helpful—we got to hear both sides of the issues from both their perspectives.*
- *Using the LENS process developed by the Council on Quality Leadership facilitated the development of the ICAT. It has been accepted even more than I originally thought and has been very successful.*
- *Using the UNH/IOD ICAT.*

Factors That Impeded the Development/Selection of an Informal Caregiver Assessment Tool

Grantees identified a number of factors that impeded the development/selection of an informal caregiver assessment tool. These include:

- *A challenge has been assessing the natural support systems in the state, particularly in rural areas and Inuit communities and having the professional support system to do this.*

- *Making sure consumers feel comfortable going through the PCP process, their voices are heard, and their plans reflect their needs and desires, has been a challenge.*
- *Delays in getting our contract in place with our consultant subcontractor.*
- *Waiting for UNH/IOD to finalize the ICAT.*
- *Trying to reconcile the informal caregiver assessment tool with our grant and traditional caregiver assessment tools has been a challenge.*

Stakeholder Involvement with the Development/Selection of an Informal Caregiver Assessment Tool (ICAT) and Benefits

In general, grantees included stakeholders in the development/selection of an ICAT through membership in grant advisory/steering committees and workgroups. Some grantees also conducted special roundtables/focus groups and surveyed stakeholders to obtain feed-back on PCP Grant design, implementation and deliverables related deliverables (such as field testing websites, networks and informal caregiver assessment tools). When the target population is the elderly, grantees reported it is a challenge to recruit elders and their family members to participate as stakeholders for their PCP Grants. The following describes some ways in which grantees included stakeholders (including consumers and family members) in the development of an ICAT and some benefits for doing it.

- *Stakeholders have been involved through the PCP Advisory Group and their input has been invaluable related to their knowledge of and experience with the Inuit culture and community.*
- *Stakeholders have been involved since the beginning of the Grant and we have based many of our decisions on feed-back we have received from stakeholders at the pilot sites-they have a lot of family voice and involvement.*
- *Stakeholders were involved through attending 10 focus groups and also training sessions at the two state psychiatric facilities.*
- *Stakeholders were involved through the Project Steering Committee and the provision of survey feed-back from the WRAP groups. Over 50 percent of the Project Steering Committee is comprised of consumers, family members and community-based providers. It was the Steering Committee that determined that there was no need for an ICAT training curriculum or trainings.*

Potential Promising Practices

Although it is too early to determine if there are any promising practices related to the development/ selection of an informal caregiver assessment tool (ICAT), New Hampshire's ICAT may be emerging as a possible promising practice.

Development of Customized Intervention Process and Interventions

A third mandatory component activity that grantees should be close to completing by the 18-month mark of the PCP Grant is the development of a customized intervention process and interventions. Table 9 below describes the progress grantees have made with this activity as of the 18-month mark of the grant.

Table 9. Development of Customized Intervention Process and Interventions - Percent Complete by Grantee

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Alaska[11]	X				
Arizona			X		
Arkansas		X			
Connecticut	X				
Florida		X			
Guam	X				
Idaho	X				
Louisiana (Aging and Adults w/ Disabilities)	X				
Louisiana (Mental Health)				X	
Massachusetts	X				
Missouri[12]	Not completed				
North Carolina	X				
USM Institute for Disability Services		X			
UNH Institute on Disability			X		
Tennessee					X
VCU (applies to all states in the collaborative)	X				
Washington		X			
Wisconsin	X				

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

Only one grantee (5.6%) reported completing their customized intervention process and interventions (TN), and being >75 percent complete (LA OMH); and two grantees (11.1%) reported being 51-75 percent complete (AZ and UNH/IOD). The remaining grantees reported being less than 51 complete with this activity.

[11] This activity was not included in Alaska's original, CMS approved proposal. The 18-month report states, *This project has not defined a set of processes for family/caregiver interventions outside of the youth's PCP, as it is outside the scope of our accepted proposal. However, interventions need to ensure that the success of the PCP are incorporated into the planning process.* The grantee reported the activity as being 1-25 percent complete.

[12] This activity was not included Missouri's original, CMS approved proposal.

Issues Related to the Development of a Customized Intervention Process and Interventions

Two grantees (AK and MO) reported this activity was not included in their original CMS approved grant proposal. Missouri chose not to include it. Alaska reported it is being addressed through the planning process and growing formal and informal connections (e.g., aide in the classroom, respite worker, neighbor) building not only on family connections but also with other key individuals to expand the individual's formal network.

Factors that Facilitated the Development of Customized Intervention Process and Interventions

Grantees reported a number of factors that facilitated the development of a customized intervention process and interventions. They include:

- *Funding received from the state legislature has facilitated the development of a customized intervention process and interventions. We are working hard to get new funding and to use existing funding effectively.*
- *It was realizing our system was broken and seeing a rise in hospitalizations, particularly with kids under the age of five.*
- *Using UNH/IOD's customized intervention process and interventions.*
- *Just the way the WRAP process is set up facilitates the development of a customized intervention process and interventions.*

Factors that Impeded the Development of Customized Intervention Process and Interventions

Grantees reported a number of factors that impeded the development of a customized intervention process and interventions. They include:

- *Not having sufficient funding to do what we need to do.*
- *A challenge is we are breaking new ground towards developing a customized intervention process and interventions to meet the needs of caregivers.*
- *The majority of impediments have been attitudinal. People are not use to doing business this way. Clinicians feel they are loosing some power. Some people have reported "This is not part of my job. We do systems, we do groups." Whether or not they [people in recovery] make a life in the community is up to them.*
- *Some sites have a large peer support staff while other sites do not. This makes a big difference.*
- *We had to go back to the drawing board with the support coordinators and their expectations. They had drifted away from focusing on individual planning and trying to*

construct services with an individual focus because of bureaucracy, our pre-service authorization system and state fiscal issues.

- *Waiting for UNH/IOD to complete their customized intervention process and interventions.*
- *Obtaining feedback from all partners and stakeholders and meeting timelines was a challenge.*

Stakeholder Involvement in the Development of a Customized Intervention Process and Interventions and Benefits

In general, grantees included stakeholders in the development of a customized intervention process and interventions through membership in grant advisory/steering committees and workgroups. Some grantees also conducted special roundtables/focus groups and surveyed stakeholders to obtain feed-back on PCP Grant design, implementation and deliverables related deliverables (such as field testing websites, networks and informal caregiver assessment tools). When the target group is the elderly, grantees reported it is a challenge to recruit elders and their family members to participate as stakeholders for their PCP Grants.

The following describes some ways in which grantees included stakeholders (including consumers and family members) in the development of a customized intervention process and interventions and some benefits identified for doing it.

- *Stakeholders have been involved since the beginning of the Grant and we have based many of our decisions on feed-back we have received from stakeholders at the pilot sites-they have a lot of family voice and involvement.*
- *Stakeholders on our PCP Advisory Group reviewed the three different tools being used to determine if they think they are appropriate to continue including them in training, and if not, what changes need to be made.*
- *Stakeholders have been involved as peer mentors. Peer mentors have been able to provide authentic testimony to people who are in doubt- PCP is a life changing process and it helps to validate the process and where our system is going.*
- *Stakeholders were involved through our Interagency Quality Council.*

Potential Promising Practices

It is too early to identify promising practices related to this activity at this time.

Development of an ICAT Training Curriculum and Conducting ICAT Training

A fourth mandatory component activity that grantees should be close to completing by the 18-month mark of the PCP Grant is the development of an informal caregiver assessment tool and training on the tool should have commenced. Table 10 and 11 below describes the progress grantees have made with these two activities as of the 18-month mark of the grant.

Table 10. Development of ICAT Training Curriculum - Percent Complete by Grantee

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Alaska					X
Arizona					X
Arkansas		X			
Connecticut	X				
Florida					X
Guam	X				
Idaho		X			
Louisiana (Aging and Adults w/ Disabilities)	X				
Louisiana (Mental Health)[13]	Not completed				
Massachusetts	X				
Missouri[14]	Not completed				
North Carolina	X				
USM Institute for Disability Services	X				
UNH Institute on Disability			X		
Tennessee					X
VCU (applies to all states in the collaborative)			X		
Washington		X			
Wisconsin		X			

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

[13] This activity was not addressed because Project staff felt that the ICAT and written instructions were self-explanatory.

[14] This activity was not included in Missouri's original, CMS approved proposal.

Table 11. Conducting ICAT Training - Percent Complete by Grantee

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Alaska					X
Arizona					X
Arkansas	X				
Connecticut	X				
Florida			X		
Guam	X				
Idaho	X				
Louisiana (Aging and Adults w/ Disabilities)	X				
Louisiana (Mental Health)[15]	Not completed				
Massachusetts	X				
Missouri[16]	Not completed				
North Carolina	X				
USM Institute for Disability Services	X				
UNH Institute on Disability				X	
Tennessee		X			
VCU					
NC, TN, OR and VA	X				
GA and SD		X			
Washington		X			
Wisconsin	X				

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

Four grantees (22.2%) reported the development of their ICAT as complete (AK, AZ, FL and TN), none reported the activity >75 percent complete and two grantees (11.1%) reported the development of their ICAT being 51-75 percent complete (UNH/IOD and all of VCU collaborative states).

[15] This activity was not addressed because Project staff felt that the ICAT and written instructions were self-explanatory.

[16] This activity was not included in Missouri's original, CMS approved proposal.

Issues Related to the Development of an ICAT Training Curriculum and Conducting ICAT Training

As noted earlier, LA OMH and Missouri chose not to develop an ICAT training curriculum or conduct ICAT training.

Factors that Facilitated the Development of an ICAT Training Curriculum and Conducting ICAT Training

Grantees reported a number of factors that facilitated the development of an ICAT training curriculum and conducting ICAT training. They include:

- *Technology and the technical support we received have really facilitated the ICAT training curriculum. We have to do a lot of long distance learning due to the rural nature of and harsh weather in the state.*
- *Receipt of input from our PCP Advisory Group and experienced facilitators.*
- *Working with students from the Clinton School of Public Services was instrumental in helping us put the policies for the ICAT training curriculum on paper.*
- *Having funding from the legislature for training and the training academies facilitated conducting ICAT training.*
- *We are doing large group trainings on introductory issues such as 'What is PCP and how is it different from what we are doing now both philosophically and clinically - what is behind it' and exposing people to assessment and planning tools that we are encouraging them to use. We have peer mentors talk about their process and what they are doing in the southwest section of the State. Then we are doing smaller group technical assistance (targeted planning) with clinical leadership and plan writers on how to comply with the principles of PCP and also write a strong, clinically justified, reimbursable treatment plan. During these sessions we are reviewing already written treatment plans and providing feed-back on how to make them more effective.*
- *Having the Community Life LENS curriculum available to us and having the organization do the training for us.*
- *Operations Director's enthusiasm for PCP and the Grant.*
- *Using the UNH/IOD PCP/ICAT Training Manual.*
- *Having Patty Cotton from UNH/IOD participate in our training will be a benefit.*

Factors that Impeded the Development of an ICAT Training Curriculum and Conducting ICAT Training

Grantees reported a number of factors that facilitated the development of an ICAT training curriculum and conducting ICAT training. They include:

- *We had to go through the college approval process to change the number of credits that were required to offer the ICAT training course in order to meet certification standards and*

produce facilitators who meet the required level of competence. This has put us a bit behind. We hope to have the course scheduled and back on line by the end of 2009.

- *Being able to be flexible in how training and supports are provided (teleconferencing, electronic/rounds structures, etc) to promote practice implementation and reduce the burden on those receiving training.*
- *We have to closely monitor hurricane season when scheduling ICAT tool or any type of training in the state. This means avoiding the scheduling of trainings in September and October.*
- *Getting private service providers on board with the Wraparound PCP tool that never used it before or who have not been using it with fidelity has been a challenge.*
- *The extent to which clinical staff at sites will be available to the Project Team to ensure they receive an adequate initial "dose" of PCP training as a foundation for their future efforts is a concern.*
- *Due to the state budget crisis, it is difficult for Project Champions to commit to the necessary amount of training time that will allow them to be skilled as local leaders to sustain the initiative going forward.*
- *Delays in doing training due to support coordinators having to rebase 30,000 consumers' cost plans.*
- *Waiting for UNH/IOD to finalize their PCP/ICAT Training Manual.*
- *Completing the training manual has been a challenge as the PCP and ICAT tool development process continues to be modified and improved.*

Stakeholder Involvement in the Development of an ICAT Training Curriculum and Training and Benefits

In general, grantees included stakeholders in the development of an ICAT training curriculum and conducting training through membership in grant advisory/steering committees and workgroups. Some grantees also conducted special roundtables/focus groups and surveyed stakeholders to obtain feed-back on PCP Grant design, implementation and deliverables related deliverables (such as field testing websites, networks and informal caregiver assessment tools). In some cases stakeholders participated in the training sessions. When the target group was the elderly, grantees reported it was a challenge to recruit elders and their family members to participate as stakeholders for their PCP Grants.

The following describes some ways in which grantees included stakeholders (including consumers and family members) in the development of an ICAT training curriculum and conducting training and some benefits identified for doing it.

- *Stakeholders are included through our PCP Advisory Group. They provided us with ideas about how we can make sure that people are really coming out of the curriculum with a perspective of thinking about the difference we have in the state and the importance of consumer/family needs and desires.*

- *Stakeholders were involved through the Interagency Quality Council and their enthusiasm for PCP and the training was particularly helpful.*

Potential Promising Practices

Although it is too early to determine if there are any promising practices related to the development/ selection of an informal caregiver assessment tool (ICAT) training curriculum, the New Hampshire PCP/ICAT Training Manual may be emerging as a possible promising practice.

Development of Statewide PCP Policies and Procedures

Overall, grantees have made significant progress with developing statewide PCP policies and procedures at the 18-month mark of the grant (See Table 12 below). While no grantee reported the development of statewide PCP policies and procedures to be complete, three grantees (16.7%) reported the task to be >75 percent complete (TN, WA and OR and SD under the VCU grant), and four (22.2%) reported the development of statewide PCP policies and procedures to be 51-75 percent complete (LA OMH, MO, GA, WI and NC under the VCU grant).

Table 12. Development of Statewide PCP Policies and Procedures - Percent Complete by Grantee

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Alaska		X			
Arizona	X				
Arkansas		X			
Connecticut		X			
Florida	X				
Guam	X				
Idaho	X				
Louisiana (Aging and Adults w/ Disabilities)		X			
Louisiana (Mental Health)			X		
Massachusetts		X			
Missouri			X		
North Carolina	X				
USM Institute for Disability Services	X				
UNH Institute on Disability		X			
Tennessee				X	

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
VCU					
TN and VA		X			
GA and NC			X		
OR and SD				X	
Washington				X	
Wisconsin			X		

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

Issues Related to the Development of Statewide PCP Policies and Procedures

A number of grantees reported they haven't made significant progress on this activity for a variety of reasons (i.e., PCP model, ICAT tool and customized intervention process and interventions and ICAT training curriculum and training has not been completed yet). When asked if statewide policies and procedures had been developed, one grantee responded:

> *Kind of. We have changed the wording and our expectations of our operations manual. But to be honest, our rhetoric precedes our actual development and implementation of statewide policies and procedures.*

Another grantee reported:

> *There have been no real changes, just enhancements. We are talking with our legal staff about if we have changes in policy directives* [that effect agency staff performance] *will we also need a change in rules* [rules also can effect service provider performance]. *The state statute that governs our agency references PCP throughout. This language will need to be updated to reflect our new approach, changes to Medicaid waivers, and operations procedures and policy directives.*

One state (New Hampshire) has state law that requires that all long-term care planning be conducted using person-centered planning methods. The grantee reported that state rules and Medicaid waivers also reflect the use of PCP and this focus will become stronger as existing Medicaid waivers and rules are revised.

Finally, one grantee reported that standardizing the PCP process through the development and implementation of statewide PCP policies and procedures could have a negative effect on the person-centered planning implementation in states. The grantee noted that standardization of statewide PCP policies and procedures might provide planning staff with an incentive to create "cookie cutter" plans that are less customized to consumers' needs and preferences, defeating the purpose of person-centered planning.

However, one could argue that developing and implementing standardized statewide PCP policies and procedures would enhance PCP "system equity" in states that would ensure that consumers and their family members what they could expect related to PCP no matter where they lived in a state.

Factors that Facilitated the Development of Statewide PCP Policies and Procedures

Grantees reported a number of factors that facilitated the development of statewide PCP policies and procedures. These include:

- *Political will to implement PCP has facilitated the implementation of statewide PCP policies and procedures.*
- *It has been helpful to have the Project Champions at the different sites sharing their experience, insights and expertise.*
- *It has been helpful to have the agency's Commissioner and Deputy Commissioner as Project Champions.*
- *Our management team really sees the PCP grant as an opportunity to develop new policy that supports the implementation of PCP. The training curriculum will have built in a series of new policies and statements of policy that will be drives for our assessment and support planning processes putting the focus on the individual.*
- *State law requires that all long-term care planning be conducted using person-centered planning methods. State rules also reflect the use of PCP and this focus will become stronger as existing Medicaid waivers and rules are revised.*

Factors that Impeded the Development of Statewide PCP Policies and Procedures

Grantees reported a number of factors that impeded the development of statewide PCP policies and procedures. These include:

- *Resource issues related to conducting the analysis required and getting the monies included in the state General Fund for a new service (PCP).*
- *What we have found to be a challenge is to facilitate the accreditation process and CMS and Department of Public Health regulations. A lot of people are being "dinged" for having treatment plans that are not individualized so they have changed their facility level policies. We have changed the wording and the expectations in our operations manual. But to be honest our rhetoric precedes our actual development and implementation of statewide policies and procedures.*
- *There is traditional" home rule" in our state. We have 158 towns, all of which have their own opinions and a lot of authority has been granted to them. There always has been cultural resistance and a "we do it best here" mentality. This is a leadership and culture issue that I hope gets changed as a result [possibly] from the state budget crisis and the need for streamlining processes.*
- *Gathering information on state infrastructure and policies has been slow and is dependent on collaboration with various agency staff.*

Stakeholder Involvement in the Development of Statewide PCP Policies and Procedures and Benefits

In general, grantees included stakeholders in the development of statewide PCP policies and procedures through membership in grant advisory/steering committees and workgroups. Some grantees also conducted special roundtables/focus groups and surveyed stakeholders to obtain feed-back on PCP Grant design, implementation and deliverables related deliverables (such as field testing websites, networks and informal caregiver assessment tools). When the target population was the elderly, grantees reported it was a challenge to recruit elders and their family members to participate as stakeholders for their PCP Grants.

The following describes some ways in which grantees included stakeholders (including consumers and family members) in the development of statewide PCP policies and procedures and some benefits identified for doing it.

- *Stakeholders were involved through the PCP Advisory Group and other existing groups and channels.*
- *Stakeholders were involved through attending 10 focus groups and also trainings at the two state facilities. They also were involved on our Project Steering Committee and other workgroups. Key stakeholders included regional mental health boards, consumers, families, citizen advisory groups, nonprofit provider agencies, state psychiatric hospital staff, our state board of the local chapter of NAMI and two mental health advocacy groups. They were brought in very early to help us understand the challenges in our current treatment planning system and the lack of consumer involvement.*
- *Stakeholders have been involved through the Interagency Quality Council.*

Potential Promising Practices

It is too early to identify any potential promising practices related to the development of statewide PCP policies and procedures.

Development of Informal Community Network Assessment and Intervention Process

Grantees' progress in developing their informal community network assessment and intervention process varied considerably (See Table 13 below).

Table 13. Development of Informal Community Network Assessment and Intervention Process - Percent Complete by Grantee

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Alaska					X
Arizona				X	
Arkansas	X				
Connecticut		X			
Florida			X		
Guam	X				
Idaho		X			
Louisiana (Aging and Adults w/ Disabilities)	X				
Louisiana (Mental Health)					X
Massachusetts	X				
Missouri		X			
North Carolina	X				
USM Institute for Disability Services			X		
UNH Institute on Disability				X	
Tennessee		X			
VCU (applies to all states in collaborative)			X		
Washington		X			
Wisconsin		X			

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

Seven grantees (38.9%) reported that their development efforts were at least 50 percent complete (AK, AZ, FL, LA OAAS, USM/IDS, UNH/IOD, and VCU collaborative states) with only two reporting 100 percent completion (AK and LA OAAS). The majority of grantees (11) reported that their development efforts were 50 percent or less complete.

Issues Related to the Development of an Informal Community Network Assessment and Intervention Process

An issue that was raised related to the development of informal community network assessment and intervention process was the challenge presented when a state is very rural and/or when it serves native

cultures such as the Inuit. Grantees also reported that small communities often have limited resources and limited access to technology.

Factors That Facilitate the Development of an Informal Community Network Assessment and Intervention Process

Grantees reported a number of factors that facilitated the development of an Informal Community Network Assessment and Intervention process. These include:

- *As we do the trainings we are making staff aware of and introducing them to community options and have them thinking outside of the state system.*
- *Meeting with and including representatives from our Office on Aging Caregiver Project in discussions about informal caregiver assessment and interventions has been valuable and will likely lead to future collaboration to better serve consumers and their families.*

Factors That Impeded the Development of Informal Community Network Assessment and Intervention Process

Grantees reported a number of factors that impeded the development of an Informal Community Network Assessment and Intervention process. These include:

- *We have a lot of people with good intentions where kids are involved but they have different mission statements when it comes to their organizations so there can be competition for scarce resources. Instead of collaborating sometimes they compete. This is something we are trying to get the Family and Youth Assistance Network (FYAN) to overcome. We are trying to encourage more individual versus advocacy organization participation and have PCP be more about individuals rather than groups supporting families.*
- *In this economic climate, we will be depending on existing resources/services and connecting people to what is already available while planning for future development of formal and informal resources/services as identified through gap analysis.*
- *Drastic cut backs in the availability of cars, gas and mileage allowances have been impeding our ability to do more face-to-face contacts outside of the office in the community.*
- *The development of an informal community will be individualized for each consumer and will depend on the status of the local community in which they live. This could vary by community.*
- *The state only has a few urban areas and the rest consists mostly of small rural communities. The informal network in the rural communities may be small, but the ultimate size will depend on the individual. Geographic isolation and lack of access to technology may be impediments.*

Stakeholder Involvement with the Development of Informal Community Network Assessment and Intervention Process and Benefits

In general, grantees included stakeholders in the development of informal community network assessment and intervention process through membership in grant advisory/steering committees and workgroups. Some grantees also conducted special roundtables/focus groups and surveyed stakeholders to obtain feed-back on PCP Grant design, implementation and deliverables related deliverables (such as field testing websites, networks and informal caregiver assessment tools). When the target population was the elderly, grantees reported it was a challenge to recruit elders and their family members to participate as stakeholders for their PCP Grants.

The following describes some ways in which grantees included stakeholders (including consumers and family members) in the development of an informal community network assessment and intervention process and some benefits identified for doing it.

- *Stakeholders were involved through the PCP Advisory Group and other existing groups and channels.*
- *Stakeholders helped write the SAMHSA Mental Health Transformation Grant. We have a smaller group of stakeholders who take the website for "test drives" and gives us feed-back.*

Potential Promising Practices

It is too early to identify potential promising practices for this activity.

Incorporating Connections to the Community and "Friendships" into the PCP

Grantee progress in incorporating connections to the Community and "Friendships" varied as of the 18-month mark of the Grant (See Table 14 below).

Table 14. Incorporating Connections to the Community and "Friendships" into PCP - Percent Complete by Grantee

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Alaska				X	
Arizona				X	
Arkansas		X			
Connecticut			X		
Florida		X			
Guam			X		
Idaho			X		
Louisiana (Aging and	X				

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Adults w/ Disabilities)					
Louisiana (Mental Health)					X
Massachusetts	X				
Missouri		X			
North Carolina	X				
USM Institute for Disability Services			X		
UNH Institute on Disability				X	
Tennessee		X			
VCU (applies to all states in the collaborative)			X		
Washington		X			
Wisconsin	X				

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

One grantee (5.6%) reported the activity to be complete (LA OMH) and three grantees reported the activity >75 percent complete (AK, AZ, and UNH/IOD). Five grantees (27.8%) reported the activity being 51-75 percent complete (CT, GU, ID, USM/IDS and VCU all collaborating states) and 26-50 percent complete (AR, FL, MO, TN and WA). Finally, four grantees (22.2%) reported incorporating connections to the community and "friendships" into PCP being 1-25 percent complete (LA OAAS, MA, NC and WI).

Among the grantees incorporating connections to the community and "friendships" into PCP, none reported issues of note specific to the activity, particular factors that facilitated or impeded their progress in completing the activities, how stakeholders, including consumers and family members, were included in the design and implementation of each activity, or any promising practices that appear to be emerging. For the latter, it is too early to identify any promising practices related to this activity.

Development of Evaluation Methodologies

Grantees' progress in developing their evaluation plans and methodologies varied considerably (See Table 15 below).

Table 15. Development Evaluation Methodologies: CMS Evaluation Questions - Percent Complete by Grantee

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Alaska					
Question #1					X
Question #2					X
Question #3					X
Arizona					
Question #1				X	
Question #2				X	
Question #3					X
Arkansas					
Question #1		X			
Question #2		X			
Question #3		X			
Connecticut					
Question #1				X	
Question #2				X	
Question #3				X	
Florida					
Question #1	X				
Question #2	X				
Question #3	X				
Guam					
Question #1	Not reported				
Question #2	Not reported				
Question #3	Not reported				
Idaho					
Question #1	X				
Question #2	X				
Question #3	X				
Louisiana (Aging and Adults w/ Disabilities)					
Question #1		X			

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Question #2		X			
Question #3		X			
Louisiana (Mental Health)					
Question #1					X
Question #2					X
Question #3					X
Massachusetts					
Question #1		X			
Question #2	X				
Question #3	X				
Missouri					
Question #1		X			
Question #2		X			
Question #3			X		
North Carolina					
Question #1			X		
Question #2			X		
Question #3			X		
USM Institute for Disability Services					
Question #1				X	
Question #2			X		
Question #3		X			

Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
UNH Institute on Disability					
Question #1					X
Question #2	X				
Question #3		X			
Tennessee					
Question #1	X				
Question #2	X				
Question #3	X				
VCU (applies to all states in collaborative)					
Question #1			X		
Question #2	X				
Question #3	X				
Washington					
Question #1				X	
Question #2			X		
Question #3				X	
Wisconsin					
Question #1					X
Question #2				X	
Question #3					X

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

Nine grantees (50%) reported that the development of their evaluation methodologies was 50% or less complete (AR, FL, ID, LA OAAS, MA, MO, UNH/IOD, TN, and VCU all collaborating states). Of the remaining nine grantees, eight reported development efforts that were 51 percent or more complete, and one grantee (5.6 %) did not report any percentages (5.6 %). While generally there was consistency in the status of the evaluation questions within a grant (i.e., all three evaluation questions having the same percentage of completion), eight grantees (44.4%) reported variability with completing the three evaluation questions (AZ, MA, MO, USM//IDS, UNH/IOD, WA, WI and VCU all collaborating states).

Issues Related to the Development of Evaluation Methodologies

A number of issues were raised by grantees related to the development of evaluation methodologies. First, it should be noted that unlike the Systems Transformation grantees who had to engage an independent evaluator for their grants, PCP grantees were responsible for developing and implementing

their own evaluation methodologies. Some PCP grantees were better prepared than others to perform this activity.

Second, although some grantees have made progress with developing their evaluation plans, outcome measures and data collection tools, it was not clear that all had incorporated the three CMS-required outcome questions in their evaluation plans.

Third, through the telephone interviews, some grantees discovered that their data collection activities would not be complete by the end of the grant, thus calling to question the completeness of their grant evaluation efforts.

Finally, one grantee reported receiving formal IRB approval for the evaluation component of their PCP program in early March 2009.

Factors That Facilitate the Development of Evaluation Methodologies

Grantees reported a number of factors that facilitated the development of their evaluation methodologies. These include:

- *Participation of the PCP Advisory Council in developing the evaluation methodology is expected to ensure a commitment to a formative evaluation.*
- *The willingness of the state to use the Wraparound Fidelity Instrument (WFI) represents a big step forward for family-driven care and allows us to measure on services and supports as well as providing us with an opportunity to evaluate the Wraparound process from the Family and Youth perspective. It also will establish and provide accountability for the full four phases of the state's Wraparound Model as opposed to Wraparound models which lack an outcome measure.*
- *The issuance of "friendly" reminders of the importance of the surveys should facilitate the collection of data.*
- *Using the Participant Experience Survey (PES) and adding additional questions has helped facilitate data collection.*

Factors That Impeded the Development of Evaluation Methodologies

Grantees reported a number of factors that impeded the development of their evaluation methodologies. These include:

- *The Wraparound Fidelity Instrument (WFI) presents a barrier in that it will be expensive and time consuming to use on a large scale. However, System of Care staff will provide training and technical assistance to providers and families in the hopes of reducing some of these barriers through education and resource mapping within local communities.*
- *A barrier to data collection is the assurance that surveys are distributed and received at the end of each WRAP class.*

- *In some cases it has been difficult to get reliable information using our four point scale. Some project participants do not understand these concepts so information gathering is inconsistent.*

Stakeholder Involvement with the Development of Evaluation Methodologies and Benefits

In general, grantees involved stakeholders primarily as respondents/subjects in their evaluation. Some also reported involving them through their Grant Steering Committee or Advisory Council, while others reported not being sure about how stakeholders would be included in grant evaluation activities. Grantee comments included:

- *Participation of the PCP Advisory Council in developing the evaluation methodology is expected to ensure a commitment to a formative evaluation.*
- *Stakeholders have not been involved in the evaluation component. Their role is yet to be determined but they will be respondents in number of ways during the evaluation.*

Potential Promising Practices

The majority of grantees have not made enough progress to identify any potential promising practices at this time.

Grantee Progress Related to Optional Component Activities

Eleven grantees (61%) chose to implement one or more Optional Components (See Table 16 below) (AK, AR, AZ, CT, GU, ID, MA, MO, NH, TN and VCU). The two grantees from Louisiana and the grantees from Florida, USM Institute for Disability Services, North Carolina, Washington State and Wisconsin chose not to design and implement an Optional Component.

Table 16. Development and Implementation of Optional Components - Percent Complete by Grantee

Optional Component/Grantee	1-25% Complete	26-50% Complete	51-75% Complete	>75% Complete	Completed
Self Direction					
Guam	Did not report progress				
Idaho				X	
Missouri		X			
VCU (applies to all states in the collaborative)		X			
Comprehensive Community-based Resource Directory (web-based)					
Arkansas	X				
Connecticut		X			
Guam					X
Idaho				X	
Massachusetts	X				
Tennessee		X			
Web-based Care Planning Tool					
Connecticut				X	
Guam	Did not report progress				
New Hampshire	X				
Evidence-based Practices					
Connecticut		X			
Tennessee		X			
Planning for Youth with Co-occurring Disorders (MH/DD/SA)					
Alaska					X
Arizona				X	

Source: PCP Grantee 18-Month Reports and Follow-Up Telephone Interviews.

No grantee chose to implement the Comprehensive Risk Management Strategy Optional Component. Of the grantees that chose to develop and implement one or more Optional Components:

- Six (54.5%) chose to implement a Comprehensive Community-based Resource Directory (web-based) (AR, CT, GU, ID, MA and TN) ,

- Four (36.4%) chose to implement Self Direction (GU, ID, MO and the VCU six collaborating states).
- Three (27.7%) chose to implement a Web-based Planning Tool (CT, GU and NH),
- Two (18.2%) chose to implement Evidence-based Practices (CT and TN), and
- Two (18.2%) chose to implement Planning for Youth with Co-occuring Disorders (AK and AZ).

Guam proposed to implement three Optional Components (Self-Direction, Comprehensive Community-based Resource Directory and Web-based Planning Tool) but only reported complete information on progress for the Comprehensive Community-based Resource Directory (100% complete).

The level of progress made in accomplishing activities related to the Optional Components varied by grantee and Optional Component (See Table 16 above). Of the three grantees that chose to implement the Self Direction Optional Component, one did not report their progress (GU) (but it is assumed they are in the 1-25% complete range), two reported the activity 26-50 percent complete (MO and VCU) and one (ID) reported the activity complete. One reason for Idaho's stellar progress on the Self Direction Optional Component is that in the last five years, the state has developed and implemented self-directed home and community-based waiver services for persons with mental retardation and developmental disabilities using one statewide Vendor Fiscal/Employer Agent. Developing and implementing PCP as a skilled service and enhancing and expanding the existing support broker training for the training and certification of PCP specialists with a focus on informal support caregivers and community development, as proposed, would complete their implementation of a self-directed service delivery system for the target population.

Of the five grantees that chose the Comprehensive Community-based Resource Directory (Web-based) Optional Component, one reported being complete (GU), one reported being >75 percent complete (ID), and two reported being 26-50 percent (CT and TN) and 1-25 percent complete (AR and MA). Four of the five grantees that chose this Optional Component reported they were building on and/or enhancing one or more existing web-based community resource directories (AR *Family and Youth Assistance Network (FYAN),* CT *Network of Care,* GU *Get Care System,* ID *Connecting Families Through the Family Support 360 Project,* MA *Aging and Disability Information Locator (MADIL)*) with the Tennessee grantee developing a new web-based resource directory "from scratch."

Of the three grantees (CT, GU and NH) that chose to implement the Web-based Care Planning Tool, Connecticut reported being >75 percent complete whereas, New Hampshire reported being 1-25 percent complete and Guam did not report their level of progress (but it is assumed they were 1-25 percent complete). One reason for Connecticut's stellar performance may be that they planned to upgrade an already existing version of their Automated Recovery Plan (ARP) that is posted online, creating a statewide planning resource for consumers and PCP teams. On the other hand, Guam reported they planned to enhance an already existing web-based planning tool, but this did not appear to facilitate their completion of this Optional Component. New Hampshire plans to have designed, field-tested and implemented a fully-accessible web-based care planning tool for use by individuals, families and professionals by December 2009.

Both of the grantees (CT and TN) that chose to implement Evidence-based Practices reported being 26-50 percent complete. Finally, the two grantees (AK and AZ) who chose to implement the Planning for Youth with Co-occurring Disorders (MH/DD/SA) either had completed the activity (AK) or was near completion (AZ at >75 percent).

Grantees' Successes and Barriers in Implementing Optional Components

Grantees reported a number of successes and factors that facilitated and barriers that impeded the implementation of the Optional Components of the PCP Implementation Grant. The following summarizes the information reported by Grantees for each Optional Component that was selected.

Self Direction

The four grantees (GU, ID, MO and VCU all collaborating states) that chose to implement Self Direction reported a number of successes and factors that facilitated the implementation of this Optional Component. These included:

- Missouri has field-tested and finalized the Self Direction and Support Broker training curriculum; updated PCP Guidelines are out for public comment review; and Life Books are being utilized in pilot sites with the transition of people from habilitation centers.
- In Missouri, CPS peer support specialists are receiving training and being hired by a majority of community mental health centers and many have been trained to assist other consumers develop Wellness Recovery Action Plans (WRAPs).
- In Missouri, an enhanced Psycho-social Rehabilitation Program (PSR) rate has been developed and will promote consumer self direction by emphasizing Illness Management and Recovery and PRocovery Circles.
- Idaho Division of Developmental Disabilities has developed and implemented a self-directed waiver service option for adults with developmental disabilities and currently 38 individuals are using self-directed waiver services statewide. The state also offers self-directed personal care waiver services to elders and individuals with physical disabilities.

Grantees reported a number of barriers that impeded the implementation of Self Direction. These included:

- In Guam it was reported, *many adults have been conditioned to accept and rely on formal supports that are offered without considering their own feelings as to which supports might be most useful.*
- In Idaho, of the 38 individuals using self-directed waiver services, 24 had their initial support and spending plans denied because of incomplete information and/or errors. It is hoped obtaining assistance from a specialist trained through the Grant will reduce errors and improve the quality of individuals' person-centered plans.
- In Idaho, there has been significant demand for PCP training from support coordinators, supports brokers, providers, teachers and others. Currently, they are not set up for that and support brokers and support coordinators do not need to use PCP in the current system

according to grant staff Grant staff reported they need determine how to provide PCP training to more people while not diluting the role of the PCP Specialist.

- In Guam, it was reported that occasionally there has been controversy about the ability of adults with disabilities to make decisions about their care. In addition, some feel that allowing adults with disabilities to author their own plans of care can result in decisions that may not seem to be in their best interest.
- *Little progress was made in promoting or implementing self-direction prior to the hiring of the Director of Special Programs and identifying regional staff to lead self direction efforts.*
- *The Division of Comprehensive Psychiatric Services (CPS) was challenged with overcoming perceived (but false) system regulatory barriers, budget constraints limiting the amount of training, technical assistance and program expansion that could occur; the lack of integration and coordination of care, and the stigma related to the potential for recovery for persons with mental illness (i.e., the medical model versus the social wellness model).*
- *Collaborating states are at different stages and there are variations in approach) in implementing self direction.*

Comprehensive Community-based Resource Directory (Web-based)

The six grantees (AR, CT, GU, ID, MA, and TN) that chose to implement Comprehensive Community-based Resource Directories reported a number of successes and factors that facilitated implementing this Optional Component. These included:

- The Arkansas Family and Youth Assistance Network (FYAN) has been able to stay independent while working on implementing the resource directory and investigating how best to host and sustain the resource directory website beyond the grant period.
- *Our subcontractor, Partners for Inclusive Communities', unique status (as a quasi-state agency) and their relationship with the state has been very helpful.*
- *The use of already existing community resource directory (being able to link up with the Network of Care website) has promoted further integration into the community and draws upon the power of multi-end user updated databases to the degree to which we would be unable to reach with current State and grant funding levels.*
- In Guam, the resource directory (GU Get Care System) has grown since its initial implementation, with the addition of new services. It currently has over 250 listing.
- A comprehensive community-based resource directory was re-launched under a new title and address www.IdahoHelp.info, an announcement was sent to stakeholders across the state, and 8,369 resources are now listed on the database. An electronic survey was conducted with stakeholders related to the quality of the site. Of the 25 responses, which included 12 families and individuals with disabilities, 96 percent were very satisfied or satisfied with the effectiveness of how they were able to move within the site; 92 percent were very satisfied or satisfied with the site's overall appearance, and 95 percent were very satisfied or satisfied with the level of ease for finding information.

- PCP grant staff has been working with MA Aging and Disabilities Information Locator (MADIL) Steering Committee to develop a standardized tool for collecting information from local resources to be published on local resource directories and/or included in the MADIL.
- The Massachusetts grantee reported a community building consultant has been hired and key community leaders have been recruited.
- Lawrence and Greater Boston, Massachusetts coalitions have core groups developing work plans and timeframes for the community mapping activities.
- Lawrence, Massachusetts Community Coalition successfully engaged City officials in the community building process with the commitment to provide a minimum of youth employment for the community mapping activities.
- *Using a consultant to assist Project staff in understanding the technical aspects of developing a web-based Comprehensive Community-based Resource Directory developing specification to draft and issue an NOFA and conduct a planning process for the website was helpful*.

Grantees reported a number of barriers that impeded the implementation of a comprehensive community-based resource directory. These included:

- *Targeting Parenting Assistance (TPA) was included in Optional Component but has proven to be challenging. TPA is part of Kansas Keys for Networking and we are not sure how it will work in our state. Normally, TPA uses paid parent support personnel to assist and track other parents. Currently, our state does not have an existing mechanism to pay for parent support personnel. In addition, Kansas no longer uses TPA because of a concern about original choice. A decision needs to be made whether or not our state will implement TPA and have Kansas Keys for Networking will develop and deliver the TPA curriculum.*
- *Making sure there is equal access to the comprehensive community-based resource directory for all and the difficulty in finding a neutral host to maintain the directory when the grant is over*.
- *State budget crisis and lack of available funding for the directory has been a barrier to implementing a web-based Comprehensive Community-based Resource Directory*.
- *Keeping the list of community resources current and relevant to consumers looking for services*.
- *Locating community-based resources, especially in rural areas, is a challenge.* T*here is a lot going on in the rural communities but it is hard to make connections. More research is need on transportation options in rural communities.*
- One grantee reported the need to reactivate their Community Coalitions. The grantee's focus up until now has been on developing the PCP model and tools.
- *Lack of understanding of technical aspects of developing a web-based resource directory and the specifications to prepare and issue a credible Notice of Funding Availability (NOFA) was a barrier.*
- *Lack of technical proficiency and need for assistance in describing the website parameters accurately and appropriately in the Notice of Available Funding.*

Web-based Care Planning Tool

Three grantees (CT, GU and NH) chose to implement a Web-based Care Planning Tool. Few specific successes and factors that facilitated the implementation of this Optional Component were reported. One included:

- Connecticut reported creating a tool based on substantive input from people in recovery as a success.

Grantees reported a number of barriers that impeded the implementation of a Web-based Care Planning Tool. These include:

- *Due to the current state budget crisis, the state Local Mental Health Agency printing contract has been cancelled. This may limit out ability to print the Web-based Care Planning Tool Booklet on a larger scale.*
- *We experienced a long delay in contracting with our subcontractor, so we are not as far along on this activity as we should be.*
- *Getting a contractor that knows how to develop a web-based care planning tool and all that it entails can be a challenge. It is important that web-based application be a fairly simple design, user-friendly, and not need a lot of maintenance.*

Evidence-based Practices

Two grantees implemented Evidence-based Practices (CT and TN). These grantees reported a number of successes and factors that facilitated the implementation of this Optional Component. These include:

- *Due to the state budget crisis and the significant number of state staff taking early retirement, there may be opportunities for peer specialists to be hired at agencies and the state hospitals in the future if funding is available.*
- *Our peer specialist has made numerous connections across the state with key staff at each agency, building a broader state network of peer specialists. As a result we have been able to 'cross-fertilize' and bring ideas from one agency to another, with the broader perspective of the state-level implementation.*
- *Experience doing evidence-based practices in the southwest portion of the state for awhile has been a facilitating factor.*
- Five Illness and Management Recovery (IMR) classes have been conducted in Tennessee with 88 individuals trained to teach IMR. Each class participant has agreed to train five co-workers to teach IMR and to teach IMR to at least 10 mental health consumers.

Grantees reported a number of barriers that impeded the implementation of Evidence-based Practices. These include:

- *Limited number of peer specialists across nonprofit agencies and the state facilities. Despite the desire to hire more people in recovery as peer specialists, the state is experiencing severe budget deficits, staffing cuts, making hiring of new staff unlikely. The state also has offered an early retirement package to state workers, further reducing available staff. In some agencies, staff is experiencing stress around workload, and this may affect both the role of peer staff at the agency as well as the ability to supervise existing peer staff in away that maximizes their role in PCP.*
- *Many clinicians do not have the knowledge and experience related to PCP and feel they are loosing power to others because it is perceived that PCP is something you do with your peers.*
- *We encountered some initial reluctance among some of the state's community mental health agencies to send staff to the Illness Management and Recovery (IMR) trainings due to a lack of understanding on the part of mental health agencies and managed care companies that IMR is a Medicaid-reimbursable service.*

Planning for Youth with Co-occurring Disorders (MH/DD/SA)

The two grantees (AR and AZ) that implemented this Optional Component reported a number of successes and factors that facilitated and impeded implementing it. Successes/factors that facilitated it included:

- *Successes in Year 1 revolve around the process and experience of those involved in the planning and the agencies that support them.*

Barriers that impeded the implementation of Planning for Youth with Co-occurring Disorders (MH/DD/SA) included:

- *We have struggled with recruiting waiver recipients who meet eligibility criteria.*
- *The time available for completing this Optional Component by the end of the Grant is a potential barrier.*

Stakeholder Involvement in the Development and Implementation of the Optional Components

Grantees reported stakeholders were involved in a number of ways when developing and implementing the Optional Components. Some grantees included them through one vehicle for all the Optional Components (i.e., through the Grant Steering Committee or Advisory Group). Other grantees used different methods for including stakeholders depending on the Optional Component. Some grantees solicited feed-back from consumers and families separate from the Grant Steering Committee or Advisory Group). The following describes the various ways that stakeholders were involved in the PCP grants by Grantee.

- *Stakeholders, including consumers and families, were brought in through the Grant Advisory Group and other existing groups and channels.*

- *Consumer and family stakeholders are included through the Family and Youth Assistance Network, (FYAN) and grant related roundtables and other meetings.*
- *For the Web-based Planning Tool stakeholders provided input on the template and format; for Evidence-based Practices, there is a separate Advisory Group; for the Comprehensive Community-based Resource Directory, stakeholders are on the PCP Steering Committee.*
- *Consumers and families participated on the ADRC Advisory Committee. This Committee has reviewed a video on PATH, reviewed a commercial on Guam Get Care, reviewed materials posted on Guam Get Care and provided input on user friendliness of the site. The territory's Developmental Disabilities Council also has been active in the ADRC and PCP projects.*
- *Consumers and families have pre-tested grant products and provided feed-back and have participated in focus groups. Other stakeholders have participated on the Grant Stakeholder Group.*
- *For the Comprehensive Community-based Resource Directory, stakeholders, including consumers and families, are involved through the Community Coalitions.*
- *Stakeholders, including consumers and families, are brought in through the Project Workgroup.*
- *Stakeholders will have a role in field test the web-based planning tool and provide input. Any additional role is yet to be determined.*

Next Steps

Overall, the 18 PCP grantees have put forth considerable and commendable effort to implement person-centered planning in their states for their target populations. They have done so despite current state budget crises, limited state staff and funding; resistance from assessment and care planning staff and service providers; and, in some cases, with limited experience with PCP. Nonetheless, at the 18-month mark, grantee progress overall has been slow and grant spending low. In addition, a number of grantees still appear to be confused about how the different mandatory components of this grant fit together. Therefore, we recommend that CMS consider the following topics in working with the PCP Grants during their second 18-month phase of implementation.

Consider allowing no-cost extensions when appropriate. Although the question was not specifically asked of grantees, a number volunteered they would like to obtain a no-cost extension in order to successfully complete their grant goals and objectives. Many, if not most, of the grantees and their projects could potentially benefit from the additional time provided through a no-cost extension and it is recommended that CMS consider this suggestion and provide grantees with guidance about the process and conditions to obtain a no-cost extension.

Clarify grant requirements, remind grantees, and/or approve variations. A number of grantees have not met the grant requirements as described in the CMS PCP Grant Solicitation. We recommend that CMS either remind grantees of these requirements, or formally approve the variations adopted by the grantees. For example, some grantees are not addressing all of the mandatory components required under the grant; others are adapting (or would like to do so) the

requirements to better fit their vision and/or what they are learning through their planning processes.

Review and clarify evaluation requirements, grantee progress to date and next steps. The majority of grantees are experiencing some difficulties with the mandatory evaluation component. Unlike the Systems Transformation Grants, PCP grantees were not required to engage an independent evaluator for their project. Rather, evaluation activities were left up to the grantee to design and implement.

Many grantees have not fully developed or begun to implement an evaluation plan that includes the evaluation questions to be answered, including the three CMS-required outcome questions, the data collection tools to be used, and a data collection schedule and analysis plan. For example, at least one grantee has developed evaluation instruments and is offering them as "resources" to PCP planners, but not using them to implement the grant evaluation. In a number of cases, grantees have identified their data collection tools (e.g., the PES) but it is not clear if the tools include elements necessary to address the three CMS-required outcome questions or if the grantees have "connected the dots" between data collection tools and the evaluation questions to be answered. Finally, often grantees have not worked out the timing of completing their grant evaluation. For example, in at least one case, the grantee has collected baseline data successfully but just realized during the telephone interview, that the second data collection point, which is to be compared to the baseline data, will not happen until a month after the grant ends.

To better understand what is still feasible for grantees to achieve beyond this stage of the grant cycle, CMS may want to consider clarifying what is an acceptable evaluation plan for each grantee, assess what might be helpful in completing the evaluation component, and establish clear and feasible evaluation goals for each grantee to accomplish by the end of the grant period.

In summary, collectively, grantees have made progress in implementing their PCP grants and implementing PCP for their target populations. However, considerable work remains to be done in the majority of states. During the second half of the PCP Grant, guidance and support from CMS will be essential to ensure that grantees meet their grant goals and objectives.