Real Choice Systems Change Grants

Compendium Sixth Edition





U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services DEPARTMENT OF HEALTH & HUMAN SERVICES Centers for Medicare & Medicaid Services 7500 Security Boulevard, Mail Stop S2-14-26 Baltimore, Maryland 21244-1850



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

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Dear Reader:

Since 2001, CMS has awarded approximately \$280 million in Systems Change Grants for Community Living to 50 States, 2 Territories, and the District of Columbia. We have prepared this Sixth Edition of the Compendium of the Real Choice Systems Change Grants to be an ongoing user-friendly reference tool for our Grantees and others interested in these systems change grants.

The Compendium will help you learn more about how these grants will be used to allow more people of all ages with a disability or long-term illness to live and participate in their communities. We hope that Real Choice Systems Change Grantees will also find it useful to be able to identify other Grantees with similar goals and activities. A Web-based edition of the Compendium will be made available on the CMS Web site at http://www.cms.hhs.gov/RealChoice/ as well as on the Clearinghouse for the Community Living Exchange Collaborative Web site at http://www.hcbs.org.

The Compendium contains basic information about each of the Real Choice Systems Change Grants awarded in FY 2003–FY 2004. It also includes information for the Family to Family and Systems Transformation Grantees who received awards in FY 2005 and FY 2006. It is divided into sections corresponding to the different types of grants and year of award. Each section is arranged alphabetically by state. Information for each grant includes the name of the grantee organization, the title of the grant, the type of grant, the amount awarded and fiscal year awarded, the primary contacts for each grant, the target populations to be served under the grant, the primary goals and activities of each grant project, and a brief description of the grant activities. For grants that received a no-cost time extension, we have included the expected completion date. A list of the 2001 and 2002 Grantees who have completed their grant activities is included in the appendix.

With the assistance of our contractors, RTI International and Abt Associates, we will also be preparing additional reports that will provide more comprehensive descriptions of the Grantees' goals and activities and progress.

Sincerely,

Gale P. Arden

Director, Disabled and Elderly Health Programs Group

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^{*} Grantee received a supplemental award in FY 2006.
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 $^{^{\}dagger}$ Goals/activities/abstract modified since last edition.

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CALIFORNIA

Grant Information

Name of Grantee California Department of Mental Health

Title of Grant California Study on New Medi-Cal Respite Benefit for Caregivers

of Adults With Cognitive Impairment

Type of Grant Respite for Adults

Amount of Grant \$100,000 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

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Executive Director

Family Caregiver Alliance 690 Market Street, Suite 600 San Francisco, CA 94104

Target Population(s)

Caregivers of individuals with adult-onset cognitive impairment.

Goal

The goal of this feasibility study is to develop recommendations for ways that California can implement and evaluate a new respite benefit under Medi-Cal for family and informal caregivers of individuals with adult-onset cognitive impairment.

- Establish an Advisory Committee comprising representatives of key government agencies, consumers, and provider and academic entities to provide advice on issues such as consumer direction and access, information infrastructure and fiscal employer agent options, implementation issues, and an outcome evaluation.
- Review existing Medicaid respite programs including eligibility standards, assessment measures, quality assurance protocols, expenditure caps, extent of consumer direction, and alternative fiscal agent strategies.
- Analyze the need for changes in waiver requirements and investigate how to incorporate a benefit tracking system into the existing data system.
- Review existing national Medicaid data on respite programs and identify the potential benefits to the target population, scope of respite services, cost projections, estimates of caregivers who would use respite, and the impact of service limits on the target population.
- Identify client-assessment tools, protocols and procedures, and outcome evaluation methods currently used in other state programs.
- Develop an implementation and evaluation proposal for expanding respite services.

Abstract

The project will bring together representatives from state departments, consumer groups, provider associations and academic institutions to develop a plan for expanding respite services to caregivers of persons with adult-onset cognitive impairments under Medicaid funding (Medicaid is called Medi-Cal in California).

The goal of the project is to develop recommendations on ways California can implement and evaluate a new respite benefit under Medicaid for family and informal caregivers of persons with adult-onset cognitive impairment. An Advisory Committee will identify the target population, project service use, analyze the potential impact of expanding respite services with the current infrastructure, identify protocols and procedures in existing state programs and outcome methodology currently in use in California and elsewhere, and establish procedures for data collection and evaluation of respite services to measure satisfaction, outcomes, cost, and utilization.

This study complements current efforts in the State regarding Olmstead planning, consumer direction, and long-term care integration by addressing key concerns, including supports for informal caregivers and the need for systems integration.

NEW YORK

Grant Information

Name of Grantee New York State Department of Health

Title of Grant New York's Respite Care Feasibility Project

Type of Grant Respite for Adults

Amount of Grant \$74,285 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Division of Consumer & Local District Relations

Charlotte Mason, Project Coordinator 518-474-5271 cmm24@health.state.ny.us

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Albany, NY 12260

Subcontractor(s)

To be identified.

Target Population(s)

Caregivers of multiple adult populations including, but not limited to, consumers who are medically fragile, cognitively impaired, or physically disabled.

Goal

The goal of this study is to determine the feasibility of developing and implementing a model of respite care that supports both Medicaid eligible and non-Medicaid eligible individuals' ability to remain in the community, by lessening the emotional and physical hardships of their caregivers.

- Identify types of services available, target populations served, and payment and funding mechanisms being used by respite models in other states and assess the success of various respite models.
- Identify respite needs of consumers and caregivers through regional/town meetings with consumers, caregivers, providers, and government entities involved in long-term care (LTC) provision.
- Recommend revisions to New York State regulations and policies needed to support a community-based model of respite care.
- Investigate the possibility of using federal waiver or grant funds to implement a respite care model.

Abstract

The study will determine which modality(ies) of community-based respite care for adults are feasible in New York. Data will be obtained by examining respite models currently used in other states. The analysis will include, but not be limited to, types of services available, target populations served, success in achieving relief of caregiver stress, and how the use of a community-based respite care system has deterred premature institutionalization.

In addition, the Department will obtain information regarding use of different types of financing mechanisms (e.g., capitated, direct payment, voucher) to allow consumers to exercise choice, control, and responsibility over needed respite services. The study will recommend revisions to statutes, regulations, and policies that must be made or implemented to support a community-based model of respite care.

The Department of Health staff will meet quarterly throughout the study with representatives of primary LTC stakeholders to involve them in the monitoring and evaluation of the activities, reports, and recommendations of the contractor.

The ultimate goal of the Department, based on the results of the feasibility study, is the development and implementation of a community-based respite care model that will enhance the State's community LTC system.

OHIO

Grant Information

Name of Grantee Ohio Department of Aging

Title of Grant Ohio's Respite for Adults Project

Type of Grant Respite for Adults

Amount of Grant \$73,854 Year Original Funding Received 2003

Contact Information

Sharon Evanich, Grant Project Manager 614-644-5192 sevanich@age.state.oh.us

50 West Broad Street, 9th Floor Columbus, OH 43215-5928

A copy of the study can be found at:

http://www.cas.muohio.edu/scripps/publications/Real Choices.html

Subcontractor(s)

The Miami University, SCRIPPS Gerontology

Target Population(s)

Caregivers of in-home care recipients.

Goal

The goal of this study is to examine the feasibility of providing respite services as a part of the PASSPORT (Pre-Admission Screening System Providing Options and Resources Today) program, the 1915(c) Medicaid waiver service for seniors.

- Use census data to compile demographic information on potential adult respite consumers, and prepare an inventory of available publicly and privately funded respite services.
- Conduct focus groups and independent research to analyze the respite services currently available within state, county, and local governments.
- Determine options for the development and implementation of an adult respite service.
- Conduct a cost/benefit analysis of various methods for providing respite services.
- Estimate state savings resulting from the implementation of a respite model.

Abstract

In keeping with national trends, Ohio has endeavored to restructure its long-term care delivery system with a renewed emphasis on providing home and community services. As the State moves to expand those services, the need to provide a community support network for families of those in home care is increasingly apparent. Ohio's Respite for Adults project will evaluate the feasibility of implementing an adult respite benefit as part of Ohio's PASSPORT program: the 1915(c) Medicaid waiver service for seniors age 60 and older. The study will also allow Ohio to identify and coordinate respite services currently in place to provide caregivers with the time off that they need and deserve.

The Ohio Department on Aging will contract with an outside entity to (1) conduct focus groups and independent research, (2) perform a thorough analysis of the State's existing caregiver support structure, both public and private, and (3) evaluate the impact of a Medicaid respite benefit. Input from stakeholders and industry experts will be incorporated to develop the framework for this new service and implementation strategies.

RHODE ISLAND

Grant Information

Name of Grantee Rhode Island Department of Human Services (DHS)

Title of Grant Respite Care for Adults Feasibility Study

Type of Grant Respite for Adults

Amount of Grant \$100,000 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

Frank Spinelli, Project Director

401-462-1892

Fspinell@dhs.ri.gov

Authority Authori

Subcontractor(s)

ACS

Target Population(s)

Working age adults and elderly persons with disabilities.

Goal

The goal of this study is to determine whether consumers and caregivers would accept respite care as an alternative to institutional or more costly home and community services.

- Conduct a comprehensive needs assessment and literature review on respite care.
- Analyze the current availability and future capacity of organizations to provide respite services.
- Identify best practices used by other states to inform the design and implementation of a respite program.
- Estimate potential savings to the Medicaid Program as a result of providing respite care, and determine the best ways to coordinate public and private resources in the provision of respite services.
- Design a respite care benefit and develop implementation tools (e.g., credentialing process, provider agreements).
- Develop an evaluation plan.

Abstract

Only one of Rhode Island's six 1915(c) Home and Community-Based Services (HCBS) waivers for elderly persons and younger adults with disabilities includes respite services. The purpose of this project is to enable the Department of Human Services to determine the nature, scope, and magnitude of the need for respite care in Rhode Island and to expand the respite services currently being provided to consumers by the Diocese of Providence.

This project will determine the need for respite services and assess the parameters and impact of providing respite care for adults with disabilities. Stakeholders will be involved in all phases of project activities, which include determining the needs criteria for respite services; estimating the number and characteristics of people needing respite services; identifying roadblocks and best practices; evaluating current respite initiatives; assessing unmet needs; determining system capacity to provide needed respite services; and designing a benefit that defines type, scope, settings, locations, and providers.

ALABAMA

Grant Information

Name of Grantee Alabama Department of Mental Health and Mental Retardation

Title of Grant Alabama's Respite for Children Project

Type of Grant Respite for Children

Amount of Grant \$100,000 Year Original Funding Received 2003

Contact Information

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Montgomery, AL 36140

http://www.alfamilyties.org

Subcontractor(s)

Alabama Family Ties Censeo Research, Inc.

Target Population(s)

Children and their families with serious emotional disturbance.

Goals

- Conduct a feasibility study and develop an implementation plan to guide the creation of a coordinated and accessible respite program.
- Increase the availability of respite care for children and their families with serious emotional disturbance.

- Conduct a needs assessment by identifying the scope and type of respite services available, preliminary cost projections, and estimates of the number of persons likely to use services.
- Conduct research on best practices in respite care approaches used nationwide.
- Develop the necessary protocols, tools, procedures, and other elements of the infrastructure needed to implement a respite program, such as screening and assessment instruments and a certification or licensing process for providers of respite services.
- Revise the State's Medicaid Plan and All Kids Plan to include respite services as a standalone, billable expense for children with serious emotional disturbance and their caregivers.
- Develop an implementation plan.

Abstract

The Alabama Department of Mental Health and Mental Retardation (DMH/MR) is undertaking this study to determine the feasibility of developing and implementing a statewide respite care system for children with serious emotional disturbance and their families. The Department will focus on a capacity- and infrastructure-building process. With an estimated 87 percent of children and their families in need of respite services, the DMH/MR is committed to addressing their needs.

DMH/MR will conduct a full-scale needs assessment to identify the caregivers of children in need and determine the type and scope of currently available respite services. It will also develop preliminary cost projections, estimate the number of persons likely to use services, determine an appropriate cap for respite services that can be received by any one individual, and analyze the impact of that cap. The DMH/MR will also develop an implementation plan that will establish the necessary protocols, tools, procedures, and other elements of the infrastructure needed to implement a respite program, and work for an amendment to the State Medicaid Plan and All Kids Plan to include respite services as a reimbursable service.

ARKANSAS

Grant Information

Name of Grantee Arkansas Department of Human Services

Title of Grant Arkansas' Respite for Children Project

Type of Grant Respite for Children

Amount of Grant \$75,000 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

University of Arkansas for Medical Sciences/Partners for Inclusive Communities

Target Population(s)

Caregivers of children with special health care needs.

Goal

The goal of this study is to expand the number of participants in Arkansas's respite program for children with special health care needs from 132 to 275, and to increase self-reported consumer satisfaction with the program.

- Assess the need for respite care and barriers to obtaining respite services by (1) reviewing data from the current program; (2) conducting surveys and focus groups about the perceptions of the program, the need for respite, and barriers encountered; and (3) interviewing respite program administrators.
- Develop projected use rates, cost projections, and cost savings resulting from program revisions.
- Identify sources of funding for providing respite services (either private foundations or Medicaid).
- Revise policies and procedures of the current respite program.
- Evaluate the revised plan by using focus groups followed by a mail survey.
- Develop recommendations for further modifications based on an evaluation of the project.

Abstract

Children's Medical Services (ChMS), the Arkansas Title V program for children with special health care needs, is located in the Arkansas Department of Human Services. ChMS will conduct a feasibility study to determine how to increase participation in a State Medicaid respite project targeted to caregivers of children with special health care needs.

The goal of this project is to expand participation in the respite care program for children and adolescents with special health care needs. Another goal is to increase self-reported consumer satisfaction with the program and to reduce caregivers' stress.

ChMS operates two 1915(c) waivers that have combined funding to allow caregivers of 275 children not receiving waiver services to receive respite services. Eligible children must be under age 19 and eligible for either SSI or TEFRA. Out of 315 applications for the 275 slots, only 228 met eligibility requirements. Of the 228, only 132 caregivers have met Medicaid billing requirements. The remainder failed to send in required information—particularly a Plan of Care naming a registered nurse who will certify that the caregiver is qualified to take care of the child and can appropriately carry out nurse delegated duties.

Through a subgrant, Partners for Inclusive Communities will undertake the following major activities: (1) assess the existing needs for respite and barriers to program participation, (2) develop one or more proposals for additional funding for respite services, (3) implement a revised plan for the respite program, (4) evaluate the revised plan, and (5) recommend further modifications to the revised plan.

The Steering Committee, comprising consumers and family members and key stakeholders, will be involved in all aspects of the project, including analyzing the problem, planning changes to the current program, overseeing implementation of the revised program, and evaluating the program's activities and impact.

MARYLAND

Grant Information

Name of Grantee Mental Hygiene Administration, Maryland Department of Health

and Mental Hygiene

Title of Grant Maryland Respite for Children

Type of Grant Respite for Children

Amount of Grant \$100,000 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

Center for Health Program Development and Management, University of Maryland, Baltimore County

Target Population(s)

Children under 18 with developmental disabilities, mental health conditions, and special health care needs, who meet the SSI definition of disability and are eligible for Medicaid, and their family caregivers. In the beginning, the project will target children with serious emotional disturbance and then phase in youth with other disabilities.

Goals

- Conduct a feasibility study as a foundation for a demonstration project that integrates respite services for family caregivers of children with disabilities using a Medicaid-type delivery model.
- Develop an implementation plan for the proposed demonstration.
- Develop an evaluation plan for the proposed demonstration.

- Identify the target population and site where the demonstration will take place.
- Analyze strengths and weaknesses of regional versus statewide infrastructure, which includes a review of the State's information and referral systems.
- Explore different types of respite care (i.e., in-home, community activities, foster homes, etc.) and the regulatory change needed to develop a new model for respite care.
- Establish maximum service levels based on variables such as severity of disability, medical necessity, family factors, and other extenuating circumstances.
- Develop social marketing strategies to increase provider recruitment, increase family member involvement in policy making, reduce the stigma of disabilities, and increase multiagency buy in.
- Review existing provider training requirements to set standards or operational procedures that ensure a consistent level of quality.
- Develop a local governance infrastructure to oversee the demonstration.
- Develop an implementation and evaluation plan for the proposed demonstration.
- Survey respite providers and families to gather information on different types of respite services being used and the benefit of those services.
- Review state regulations governing respite in Maryland to understand services requirements across disabilities.
- Develop a cost model to analyze existing or potential funding structures for expanding respite options for children.

Abstract

The Mental Hygiene Administration, a unit of the Department of Health and Mental Hygiene, is leading this project on behalf of the Maryland Caregiver Support Coordinating Council. The Council is a legislatively mandated coordinating body comprising public agencies, private providers, family and consumer representatives and their advocates, and other caregiver supports across the State. The Council will study respite care and make recommendations to the Governor concerning service improvement.

A major component of the project includes the development of a new cost model for respite care. To accomplish this goal, the need for regional versus statewide infrastructure will be examined and regulations and changes needed to support the demonstration will be reviewed. In addition, the project will develop social marketing strategies to achieve a number of specific aims. These include (1) recruiting providers, (2) expanding outreach to families to improve family access to services and increase family member involvement in policy making processes, (3) promoting a better understanding of family burden, (4) reducing the stigma of disabilities, and (5) increasing organizational buy-in to the system change.

The project will include the broadest possible targeted population within the established parameters—children under 18 with disabilities who meet the SSI definition of disability and are Medicaid eligible. Site selection will be based on the availability of current respite program infrastructure in a given community and community readiness to undertake a demonstration project. Family members and key stakeholders will be involved in all aspects of the planning, research, and evaluation.

MICHIGAN

Grant Information

Name of Grantee Division of Mental Health Services for Children and Families,

Michigan Department of Community Health

Title of Grant Michigan's Respite for Children Project

Type of Grant Respite for Children

Amount of Grant \$99,399 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

Michigan Public Health Institute

Target Population(s)

Families of children with developmental disabilities (DD) and/or serious emotional disturbance.

Goal

The goal of this study is to support the increase of Medicaid-funded respite for children as a (b)(3) service when it is medically necessary and identified through a person-centered planning process in an Individual Plan of Service (IPOS).

- Conduct a needs assessment using surveys, interviews, and case studies to identify the options needed to provide real choices to families.
- Determine the costs of various models of respite services, factoring in eligibility, limits on amounts of respite, and the extensiveness of options.
- Standardize respite services using information obtained from the study.
- Modify the state data collection system to identify children with DD as a specific population, and collect data on family and child satisfaction with respite services and caregiver wellbeing.
- Develop an implementation plan.
- Develop an evaluation plan.

Abstract

The Partnership Panel on Respite (PPR) was established by the Division of Mental Health Services for Children and Families (MHSCF), Michigan Department of Community Health (MDCH), to identify barriers to family choice and control over respite services, develop a list of strategies to improve family choice and control, and select the strategies to be included in the feasibility study. The PPR includes family members, respite providers, advocates, and MHSCF staff.

The primary goal of this project is to support the increase of Medicaid-funded respite for children as a (b)(3) service when it is medically necessary and identified through a person-centered planning process in an IPOS. Planned products of this project are (1) a feasibility study of providing respite as a Medicaid-covered mental health service, (2) a detailed implementation plan to phase in respite as a Medicaid-covered mental health service, (3) a detailed implementation plan to phase in a standardized array of respite services at Community Mental Health Service Programs (CMHSPs), and (4) an evaluation plan.

The project has several well-defined outcomes. The Medicaid-managed specialty services 1915b/c Waiver will be amended to include respite as a (b)(3) mental health service. State policy will be amended to require CMHSPs to provide an array of respite services. The state data collection system will be modified so that the impact of these changes can be evaluated.

The PPR will include the State Medicaid Agency, three to four community mental health service programs, the Michigan Developmental Disabilities Council, the Michigan Mental Health Planning Council, Michigan Protection and Advocacy, and ARC-Michigan. The Panel will provide guidance and feedback to MDCH and to the Michigan Public Health Institute, Systems Reform Office, which will carry out the feasibility study under contract with MDCH.

OREGON

Grant Information

Name of Grantee Oregon Department of Human Services, Seniors and People with

Disabilities

Title of Grant Oregon's Respite for Children Feasibility Project

Type of Grant Respite for Children

Amount of Grant \$99,274 Year Original Funding Received 2003

Contact Information

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Oregon Department of Human Services

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Subcontractor(s)

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Project Coordinator 503-924-3789 (f)

Human Services Research Institute (HSRI)

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Portland, OR 97224

Target Population(s)

Children with developmental disabilities and their primary caregivers.

Goals

The goal of this study is to determine the feasibility of, and develop an implementation plan for, using Medicaid funding to expand and improve existing respite care services for children with developmental disabilities.

- Analyze the current respite delivery system, compare the current system to other options for providing respite services, and determine the level of need for respite care.
- Evaluate the risks and benefits of providing respite services in the context of family support.
- Identify tools (e.g., assessment and screening, outreach, payment techniques) that can be used in a statewide implementation.
- Develop an implementation and evaluation plan for future respite services.
- Revise Oregon Administrative Rules for possible implementation in July 2006.

Abstract

The Oregon Department of Human Services, Seniors and People with Disabilities (SPD), will conduct a feasibility study and develop an implementation plan for using Medicaid funds to provide respite care for children with developmental disabilities. The Department will examine current state respite care services and delivery systems to (1) obtain and evaluate data related to needs and capacity requirements, (2) research the risks and potential for service expansion and improvement through Medicaid State Plan or waiver services, and (3) develop a plan to implement recommendations obtained through grant activities.

RHODE ISLAND

Grant Information

Name of Grantee Rhode Island Department of Human Services

Title of Grant Real Choice Systems Change Grants for Community Living:

Respite for Children

Type of Grant Respite for Children

Amount of Grant \$100,000 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

None at this time.

Target Population(s)

Children with special health care needs and their families.

Goal

The goal of this project is to assess the need for and the feasibility of providing cost-effective respite care services for children with special health care needs and their caregivers.

- Conduct a comprehensive needs assessment to determine the nature, scope, and magnitude of the need for respite care.
- Assess the current provisions for respite services to families and caregivers of children with special health care needs (CSHCN) by public and private agencies, using qualitative and quantitative analysis of current availability and future capacity of organizations that provide respite services.
- Conduct a literature review on respite care services for children with special health care needs to identify models used and lessons learned.
- Identify best practices used by other states that have respite care programs.
- Design a respite care benefit that includes estimates of costs and use.
- Identify state legislation and Medicaid State Plan amendments or waivers needed to implement a broader respite care program.
- Draft an implementation and evaluation plan.

Abstract

The Rhode Island Department of Human Services (DHS) has led the State in developing a system of care for children with special health care needs (CSHCN) that is responsive to consumer needs. Until recently, DHS and the Department of Mental Health, Retardation and Hospitals (MHRH) jointly administered, but MHRH actively managed, a Home and Community-Based Services (HCBS) waiver to provide respite care and related services to persons with mental retardation and other developmental disabilities, including children. In addition, MHRH has provided respite care for approximately 300 children under a state-funded program. The Rhode Island General Assembly transferred responsibility for both programs to DHS effective July 1, 2003. DHS will now have an active role in ensuring the provisions of respite care for a designated population.

This study will begin with a thorough analysis of the programs DHS has inherited from MHRH to determine who receives respite care, under what circumstances, provided by whom, and at what cost. DHS will also review more than 1,000 cases that have been assessed by the Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Reevaluation (CEDARR) Family Centers to quantify the need for respite care and to update estimates from earlier focus groups. DHS will work with the Leadership Roundtable families and the CEDARR Interdepartmental Team to consider the benefit design options in providing respite care, to whom, at what cost, and with what potential for offsetting other costs. Particular attention will be paid to the possible role(s) of the CEDARR Family Centers in respite care.

This project may also be used to help develop tools necessary for implementing a more expansive respite care benefit, pending state budget approval. Activities may include drafting certification standards for providers, developing a recruitment and training program for providers, designing an outreach program for consumers, developing a monitoring and evaluation plan, outlining state legislation and State Plan amendments and/or waivers, and preparing an implementation and phase-in strategy.

ILLINOIS

Grant Information

Name of Grantee Illinois Department of Human Service

Title of Grant Illinois' Feasibility Study and Development Project for Community

Based Treatment Alternatives for Children

Type of Grant Community Based Treatment Alternatives for Children

Amount of Grant \$100,000 Year Original Funding Received 2003

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Subcontractor(s)

None at this time.

Target Population(s)

Children and adolescents with serious emotional disturbance who have been awarded Individual Care Grants (ICGs) and their families.

Goal

The State of Illinois, Department of Human Services, Division of Mental Health provides residential treatment services to children and adolescents with serious emotional disturbance (SED) through the ICG program. The goal of this study is to determine the feasibility of developing a Medicaid waiver to provide community services as a viable alternative to residential treatment under the State's ICG program.

- Develop a set of recommendations for the ICG program to improve its community-based option as an alternative to residential treatment.
- Conduct focus groups with providers, parents, and adolescent ICG service recipients to assess the barriers to providing community-based mental health care, and to identify factors that will strengthen the community-based ICG program.
- Make recommendations for legislative changes to the ICG administrative rule.
- Identify potential providers for new services under the ICG program and develop a plan for monitoring service delivery.
- Make recommendations to the Department regarding the development of a Medicaid waiver for children and adolescents with SED.

Abstract

The goal of the Illinois Department of Human Services, Division of Mental Health feasibility study is to form a coalition to (1) address barriers to receiving respite services, (2) to develop an appropriate package of services to adequately support SED children and adolescents in their homes, and (3) avert residential treatment care (RTC). The coalition will comprise parent consumers, private, community-based mental health providers, the Illinois Federation of Families, and representatives of the state mental health authority. RTC would remain an option; however, families would have a choice regarding the location of their child's treatment.

The ICG Parent's Group will be a key partner, assisting with the development, implementation, and evaluation of this study. A parent will also serve as the co-principal investigator.

The data gathering and analysis involved in this study will be obtained through a contract with a health care consultant. The consultant will conduct focus groups and telephone interviews with ICG parents, community mental health agency providers, and ICG teen recipients. The consultant will also analyze the information and assess the financial feasibility of providing recommended services. The possibility of using a Medicaid waiver to provide these services will also be assessed.

MARYLAND

Grant Information

Name of Grantee Mental Hygiene Administration, Maryland Department of Health

and Mental Hygiene

Title of Grant Maryland's Community Based Treatment Alternatives for Children

Type of Grant Community Based Treatment Alternatives for Children

Amount of Grant \$100,000 Year Original Funding Received 2003

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Subcontractor(s)

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University of Maryland School of Medicine, Center for Mental Health Services Research

Target Population(s)

Youth who meet the level-of-care requirements for admission to a psychiatric residential treatment facility (PRTF).

Goals

- Conduct a feasibility study for a demonstration of home and community services that provide a level of care comparable to PRTFs.
- Develop an implementation and evaluation plan for the demonstration.

- Define strategies, standards, and system conditions to support high-quality provision of care, planning, and implementation via the wraparound approach.
- Identify issues related to marketing the effectiveness of community services.
- Determine factors and legal requirements related to site selection.
- Outline the site selection process and conduct formal site selection activities.
- Develop specifications for the wraparound model, including enrollment and eligibility procedures, a training plan, and a demonstration model.
- Design a quality assurance process and a formal feedback mechanism for formative review.
- Develop a full evaluation plan.

Abstract

The Mental Hygiene Administration, a unit of the Department of Health and Mental Hygiene, will conduct the study to fulfill a major recommendation of the Governor's Council on Custody Relinquishment. The Council was created to study alternatives to the forced or voluntary relinquishment of parental custody to gain access to health services. This problem has subsequently been identified in a General Accounting Office (GAO) report and acknowledged as a problem of major scope by the President's New Freedom Commission on Mental Health.

Maryland has played a major role in articulating the need for a program like Community Based Treatment Alternatives for Children (C-TAC) which will allow demonstrations of home and community services that provide a level of care comparable to a PRTF. The principal goals of the project include (1) completing a feasibility study, (2) developing an implementation plan for the demonstration, and (3) developing an evaluation plan.

A major focus of this project is on family involvement in all aspects of the planning, research, and evaluation development. The demonstration model will be based on the experience of "Wraparound Milwaukee" and other similar demonstration projects, and two Center for Mental Health Services Children's Imitative grants that have been implemented in Maryland.

MASSACHUSETTS

Grant Information

Name of Grantee Executive Office of Health and Human Services

Title of Grant Building and Financing Sustainable Systems of Care:

A Feasibility Study and Development Grant for Community Based

Alternatives for Children with SED in Massachusetts

Type of Grant Community Based Treatment Alternatives for Children

Amount of Grant \$100,000 Year Original Funding Received 2003

Expected Completion Date September 2007

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Subcontractor(s)

University of Massachusetts Medical School, Center for Health Policy & Research

Target Population(s)

Children with serious emotional disturbance (SED) in out-of-home placement or imminently at risk for such placement.

- Evaluate the feasibility of expanding community treatment alternatives for children with SED.
- Identify replicable models of community treatment alternatives based on a review of best practices.

- Map and analyze the program capacity and current spending for the target population.
- Conduct a survey to determine the percentage of children that can reasonably and safely be treated in community settings.
- Conduct a legal analysis of current service and reimbursement options, including relevant Medicaid laws and laws governing the target population, to determine which services can be provided and reimbursed with matched Medicaid funds.
- Determine the type of waiver authority needed to broaden covered services.
- Review the evidence-based best practices among wraparound programs and analyze reimbursement methodologies and cost data associated with community treatment.

Abstract

The project will evaluate the financial feasibility of expanding community treatment alternatives for children with SED. State staff will define the population of children currently served in out-of-home placement by systematically evaluating state agency expenditures for children with SED. In particular, the project will evaluate (1) the inpatient and residential services provided by other state agencies, and (2) state and local special education expenditures for children in residential placements pursuant to a behavior diagnosis on their Individualized Education Plan (IEP). A clinical analysis of children in out-of-home placements to determine the "universe" of children that could be safely served in a community setting will also be conducted.

The project will also evaluate the services currently provided and reimbursable as State Plan services under existing Medicaid guidelines and those community services that are "state only" funded. In addition, the project team will evaluate regulations or other limitations that apply to the population to determine the legal feasibility of applying for a 1915(c) waiver to serve children with SED. Other efforts to redeploy state funding or to use grant resources to expand community treatment alternatives for children with SED will be explored.

Finally, the Commonwealth will convene an interagency public-private group to evaluate community program models to determine the programmatic and financial structures that will provide the most effective and replicable community treatment alternatives for children with SED. This group will involve providers from all settings, families, medical and psychiatric professionals, and individuals from the special education system.

An interagency policy group, composed of senior staff from the relevant state agencies, will also meet regularly to ensure that the project coordinates with other efforts to address the needs of children with SED. Families and providers will be involved through specific work groups and focus groups and frequent reporting to the Mental Health Commission for Children.

MISSISSIPPI

Grant Information

Name of Grantee Division of Medicaid

Title of Grant Mississippi's Community Based Treatment Alternatives for

Children Project

Type of Grant Community Based Treatment Alternatives for Children

Amount of Grant \$99,000 Year Original Funding Received 2003

Expected Completion Date September 2007

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Bureau Director

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Subcontractor(s)

MS Families as Allies for Children's Mental Health Vanderbilt University

Target Population(s)

Children with serious emotional disturbance (SED).

Goal

The goal of this project is to examine the feasibility of developing a waiver program that will provide home and community services for children with SED who have a history of placement at psychiatric residential treatment facilities (PRTFs) or who are at immediate risk for being placed in a PRTF.

- Conduct focus groups and surveys to assess community treatment alternatives to residential treatment or institutionalization.
- Analyze and publish findings from the feasibility study.
- Develop an implementation and evaluation plan based on findings from the feasibility study.

Abstract

Over the past 5 years, many factors have occurred in Mississippi that have readied the State for a concerted effort to promote community treatment alternatives in a creative manner. A coordinated system of community-based treatment serves the majority of SED children in Mississippi. However, a small percentage of children, estimated from 1 to 3 percent, still are not served. For these children, the State plans to pursue flexible treatment options that will allow them to have access to a continuum of care to meet their specific needs.

This feasibility study will allow the Division to determine the potential costs and cost savings associated with a waiver program for this population. Families of children with high-intensity needs will be included so that their needs will be taken into account and addressed in the development of services. The Division of Medicaid will also develop an implementation plan for a potential waiver program and an evaluation plan that will determine if the goals of the program are being accomplished.

The ultimate goal of this project is to assess community based alternatives to residential treatment or institutionalization, which will position the State to make a successful application for a 5-year PRTF demonstration grant outlined in the Deficit Reduction Act to operate an HCBS waiver for children with SED.

MISSOURI

Grant Information

Name of Grantee Department of Mental Health

Title of Grant A Feasibility Study and Development Grant for Community Based

Alternatives for Children with Serious Emotional Disturbance

Type of Grant Community Based Treatment Alternatives for Children

Amount of Grant \$99,821 Year Original Funding Received 2003

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Subcontractor(s)

Alicia Smith and Associates

Target Population(s)

Families of children with serious emotional disturbance (SED).

Goal

The goal of the project is to conduct a feasibility study that will assist the State in the design and implementation of a comprehensive system of community services and supports for children with SED who would otherwise require care in a psychiatric residential facility.

- Develop a single intake and assessment process to be used by all state agencies.
- Modify existing policies related to access and services for children with SED to ensure equal access to services regardless of point of entry.
- Modify existing regulations to ensure consistency with state policy.
- Evaluate existing waivers and explore the need for additional waivers.
- Develop a quality assurance system that measures inputs (e.g., ease of intake processes) and outputs (e.g., effectiveness of outreach strategies).
- Modify existing information systems for compatibility among state agencies or design new ones as needed.

Abstract

The activities under this feasibility study will assist the State's efforts to design and implement a comprehensive system of community services and supports for children with SED who would otherwise require care in a psychiatric residential facility. The State's goal is to expand services that will enable a child to stay in the home and organize those services in a comprehensive system that will provide a single point of entry regardless of how the child first contacts the system, provide a continuum of effective services, and blend disparate funding streams to support the system. The State hopes the revised system will result in

- an increased number of children with SED who can remain safely in their homes, schools, and communities while receiving necessary services.
- a reduction in the residential treatment population in the child welfare and juvenile justice systems.
- a reduction in the number of inpatient days for mental health diagnosis for Medicaid-eligible children, and improved child outcomes and parent satisfaction with services.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

TEXAS

Grant Information

Name of Grantee Texas Health and Human Services Commission

Title of Grant Feasibility Study and Development Grant for Community Based

Treatment Alternatives for Children

Type of Grant Community Based Treatment Alternatives for Children

Amount of Grant \$93,600 Year Original Funding Received 2003

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Subcontractor(s)

Community**TIES** of America, Inc.

Target Population(s)

Children with serious emotional disturbances (SED).

Goal

The goal of this project is to identify alternatives to out-of-home placement that allow children to live in the most integrated community setting, to give families choices about treatment options, and to expand the quality array of intensive treatments and supports.

- Conduct a feasibility study that identifies three options—a 1915(c) waiver, a demonstration project, and a "state funds only" strategy—that would emphasize community services as an alternative to institutional placements.
- Develop an implementation and evaluation plan for each of the three options.

Abstract

Texas is under-serving children with SED, and those being served are not always in the most appropriate setting. The majority of the State's community mental health services are limited in type, amount, scope, and duration. Texas has little capacity for community services such as intensive in-home services and treatment, and foster care, which have been demonstrated to effectively manage and treat children with SED in home and community settings. Consequently, many children are placed away from their families and communities at higher costs than if appropriate treatment in the community had been available. In a time of limited resources, Texas needs to develop a strategy to redirect the use of institutional funds to home and community services. This project will study the feasibility of and the most appropriate plan for providing more effective home and community services to children with SED, whether via a waiver, demonstration project, or through a state-only approach. The study will assess which of the options best enhance existing efforts and will develop a detailed financing, implementation, and evaluation plan for each recommended option.

The ultimate goal of this feasibility study is to identify treatment mechanisms that allow children to live in the most integrated community setting, that give families choices about treatment options, and that expand the array of quality, intensive treatments, and supports. The study will produce feasible solutions for using a waiver or demonstration to integrate funding, coordinate services, and develop a comprehensive provider base to (1) increase the number of Texas children with SED who are provided quality treatment in their homes and communities and (2) decrease the number of Texas children placed in institutional settings.

CALIFORNIA

Grant Information

Name of Grantee State of California

Title of Grant Bay Area Quality Enhancement Initiative

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$499,844 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

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Project Director

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Consultants to be hired.

Target Population(s)

Individuals with developmental disabilities.

- Design a model and corresponding plans to implement the Bay Area Quality Management System to provide person-centered and person-directed quality services and supports to people served within the Bay Area.
- Adopt a systematic approach to measure consumers' satisfaction with services and supports in meaningful ways at important intervals to guide system improvement efforts.
- Apply the "lessons learned" from the project activities to make statewide system reforms.

- Design the necessary structures and processes and identify the needed resources and supports that will be required to implement a Quality Management System in the pilot area and implement the plan.
- Institute new methods for assessing consumers' and family members' satisfaction with their services and supports.
- Design and implement new methods, structures, and processes to strengthen the quality assurance and quality improvement system.

Abstract

The California Department of Developmental Disabilities Services (DDS) has various initiatives and efforts underway to address systemic weaknesses identified through a self-assessment that compared the current Quality Assurance and Quality Improvement (QA/QI) system within the context of the HCBS Quality Framework. Through this project, DDS will target specific problem areas in two critical dimensions of home and community-based service delivery: provider capacity and capabilities and participant outcomes and satisfaction. DDS will use the San Francisco Bay Area as a pilot area to test new models, methods, and processes and apply the lessons learned to make statewide reforms to the QA/QI system.

The Bay Area Quality Management System will be a collaborating consortium involving representatives of three regional centers, a developmental center, consumers and family members, service providers, advocacy organizations, and others. The model for the system will be designed using a quality management approach. Specific implementation plans will be developed to provide a blueprint of the necessary steps and resources needed to successfully launch system operations. Focus areas of the implementation plans include (1) a process in which performance expectations are specified and tied to the provider's ability to become certified to offer services and supports; (2) a system for providing training and technical assistance to providers to achieve higher levels of quality in their services and supports and meet their performance expectations; (3) a process for expanding the available network of generic resources and service providers; (4) activities to support consumers' and family members' involvement in decision-making, including a Quality Review Commission comprising stakeholders; and (5) identification of the resources and supports needed to support the operations of the Bay Area Quality Management System.

DDS will also institute new methods for assessing consumers' and family members' satisfaction with their services and supports to provide all levels of decision-makers with needed information to assess overall performance. Through this project, DDS will define an improved assessment process, including the assessment tool and sample selection methods. DDS will then partner with an organization or entity to conduct the actual assessment of consumer satisfaction.

Evaluation activities will be incorporated throughout the project so that midcourse corrections may be made, as well as decisions concerning application to other regions. At strategic points throughout the project, decision-makers will consider the readiness to make system improvements on a statewide basis.

COLORADO

Grant Information

Name of Grantee Colorado Department of Human Services, Division for

Developmental Disabilities

Title of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services for Colorado's Citizens with

Developmental Disabilities

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$499,851 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Colorado waiver participants with developmental disabilities.

Goals

- Improve efficiency and effectiveness of existing quality assurance/quality improvement (QA/QI) systems.
- Promote the more active and effective involvement of consumers and families in QA/QI through Web-based information technology (IT) resources and direct assistance to strengthen self-advocacy and family advocacy.

Activities

- Define and standardize a critical subset of quality assurance measures and apply these statewide.
- Acquire and adapt a Web-based incident reporting system.
- Purchase and implement an automated data capture system.
- Establish a Web-based resource to provide information to and receive information from participants and families.

- Provide training and assistance, including Web-based resources, for self-advocacy and family advocacy groups.
- Award subgrants to enhance the effectiveness of local self-advocacy groups in improving the quality of waiver services.

Abstract

Colorado has a complex, decentralized developmental disabilities system that emphasizes small group living arrangements, promotion of individual and family choice of services/supports and providers, and a large number of providers. Colorado's incident management system is multitiered, with both county-based Community Centered Boards (CCBs) and service agencies having line responsibility for preventing, identifying, and following up on critical incidents. Colorado's baseline quality assurance standards and processes are fundamentally sound, but the challenge facing Colorado is to position QA/QI for HCBS to make smart use of IT to support quality management and improvement. The Division for Developmental Disabilities (DDD) does not currently have an efficient or effective system to capture information about critical incidents in real or near-real time, or to support trend and root cause analysis of such incidents. The lack of solid IT capabilities undermines the capacity to conduct performance appraisals, engage in effective quality improvement, and furnish important information to participants and families to aid them in selecting providers.

This project will provide the IT capabilities that DDD needs to efficiently and effectively identify trends and conduct root cause analysis regarding critical incidents. Further, this project will establish a statewide Project Advisory Committee to review critical incident data and will institute a review process to ensure that DDD and the CCBs demonstrate competence and diligence in responding to critical incident data. These efforts will enhance the efficiency and effectiveness of discovery, remediation, and systems improvement. The project will also provide a needed degree of standardization in information collection, without requiring administratively burdensome and costly changes to the systems that are already in place. DDD will seek only a subset of information, most of which is likely being collected already, and will provide an easily-accessible, automated data capture system to receive it.

The project also seeks to enhance the role and effectiveness of self-advocates as key guarantors of quality services. DDD has acknowledged the importance of self-advocacy in ensuring the quality of waiver services in Colorado and through this project will provide subgrants to local self-advocacy and family advocacy groups to support the development of new self-advocacy organizations or to expand the efforts of existing organizations (e.g., Speaking for Ourselves, Association for Persons in Supported Employment, etc.). This project will also reimburse travel expenses for self-advocates to attend and participate in DDD's Self-Advocate Advisory Council, which provides direct input to the DDD Director on statewide policy issues.

This project will position Colorado for sustained improvement in its QA/QI activities. The new systems and improvements to existing systems that the project will introduce are highly efficient and based on inexpensive, proven IT. Finally, the project will build the support of stakeholders for the information collection system through their involvement in the Project Advisory Committee and their continued involvement in an ongoing, statewide Quality Improvement Council.

CONNECTICUT

Grant Information

Name of GranteeConnecticut Department of Mental RetardationTitle of GrantConnecticut Quality Review and Improvement

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$499,000 Year Original Funding Received 2003

Expected Completion Date September 2007

http://www.cgi-ams.com

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Subcontractor(s)		
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CGI-AMS
Greater Boston Area
600 Federal Street

Andover, MA 01810

Target Population(s)

All people served by the Connecticut Department of Mental Retardation (DMR).

- Develop the capacity to input, store, analyze, and report quality indicators from the Department's new quality review system.
- Ensure and improve quality for individuals living in their own or family homes.
- Involve individuals and their families in defining, determining, and improving quality.
- Develop and provide a wide range of training activities for various participant users of the new quality system.

- Develop browser-based technology to enable secure, real-time data entry and access to DMR applications.
- Design additional data management systems and modify existing systems to incorporate new quality indicators for analysis, reporting, and follow-up functions.
- Establish a methodology to risk-adjust data, establish valid benchmarks, and analyze quality and incident data to identify patterns, trends, and variables that predict risk.
- Develop new or revise all current DMR policies and procedures related to participant safeguards.
- Develop multimedia materials in English and Spanish to support education activities, and provide home safety and emergency preparedness information and resources to individuals and families.
- Establish a Self Advocate Leadership Institute that will develop consumer skills to participate in the Department's quality initiatives.
- Create a Self Advocate Speaker Bureau, and establish Family and Individual Networks to support self-determination.
- Identify areas for training and technical assistance to improve quality review techniques and service enhancements.
- Train families and individuals who are managing their own services to effectively use enhanced Web-based recruitment tools to find potential employees, and to use local emergency backup staff arrangements.

Abstract

The Connecticut DMR is using Real Choice Grant funding to strengthen its quality review system by developing data applications to provide more timely, accurate, integrated, and comprehensive information that will identify trends and provide a foundation for improvement initiatives. The grant project also includes activities to involve consumers and family members in the design, implementation, and evaluation of DMR's new quality review and improvement system. As part of this effort, DMR will establish state-level review teams and regional and statewide quality improvement councils with consumer and family membership. Self-advocates will also be involved in a Leadership Institute, which will train them to assume influential roles in the quality system. The planned outcomes of this grant include

- a fully operational quality data management system.
- a risk adjustment methodology to compare provider performance fairly against established benchmarks for various quality indicators.
- quality indicators for safety and emergency preparedness and a review of methodologies for people who direct supports in their own or family homes.
- quality review and improvement mechanisms that incorporate meaningful roles for consumers and families.
- more knowledgeable and informed consumers and families who are influential in improving HCBS waivers and self-direction options in Connecticut.

DELAWARE

Grant Information

Name of Grantee Division of Developmental Disabilities Services (DDDS)

Title of Grant Consumer Centered Quality Assurance and Quality Improvement

in Home and Community Based Services Protocol

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$351,702 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

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Human Services Research Institute

Cambridge, MA

John Ashbaugh 781-400-1110

Danic Technology Inc.

Needham, MA

Target Population(s)

Consumers with developmental disabilities.

- Assess current quality management functions for waiver and nonwaiver Home and Community-Based Services (HCBS).
- Develop a strategic plan based on assessment findings that outlines specific objectives to formulate the Division's quality assurance/quality improvement (QA/QI) program consistent with the CMS HCBS Quality Framework focus areas and desired outcomes.
- Implement the QA/QI HCBS system after conducting a pilot test that can be evaluated for effectiveness and efficiency, usefulness in measuring desired outcomes, and timeliness.
- Develop a quality management system that will address a proposed HCBS Family Support waiver.
- Establish a quality council review body.

- Assess the status of policies, practices, and documentation/data by collecting data through the National Core Indicators project (ongoing) and various other relevant surveys.
- Establish/revise policies, practices, and documentation/data systems to address weaknesses or gaps identified by the assessment.
- Establish an ongoing protocol for assessing individual satisfaction and outcomes, based on the National Core Indicators project or other applicable project surveys.
- Establish and/or revise QA/QI management monitoring functions for gathering real-time data on outcomes and client satisfaction.
- Establish a reporting and remediation system where remediation and improvement plans are implemented, monitored, and tracked.
- Establish an interactive consumer feedback system to provide periodic feedback to the Division of Developmental Disabilities Services (DDDS) and service providers on satisfaction and service delivery problems.
- Conduct and evaluate a pilot of the QA/QI HCBS system with a representative group of individuals and service providers.
- Develop a plan for expanding the QA/QI HCBS management functions to all home and community services.
- Identify key Division staff to oversee the establishment of a quality council; and identify
 and recruit quality council members from a cross-section of people with disabilities, family
 members of people served, service providers, advocates and DDDS staff.
- Conduct training of quality council participants following the preparation of orientation and training materials.
- Develop survey tools and procedures to effectively measure the quality of the services delivered under the Family Support waiver program, and develop the necessary DDDS policies concerning the program.
- Assess the current DDDS data systems to make recommendations for future information technology development.

Abstract

Founded on DDDS participation in the National Core Indicators project and in the Re-inventing Quality Conferences, a multiyear plan for developing a consumer-centered QA/QI system for home and community services was developed, serving as the basis for the Systems Change grant application. A Consumer/Stakeholder Task Force was formed at the grant's inception to direct the project. The CMS HCBS Quality Framework and waiver assurances will constitute the grounds for instituting changes to the Division's QA/QI system.

The project has three phases: (1) to assess quality management functions in the current QA/QI HCBS residential program, (2) to develop a QA/QI HCBS strategic plan around the HCBS Quality Framework focus areas and desired outcomes, and (3) to implement the new QA/QI HCBS system. The activities of this project will lead to a fundamental alteration in the Division's QA/QI HCBS system, which will be person centered around the seven focus areas and related desired outcomes of the HCBS Quality Framework.

GEORGIA

Grant Information

Name of Grantee Georgia Department of Human Resources

Title of Grant Georgia Quality Assurance and Quality Improvement in Home and

Community Based Services

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$475,000 Year Original Funding Received 2003

Expected Completion Date September 2007

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Project Coordinator

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Target Population(s)

Persons with mental retardation and other developmental disabilities (MR/DD) and their circle of support, support coordinators, and providers.

- Promote greater statewide understanding and provision of person-centered practices.
- Design enhanced consumer outcomes that are objective and person centered to complement the National Core Indicators (NCI) survey.
- Establish an efficient and comprehensive, real-time data system that produces easily accessible information and reports.

- Conduct two pilot programs (for 20 to 40 consumers) of active learning training and supports to create and implement a person-centered plan and provide follow-up support.
- Establish three additional person-centered planning groups in various areas of Georgia.
- Conduct five statewide Person-Centered Planning Concept trainings for families, providers, support coordinators, and community leaders.
- Coordinate technical assistance to provide communication devices for person-centered planning participants.
- Design enhanced consumer outcome measures that are objective and person centered.
- Train Support Coordination agencies to complete the NCI survey tool.
- Conduct study to evaluate the validity and accuracy of NCI survey methods, procedures, and protocols.

Abstract

The Department of Human Resources (DHR) is the primary human service agency of Georgia, and the Division of Mental Health, Developmental Disabilities and Addictive Diseases (DMHDDAD) is a division of DHR. Two separate Home and Community-Based Services (HCBS) waiver programs based in DMHDDAD currently serve persons with MR/DD. DMHDDAD is planning to engage in a redesign process for these waivers to encourage services that are person-directed, person-centered, and afford greater flexibility to individuals served and providers.

Although Georgia is raising awareness of self-determination and self-directed services, a gap between knowledge and practice of these principles exists. Many providers have received person-centered training, but lack the skills to develop and implement a person-centered plan. This project will enable professionals to utilize their skills in implementing these principles.

Georgia currently maintains four databases, which collect, store, and track various issues that impact people with developmental disabilities and their services. These systems, however, function independently and do not share information, making data entry and review cumbersome and repetitious. The project will be instrumental in linking these systems to facilitate access to information.

INDIANA

Grant Information

Name of Grantee Indiana Family and Social Services Administration/Division of

Disability, Aging and Rehabilitative Services

Title of Grant The Indiana Quality Assurance/Quality Improvement System for

Home and Community Based Services

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$500,000 Year Original Funding Received 2003

Expected Completion Date September 2007

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Indiana Family and Social Services

Administration

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Subcontractor(s)

None.

Target Population(s)

Individuals receiving services funded by the Aged and Disabled waiver, the Traumatic Brain Injury waiver, and the Assisted Living waiver administered by the Division of Aging.

- Design a quality assurance/quality improvement (QA/QI) system for home and community services in which methods for gaining current information about providers and individuals receiving services are built into the system.
- Design a QA/QI system that allows staff to evaluate information and determine appropriate action in an expeditious manner.
- Develop systems to allow staff to analyze data and identify patterns, which will result in increased quality through continuous evaluation of the QA/QI system.
- Implement an automated system by which data can be collected, synthesized, and stored for retrieval by personnel responsible for quality assurance and quality improvement.
- Implement a system by which the project will be monitored to ensure the goals are met.

- Design and implement an annual survey of at least 20 percent of beneficiaries, and conduct annual focus groups to obtain overall feedback on the service system.
- Establish and implement an ongoing review process to ensure that emergency backup systems are in place and effective.
- Develop and implement a standardized and effective system of incident reporting and response.
- Develop, monitor, and enforce standards for service providers.
- Develop and implement effective and automated incident reporting and complaint systems.
- Develop and implement automated systems to collect and analyze operational data from the QA/QI system.

Abstract

The Indiana Division of Disability and Rehabilitative Services, (DDRS) and the Division of Aging (DA) support a statewide in-home services program. A recently passed statute laid the framework for shifting the State's long-term care spending from predominately nursing homes to a greater reliance on home and community services. In January 2000, the Bureau of Quality Improvement Services (BQIS) was established to develop and implement QA/QI systems for all programs within the Divisions.

This grant will (1) develop mechanisms to obtain participant input into the development of QA/QI systems and ongoing feedback about services; (2) create consistent standards by which all providers must abide; (3) institute uniform policies and procedures across the various state agencies and contractors who provide services; and (4) develop information technology systems that will improve data collection and the ability to review trend information, make recommendations, implement processes to be put into place, and reevaluate the effectiveness of the systems. Overall, the project will develop a QA/QI system that facilitates communication and provides effective protection and support for participants.

Consumers are represented on the Consumer/Community Advisory Council and its subcommittees, through the participation of the Indiana Home Care Task Force and the recruitment of individual consumers. Provider industry groups are also involved, as are numerous state agencies.

MAINE

Grant Information

Name of Grantee Maine Department of Health and Human Services

Title of Grant Maine's Quality Assurance and Quality Improvement Project Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$500,000 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

Julie Fralich, Project Director 207-780-4848 Edmund S. Muskie School of Public Service University of Southern Maine

Other contracts yet to be awarded.

Target Population(s)

Adults with disabilities, including older adults, adults with physical disabilities, adults with mental retardation (MR), and adults with physical disabilities who direct their own services.

- Create and formalize cross-program and consumer-centered infrastructures for quality management and improvement for home and community services.
- Develop a coordinated interdepartmental approach to quality management and improvement for Home and Community-Based Services (HCBS) waiver programs.
- Engage consumers in an active role in the planning, design, and evaluation of HCBS and systems.
- Develop a coordinated incident management system for HCBS waiver programs.
- Assess system performance on a regular and real-time basis.
- Develop a plan for sustainable interagency collaboration, consumer involvement, and coordinated quality improvement systems.

- Develop a comprehensive plan (a Quality Road Map) for interdepartmental quality assurance and improvement.
- Implement a collaborative interdepartmental quality assurance project.
- Conduct surveys of waiver participants using the Participant Experience Survey and involve consumers in the co-administration of consumer satisfaction surveys.
- Conduct a feasibility assessment to provide the framework for developing a coordinated incident management system for HCBS waiver programs.
- Develop a consolidated report on the performance of all waivers programs, including standardized measures and reports.
- Develop a plan for sustaining interdepartmental collaboration and coordinated quality management systems.

Abstract

Under the Maine Department of Health and Human Services, as lead agency and applicant, the state offices will collaborate on this grant to design a cohesive and coordinated quality management system for home and community services for adults with disabilities, including older adults, adults with physical disabilities, adults with mental retardation, and adults with physical disabilities who direct their own services.

This grant provides the opportunity to build on the recommendations of Maine's Plan Development Work Group for Community-Based Living to (1) put in place a quality management system that is "consumer-driven, comprehensive, integrated, and value-based" and (2) create an environment and infrastructure to support sustainable interdepartmental collaboration. The Work Group for Community-Based Living is Maine's Olmstead planning group comprising consumers and state officials.

The project will move efforts to improve quality by developing and implementing computerbased monitoring and reporting systems to ensure the health and welfare of individuals who participate in HCBS waiver and related programs.

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¹Maine's Plan Development Work Group for Community-Based Living, Communities, Individuals and Choices: A Roadmap for Meeting Individualized Needs in Integrated Settings and Programs, Draft, 10/2/02.

MINNESOTA

Grant Information

Name of Grantee Minnesota Department of Human Services Continuing Care

Administration

Title of Grant Minnesota's Quality Assurance and Quality Improvement Project

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$499,880 Year Original Funding Received 2003

651-431-2579

Expected Completion Date September 2007

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Contact Information

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Strategic Planner

Department of Human Services

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Subcontractor(s)

Four to be awarded.

Target Population(s)

Home and Community-Based Services (HCBS) waiver participants.

- Enhance participant safeguards and support in exercising rights and preferences.
- Support achievement of participant outcomes and participant-centered planning for, and satisfaction with, HCBS.

- Improve the incident management reporting system.
- Improve case managers' ability to respond to consumers' reports of problems with automated communications processes.
- Obtain primary data about consumers' experiences directly from them to evaluate the current HCBS program and inform systems improvement strategies.
- Increase consumer-based quality assessment and quality measurement of both services and quality of life outcomes for HCBS waiver participants.
- Create a comprehensive and integrated quality assurance/quality improvement (QA/QI)
 "data mart."
- Craft the design of the QA/QI "data mart" to permit future publication of provider profiles in MinnesotaHelp.info to provide consumers with information related to the quality of services that they can use to make choices among services and providers.

Abstract

This project will improve the design of participant safeguards and the functions of discovery and remediation related to these safeguards. It will also enhance the capacity of the HCBS waiver system by improving the measurement of satisfaction and achievement of personal outcomes for participants. This measurement data will be integrated with other division and agency data into a comprehensive statewide QA/QI "data mart."

The Quality Design Commission is a consumer group created to establish valued outcomes and recommend systems improvement strategies. By gaining substantial consumer and stakeholder input through the Quality Design Commission, Minnesota will improve its ability to systematically review the efficacy of safeguards and the extent to which waiver services support individual quality of life.

The Minnesota Department of Human Services (DHS) is the lead agency for this grant. The Department's Continuing Care Administration will be responsible for overseeing all aspects of project planning, implementation, and evaluation and will partner with the DHS Disabilities Services and Information Technology Strategies divisions, Quality Design Commission, Minnesota Board on Aging, Minnesota Department of Health Office of Health Facility Complaints, and eight county-based Adult Protection divisions, to achieve the following outcomes: (1) improved response time between discovery and remediation, (2) better identification of "poor" providers, (3) discernment of patterns or trends in complaints and investigations and targeted technical assistance, (4) consistent data to inform program decisions that ensure higher quality, and (5) use of consumer-defined measures of quality in both service delivery and service outcomes.

Formative evaluation methods will be designed and used to ensure the quality of program management, and will track the ongoing effectiveness of project development and implementation. Summative evaluation methods will be designed to document impact on consumers and evaluate the entire project at the end of the grant period. Data for this evaluation will be derived from monthly and quarterly project reports, financial records, participant surveys, anecdotal information, and oral interviews with project partners.

MISSOURI

Grant Information

Name of Grantee Department of Health and Senior Services

Title of Grant Missouri's Quality Assurance and Quality Improvement Project

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$500,000 Year Original Funding Received 2003

573-526-8601

Expected Completion Date September 2007

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Subcontractor(s)

Rose International, through request for proposal (RFP) process

Health and Behavioral Risk Research Center at the University of Missouri, Columbia, under contract to conduct consumer surveys

Target Population(s)

Participants in the Department of Health and Senior Services Home and Community-Based Services (HCBS) waiver programs.

- Identify the information systems currently in use or being developed by various state agencies; evaluate their commonalities and differences; and assess the process necessary to begin building a statewide, automated system that can be used by the agencies to store quality assurance data for participants in all HCBS waiver programs.
- Design a system to house information on nursing and social work visits to waiver program
 participants to obtain direct input regarding how services provided affect the consumer's
 health and safety in a community setting.
- Develop accurate and consistent methods for tracking complaints, and use the information gathered to prompt system changes needed to resolve recurring issues and enhance participant outcomes.

- Develop protocols and a framework for reporting quality of services.
- Select a formal client survey to assess the needs and concerns of in-home service participants by conducting a survey of 10 percent of the consumers served by the Department's programs.
- Evaluate current systems, including common and agency-specific issues.
- Develop training for providers and case managers specific to issues identified.
- Develop a Web-based report that will provide accurate and consistent data for quality improvement functions.
- Develop and implement a pilot program to test the system for participant outcomes and to evaluate the survey tool.

Abstract

The Department of Health and Senior Services will be the lead agency for the development and administration of this grant, in partnership with the Departments of Mental Health, Elementary and Secondary Education, and Social Services.

The overall objective of this project is to ensure the health and safety of persons who receive home and community services and those persons considering long-term care options for remaining in or returning to the community.

Grant funds will be used to support the interagency collaboration needed to develop a comprehensive, statewide system for tracking issues related to the HCBS waiver in community settings. Many state agencies have begun developing such systems or are in the initial stages of implementation of various quality assurance mechanisms. The ultimate goal of this project is to develop a consistent method of gathering quality assurance data for all HCBS waiver programs and to use the data to identify and address problem areas. The system will also provide the basis for improved reporting capabilities to the state Medicaid agency.

The Department will use the Participant Experience Survey for elderly and disabled individuals to assess the needs and concerns of in-home service participants. This tool will be offered to all state agencies and administrative agents for use in obtaining data that can be put into their systems, thus expediting complaints to ensure that client health and welfare are protected. The survey will be conducted in 2006 and 2007. The yearly results will be made public in a variety of stakeholder meetings and will be posted to the Department's Web site.

NEW YORK

Grant Information

Name of Grantee New York State Department of Health, Office of Medicaid

Management

Title of Grant New York's Quality Assurance and Quality Improvement Project

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$495,811 **Year Original Funding Received** 2003

Expected Completion Date September 2007

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Subcontractor(s)

To be determined by an RFA process in first year of the grant.

Target Population(s)

Participants in the State's Traumatic Brain Injury (TBI) waiver program and in the Long-Term Home Health Care Program (LTHHCP), which provides services at home to elderly persons and individuals of all ages with disabilities.

- Develop improved methods of enlisting individual waiver participants and other involved community members in active roles in the quality assurance and quality improvement (QA/QI) process for two of New York's Home and Community-Based Services (HCBS) waivers.
- Obtain information from waiver participants and their families about the quality of waiver services received, and use that information to increase service quality, respond to issues immediately, eliminate problems, and identify areas of best practice.

- A TBI QA/QI Board will be established to identify outcome measures and participant satisfaction measures, and provide input for a plan to implement an information hotline and an analysis of TBI waiver service issues.
- The LTHHCP will establish an effective means of collecting and analyzing information about participant satisfaction through the ongoing use of the Participant Experience Survey.
- A QA/QI database will be developed and implemented, which will be a permanent component of the Medicaid claims payment system, and will provide information about the availability and quality of waiver services.

Abstract

This project will ensure participants' health and safety and will create enduring systems change in the waiver programs' QA/QI processes. The systems developed from this project will include the functions of discovery, remediation, and continuous improvement of the quality of services provided to waiver participants in the target populations.

The project will establish a QA/QI Board to address a number of quality issues related to the TBI waiver, including evaluating the current QA/QI program and making recommendations for changes. Information will be gathered in statewide forums, which will include participants, family members, providers, and other interested parties. Depending on the results of this Board's work, the project will also create a QA/QI Board for the LTHHCP.

This grant will allow the State to contract with an entity to administer the Participant Experience Survey to LTHHCP participants. The results of this survey will be analyzed, providing an independent source of information about participant satisfaction. The information collected will allow the Department to accomplish two goals: (1) to share the results of the survey with local districts, providers, and participants so that they will learn from best practices or jointly take action to correct specific issues that have been identified; and (2) to pursue systemwide changes that affect the total waiver population.

Finally, the project will develop a QA/QI database for use initially with the TBI waiver and, ultimately, with the LTHHCP. This database will capture data on participant demographics, provider information, participant satisfaction, and incidents reported. This information will be used to generate reports showing where quality improvement is needed, and identifying best practices to be used as models.

NORTH CAROLINA

Grant Information

Name of Grantee North Carolina Department of Health and Human Services

Title of Grant From Institutions to Communities: Quality Management for North

Carolina's Transitioning Populations

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$475,100 Year Original Funding Received 2003

Expected Completion Date September 2007

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Subcontractor(s)

University of North Carolina at Chapel Hill—Center for Development and Learning

Target Population(s)

Individuals in psychiatric institutions, intermediate care facilities for people with mental retardation (ICF/MR), and child residential treatment facilities who are transitioning to community settings (i.e., "transitioning populations").

Goals

- Design a comprehensive quality management system to monitor and improve the quality of initiatives to help people transition to community settings from psychiatric institutions, ICF/MR, and child residential treatment facilities.
- Implement a demonstration of the quality management system.
- Evaluate the demonstration and, if successful, develop a plan for expanding the quality management system statewide for all populations with long-term care needs.

Activities

 Develop tools, protocols, and systems for collecting and managing data to identify problems and successes in structures, processes, and consumer outcomes for the transitioning populations.

- Conduct follow-up interviews with members of the transitioning populations, using trained consumers and family members as interviewers, to gather information on the transition process, outcomes, and experience.
- Develop and implement processes to review individual data, rectify immediate problems, and prevent future problems.
- Train service system staff, consumers and families, and other stakeholders in the philosophy and methods of continuous quality improvement.
- Recommend an ongoing quality management plan.
- Conduct staff training to implement the ongoing quality management plan.

Abstract

This Quality Assurance/Quality Improvement project will create a model system to monitor and improve the quality of initiatives to help people transition to community settings ("transitioning populations") from psychiatric institutions, ICF/MR, and child residential treatment facilities. The project will also devise a plan to test this system and then expand it to all state users of long-term care.

The project will build on three current initiatives in the NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS):

- The State MHDDSAS Plan to reform the service system into one that has consumer-driven, outcomes-oriented services provided in the most integrated community settings possible; consumer and family involvement in design and implementation of the system; measurable standards of safety, quality, and clinical effectiveness; and a total quality management philosophy;
- 2. The DHHS Olmstead Plan for transitioning individuals to communities from state psychiatric institutions, state- and community-based ICF/MR, and nursing homes; and
- 3. The DMHDDSAS Child Mental Health Plan, which includes transitioning children out of child residential treatment facilities and psychiatric hospitals to home and community settings.

A Quality Management Plan for the state mental health/developmental disability, and substance abuse service system will be developed by a team of DMHDDSAS staff, other state staff, consumers, family members, and local stakeholders. A demonstration project, focused on the transitioning populations, will be developed and implemented. For the demonstration, consumers and family members will be hired and trained to interview transitioning individuals about their satisfaction with the quality of their care, the transitioning process, and progress toward their personal goals. The data derived will be used to rectify problems in individual situations and improve the transition process and delivery of services and supports. Data will also be used to inform development of an ongoing quality management plan.

In preparation for the demonstration project, current outcome and satisfaction measures, tools, and methodologies will be reviewed to determine their fit with the goals of the quality management system. A Web-based data system that is currently being developed for collection and management of data on people transitioning out of psychiatric institutions will be enhanced to accommodate data about additional transitioning populations.

Finally, the project will develop a plan for expanding the model into a full Quality Management System for the North Carolina long-term care system.

OHIO

Grant Information

Name of Grantee Ohio Department of Mental Retardation and Developmental

Disabilities

Title of Grant Ohio's Quality Assurance and Quality Improvement Project

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$499,740 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Project Manager Ohio DMRDD

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Subcontractor(s)

None.

Target Population(s)

Individuals with mental retardation and other developmental disabilities.

- Design and implement a quality information management system, based on a quality framework unique to Ohio, using data generated by the service system to improve the effectiveness and efficiency of services and supports to individuals with disabilities, their families, and the system at large.
- Develop and implement computerized tools to facilitate the collection, organization, and analysis of data on quality and to provide valuable information to all systems users.

- Evaluate Ohio's current quality assurance and quality improvement (QA/QI) system activities.
- Research and develop a quality framework unique to Ohio, reflecting personal and systems outcomes, core indicators, and performance measures.
- Design a training curriculum specific to quality management and related concepts, supporting development and implementation of a quality information management system.
- Establish a statewide and a six-region quality council structure to govern, advise, and implement a quality management system.
- Design and implement the capacity to report information according to the quality framework.
- Purchase, install, and test the necessary hardware and software.

Abstract

The Ohio Department of Mental Retardation and Developmental Disabilities (ODMR/DD) is the repository of a considerable amount of data and information from Ohio's diverse county-based service delivery system. The Department collects extensive demographic information about individuals served as reported by each of 88 local county boards of mental retardation and developmental disabilities (hereafter, county board). More specifically, through "monitoring and compliance" reviews conducted by various offices of the Department, a considerable amount of data and information is amassed specific to local agencies' management and delivery of services and supports to individuals. Each of these review protocols is exhaustive in their evaluation of county boards' and private providers' compliance with federal and state law and regulation.

This project will design and implement a quality information management system in which data generated by the service system is used to develop an integrated knowledge profile. This profile will identify areas of improved effectiveness and efficiency in the management and delivery of services and supports to individuals with disabilities.

The State contends that enhanced use of information already collected by the service delivery system can be used to increase the efficiency and improve the effectiveness of the supports available to individuals with mental retardation and developmental disabilities. Successful execution of this project will yield (1) improved availability of useful information for individuals and families; (2) a comprehensive, statewide quality framework that outlines anticipated outcome measures for the service system; (3) data to determine training initiatives, technical assistance methodologies, public policy, effectiveness and efficiency measures, improved state and local resource deployment, and statistically-based trends and analyses; and (4) a system for reporting information/discoveries to local service providers, families, and individuals who use services and supports.

OREGON

Grant Information

Name of Grantee Oregon Department of Human Services, Seniors and People with

Disabilities (SPD)

Title of Grant Oregon's Quality Assurance and Quality Improvement Project

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$455,113 Year Original Funding Received 2003

Contact Information

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and Financial Eligibility
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Seniors and People with Disabilities
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Salem, OR 97301-1073

Subcontractor(s)

Human Services Research Institute

Target Population(s)

Persons of all ages with disabilities.

- Develop a system wide data collection and reporting system for health, safety, risk management, and consumer satisfaction, which permits trend analysis and system evaluation.
- Train key program staff, consumers, service providers, and other stakeholders statewide on the tools, procedures, and processes developed.
- Develop a detailed project sustainability plan that ensures continuity and ongoing improvement of the systems/practices initiated.

- Develop and support a process for consumers and stakeholders to provide input to and oversight of the project.
- Develop critical tools and implementation procedures for ensuring health, safety, and risk management of individuals receiving in-home supports from SPD.
- Assess integration possibilities for existing SPD information systems or recommend the creation of new information systems.
- Train field and technical staff, SPD consumers/stakeholders, and service providers to use the tools and implement the procedures developed.
- Develop the necessary curriculum, training protocols, and formats, and conduct the training.
- Develop and approve a sustainability plan.

Abstract

Over 36 months, the Oregon Department of Human Services, SPD proposes to develop an improved and balanced approach to quality assurance and quality improvement for in-home, long-term care services delivered to persons who are aged, physically disabled, or developmentally disabled. The top priority is to improve the systems that help ensure individual health and safety and address issues related to individual risk management.

This project addresses four quality assurance/quality improvement functions: design, discovery, remediation, and systems improvement. The project will produce more reliable, accurate, consistent, and useful information regarding health and safety matters. This information will be used for quality assurance purposes at the county, regional, and state levels, and also to ensure an effective system is in place to respond to critical incidents/events at the individual plan-level as they occur.

The project will also focus on remediation and systems improvements as better and more consolidated information becomes available. The plan for sustainability will address activities for continuing key grant-initiated activities and also prioritize the continual refinement of the remediation and systems improvement functions.

As a result of grant activities, by 2006 SPD will have developed the written tools and procedures and conducted the training needed to achieve and sustain an improvement in the quality of community-integrated services.

PENNSYLVANIA

Grant Information

Name of GranteeDepartment of Public WelfareTitle of GrantPennsylvania's Quality Project

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$498,650 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Persons with disabilities served under all Medicaid Home and Community-Based Services (HCBS) waivers.

- Develop new quality management (QM) systems for consumer-centered service planning and service provision.
- Develop an integrated data system that supports continuous quality improvement and correction of system errors, while supporting planning and policy decisions.
- Implement the new QM systems statewide.

- Develop an intake form for developing a personalized service plan across all disability groups, and train staff on how to use the form to prepare the plan.
- Develop materials (written, Web, and video) and staff capacity to provide information and support to help consumers make informed selections among services.
- Administer a survey to check that the personalized plan meets the consumers' needs.
- Develop information and staff capacity about service providers to facilitate consumer choice of qualified providers.
- Develop training and information for consumers and service providers to help consumers direct and manage their own services.
- Establish a Help Line for consumers.
- Establish a regular schedule for contacts between service coordinators and clients and a system for alerting coordinators about incidents.
- Develop an independent quality monitoring mechanism.
- Develop uniform systems for incident management and complaints.
- Develop an integrated QM data system across Aging and Welfare Departments.
- Develop a backup system for providing services.
- Phase in and pilot-test the QM systems developed and expand the system statewide.

Abstract

Pennsylvania is committed to ensuring that older persons and persons of all ages with disabilities have the ability to live independently in the community and be able to direct their services. However, the State's HCBS quality assurance system is unevenly developed across waiver programs, with varying levels of automation and use of data tracking methods to ensure adequate follow-up when things go wrong at the point of service provision.

The Governor's Office of Health Care Reform will address these identified problems through implementation of the Quality Assurance and Quality Improvement Grant project, which will execute specific tasks to improve the QM infrastructure for HCBS. These tasks include

- Integrate the CMS HCBS Quality Framework for person-centered service planning and service provision into all of the quality assurance systems for Pennsylvania's long-term care services and tie it into the Medicaid Management Information System (MMIS).
- Provide for a backup system for service breakdowns for all critical services.
- Train consumers and staff to support consumer-directed services.
- Meet and exceed the statutory and CMS requirements to ensure the health and welfare of individuals who participate in Pennsylvania's HCBS programs.

Pennsylvania proposes to have this system operational statewide by the third year of the grant. The Office of Health Care Reform will work directly with consumers, advisory groups, and state agencies to ensure that grant goals are achieved.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

SOUTH CAROLINA

Grant Information

Name of Grantee South Carolina Department of Disabilities and Special Needs

Title of Grant Validating and Expanding the Use of Peer Review Organizations

in Assessing Quality Assurance and Quality Improvement in State

Developmental Disability Systems

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$500,000 Year Original Funding Received 2003

Expected Completion Date September 2007

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Director for Quality Assurance
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SCDDSN

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Subcontractor(s)

National Association of State Directors of Developmental Disabilities, Inc.

Target Population(s)

Persons with mental retardation and related disabilities, autism, and head and spinal cord injuries.

- Evaluate the South Carolina Department of Disabilities and Special Needs (SCDDSN) peer review organization (PRO) quality assurance process to ensure that it is addressing each of the four functions and seven domains contained in the CMS Quality Framework.
- Develop and implement enhancements as needed to improve the PRO quality assurance process.

- Review the current quality assurance and quality improvement (QA/QI) process to assess agency effectiveness in addressing all aspects of the CMS Quality Framework domains.
- Revise current policies, procedures, standards, and/or the PRO process to ensure that they
 achieve the intent of the CMS Quality Framework domains.
- Evaluate the amended system to determine the effectiveness of the PRO's quality assurance activities.
- Conduct a follow-up evaluation to determine the applicability of the revised PRO model in addressing the original goals of the CMS Quality Framework.
- Develop recommendations for processes to fulfill CMS requirements for oversight reviews of Home and Community-Based Services (HCBS) waivers.

Abstract

Over the past few years, SCDDSN has developed a sophisticated, multitiered, coordinated QA/QI program that contains state-of-the-art features, including various risk management activities, contract compliance reviews, personal outcome measures, and consumer and family satisfaction measures. A large and important portion of this program is performed by a PRO, First Health Services Corporation, with whom the State contracts.

SCDDSN believes that the current best thinking in QA/QI is incorporated in its programs, but this has not been validated externally. One goal of this grant is to use an external research organization to assess the validity and reliability of the work done by the contracted PRO.

Now that CMS has developed the Quality Framework, SCDDSN sees the need to make sure that each of the four functions and seven domains contained therein are addressed by its QA/QI system. Over the course of this grant, SCDDSN will externally validate that all components of the CMS Quality Framework are adequately addressed during the work done by the PRO.

TENNESSEE

Grant Information

Name of Grantee Tennessee Department of Finance and Administration

Title of Grant People Talking to People: Building Quality and Making Change

Happen

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$452,636 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

The ARC of Tennessee

Target Population(s)

Persons with mental retardation and other developmental disabilities, and elderly disabled persons.

- Create a quality assurance/quality improvement (QA/QI) system that will result in timely remediation and systemwide quality improvement.
- Collect and analyze data from consumer satisfaction surveys and establish a single, functional database that generates useful and timely reports of findings.
- Establish a mechanism to respond to urgent and nonurgent needs for remediation within the State's QA/QI system, with monitoring and follow up to insure remediation action.
- Design and implement systems improvements using the data reports.

- Design a consumer satisfaction instrument.
- Develop a training curriculum.
- Recruit and train interviewers to conduct interviews with consumers and their families.
- Sample and interview consumers.
- Collect and analyze data from the consumer satisfaction surveys and establish a single, functional database that generates useful and timely reports of findings.
- Establish a mechanism to respond to urgent and nonurgent needs for remediation within the State's QA/QI system, with monitoring and follow up to insure remediation action.
- Design and implement systems improvements using the data reports.
- Design and implement a sustainability plan.

Abstract

The grant's QA/QI home and community services project has been endorsed by TennCare, the Tennessee Medicaid agency. The project will be a crucial and integral component of a new system of QA/QI supporting individuals with disabilities.

The overall goal of the project is to create a consumer-driven QA/QI system that will result in timely remediation and systemwide quality improvement.

Measurable outcomes include

- The establishment of three regional teams of consumers and family members to conduct consumer interviews.
- The establishment of the Tennessee Quality Services Committee, with a majority of consumer members.
- The completion of 2,316 consumer satisfaction interviews.
- The establishment of a single, functional database that generates useful and timely reports of findings.
- The establishment of a mechanism to respond to urgent and nonurgent needs for remediation within the State's QA/QI system.
- The design and implementation of a sustainability plan.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

TEXAS

Grant Information

Name of GranteeTexas Department of Aging and Disability Services (DADS)Title of GrantTexas Quality Assurance and Quality Improvement ProjectType of GrantQuality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$500,000 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

Kirk Jones, Data Analyst, began June 2005 Blake West, Business Analyst, began April 2006 Jay Parmar, Database Developer, began April 2006

Target Population(s)

Persons with intellectual/physical disabilities and the aged served in the Texas Department of Aging and Disability Services (DADS) programs.

- Develop cost-effective methods to measure individual participant experiences in the DADS programs.
- Research and develop a uniform and automated critical incident reporting process.
- Develop an integrated information-gathering system to compile and automate information regarding program provider performance and participant experiences in DADS waiver programs.
- Conduct consumer experience (developed by Human Services Research Institute) and participant experience (developed by Medstat for CMS) surveys with a statistically significant random sample of persons in all DADS Medicaid waiver and Intermediate Care Facilities for Persons with Mental Retardation Services (ICF/MR) programs.

- Establish a task force to assist DADS staff with the development and implementation of the quality assurance and quality improvement (QA/QI) project.
- Conduct literature review and identify the methodology or tool that will be used to measure participant experiences.
- Research existing tools and processes to (1) determine the best process for gathering critical incident information currently not reported to DADS on a consistent basis and (2) help develop cost-effective methods to measure individual participant experiences in DADS programs.
- Hire consultants to work with the task force on reporting formats and other design features.
- Join the National Core Indicators Project, conduct surveys, compile data, and analyze results of the participant experience survey.

Abstract

The project will redesign and improve the State's information-gathering system to integrate DADS's existing QA/QI reporting mechanisms into a comprehensive data collection system. This system will ensure that DADS's methodology to measure the quality of services ensures an accountable use of public resources and a balance between personal outcomes and flexible supports and regulatory requirements to improve the quality of the DADS programs.

The project will establish a Quality Assurance/Quality Improvement Task Force that will include participants and family members, advocacy groups, DADS program providers, local authorities, and other stakeholders. The integrated information-gathering system to be developed will

- provide stakeholders with information about specific program providers in order to facilitate participant choice of providers;
- improve upon the ability to evaluate programs at the individual component level;
- provide a foundation on which DADS can continue to build a comprehensive QA/QI system into its programs; and
- establish a centralized system for agency-wide data collection, analysis, and reporting mechanisms.

WEST VIRGINIA

Grant Information

Name of Grantee West Virginia Department of Health and Human Resources

Title of Grant Quality Assurance and Quality Improvement Project

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$499,995 Year Original Funding Received 2003

Expected Completion Date July 2007

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Subcontractor(s)

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304-720-3200 ext. 218

Target Population(s)

Persons with mental retardation and other developmental disabilities (MR/DD), elderly persons, and persons with disabilities.

- Develop, implement, and support a quality assurance process and improvement infrastructure in the design of home and community services.
- Develop and implement a data collection strategy for real-time and retrospective information to assess the performance of waiver services.
- Select, design, and implement quality assurance and quality improvement (QA/QI) strategies for the State's Home and Community-Based Services (HCBS) waivers.
- Develop and implement a QA/QI system that involves HCBS participants, their families, advocates, and allies in active roles.
- Evaluate and upgrade West Virginia's technology-based, direct care service management and data collection system.

- Define a core measurement set for assessing the quality of HCBS for the Aged and Disabled (A/D) waiver, and expand the core measurement set for the MR/DD waiver.
- Compile and organize existing data and information on the performance of A/D waiver services within the core measurement sets.
- Administer select questions from the Participant Experience Survey (PES) to MR/DD and A/D waiver participants to gather additional information on the waivers, and analyze the results.
- Design a template for A/D waiver management reports using descriptive program data and data collected for core measurement.
- Prioritize identified areas of quality concerns, select a priority issue, initiate QI projects, and disseminate the results.
- Train consumers as interviewers for the PES, conduct focus groups with consumers, and engage consumers who are members of statewide, long-term care task forces/work groups to inform development of a QA/QI system.
- Assess the required information technology functions of the A/D waiver, and determine the technology needed to support these functions.

Abstract

The project will strengthen West Virginia's ability to ensure the health, welfare, and dignity of individuals participating in the HCBS waiver, by developing an effective and systematic QA/QI system that enlists people with disabilities, their family members, advocates, and allies as active participants in the process. Current and former waiver participants will play an active role in implementing and monitoring this project. The project strengthens the four basic components of an effective and ongoing quality initiative: design, discovery, remediation, and system improvement.

The project will create a quality assurance process and improvement infrastructure with QA/QI councils and a quality improvement team. The QA/QI councils will provide guidance and feedback for the development of ongoing quality initiatives within their respective waiver programs. Each council will consist of current and former waiver participants (or their legal representatives), family members, direct care workers, providers, and advocates and allies of people with disabilities. A quality improvement team, comprising waiver staff, staff from the Bureau for Medical Services, and participant representatives from each waiver, will oversee and coordinate the efforts of both councils.

The project will strengthen West Virginia's ability to compile and use real time and retroactive data to assess the performance of both HCBS waiver programs. Approximately 300 participants in the A/D waiver will be surveyed to assess their experience in the program. All existing data will be compiled and organized to assess core measurement sets. The results of the project will be distributed to HCBS waiver stakeholders for their feedback. This will allow the project and both HCBS waivers to continually improve the quality assurance and improvement process in West Virginia.

WISCONSIN

Grant Information

Name of Grantee Department of Health and Family Services

Title of Grant Quality Close to Home

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$500,000 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

A quality systems consulting firm will design and develop quality measures. A university research center will assess consumer-experience measurement tools.

Target Population(s)

Populations served through the State's Home and Community-Based Services (HCBS) waivers including elderly persons and adults with physical or developmental disabilities.

- Improve local HCBS programs' quality management (QM) systems and increase focus on consumer outcomes.
- Identify and adopt key consumer-experience outcomes and measure them comparably across all waiver programs.
- Identify and adopt key functional and clinical consumer outcomes and measure them comparably across all waiver programs.
- Develop and implement tools, training, and technical assistance to incorporate consumer focus and consumer outcomes into HCBS programs' care management.
- Review and revise the State's HCBS programs' QM systems to enable, support, and empower more effective local HCBS QM systems.

- Develop model standards for a basic local QM program.
- Identify a key set of consumer experience outcomes.
- Develop methods to consistently measure the key consumer-experience outcomes across target groups and programs.
- Improve quality-assurance for consumers' functional screens, and identify a key set of functional and clinical outcomes.
- Review and revise standards and processes used at the state level in QM systems for HCBS programs.

Abstract

The primary objective of this project is to improve local waiver agencies' QM practices, consistent with the CMS HCBS Quality Framework. The project will also improve the State's own HCBS QM program and its ability to enable, support, and empower more effective local QM practices. The Department wants to create sustainable improvements in state and local QM systems, with the ultimate goal of improved outcomes for consumers of HCBS in Wisconsin's waiver programs and consistency in the delivery of quality HCBS.

This project will create and provide to local agencies an improved package of standards, guidelines, and benchmarks for QM systems, and more effective training and technical assistance materials that are consumer-outcome oriented. A consulting firm with expertise in QM will assist in assessing current QA/QI efforts and developing improvements, and will help develop functional, clinical, and consumer-outcome measures for use in discovery and remediation. The project will also re-examine and revise state-level QM processes to identify and correct inefficient or contradictory requirements to develop better ways to administer consumer-experience measurement tools and to put the results of those measurements to use for improving results valued by consumers. The project will also identify and implement processes to improve effective collaboration between state facilities-regulation authorities and waiver program managers at both the state and local level.

COLORADO

Grant Information

Name of Grantee Colorado Department of Health Care Policy and Financing

Title of Grant Colorado Independence Plus Initiative

Type of Grant Independence Plus Initiative

Amount of Grant \$391,137 Year Original Funding Received 2003

Contact Information

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Aggie Berens, Supervisor 303-866-3358 aggie.berens@state.co.us

Systems Change Section

Colorado State Department of Health Care

Policy and Financing 1570 Grant Street Denver, CO 80203

Subcontractor(s)

Subcontracts will be developed for a focus group facilitator and conference planner.

Target Population(s)

Individuals of all ages with disabilities who are in current or future state consumer-directed waiver programs.

- Establish a statewide emergency backup system and a critical incident management system for all current and future consumer-directed programs.
- Develop training mechanisms for critical incident management and emergency backup systems.

- Identify the State's current capacity for statewide emergency backup and critical incident management within community-based, long-term care programs.
- Develop and implement improved critical incident and emergency backup systems for the State's consumer-directed programs.
- Develop and implement conferences for consumers and other stakeholders on the use of critical incident management and emergency backup systems and consumer direction.

Abstract

The Colorado Health Care Policy and Financing (HCPF) and the Colorado Department of Human Services (DHS) are in various stages of designing, implementing, and supporting four consumer-directed programs within the State's long-term care system. The current systems for protecting consumers of the State's long-term care programs revolve around traditional agencies taking responsibility for critical incident reporting and tracking and for emergency backup measures. They do not allow consumers to take a significant role in defining and overseeing the protections that will support them in the community. The overall goals of the Independence Plus grant are to

- strengthen and build on existing capacity for a statewide emergency backup system and a critical incident management system for all current and future consumer-directed programs and
- develop training mechanisms that would further address and enhance critical incident management and emergency backup objectives.

The project will achieve these goals by identifying existing capacity, developing a consumer-derived definition of critical incidents and emergencies, implementing consumer-defined emergency backup and critical incident management systems, and modifying existing training curricula to include training around the new participant protection mechanisms and infrastructure.

CONNECTICUT

Grant Information

Name of Grantee Department of Mental Retardation

Title of Grant Level of Need and Individual Budgeting Project

Type of Grant Independence Plus Initiative

Amount of Grant \$175,000 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

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Target Population(s)

All individuals who seek substantive funding from the Department of Mental Retardation (DMR).

- Establish a Steering Committee inclusive of all stakeholders to guide design, research, and implementation of the Level-of-Need and Individual Budgeting Project.
- Establish a valid and reliable methodology to predict level of need, and establish a valid and reliable methodology to compute consumer costs associated with particular levels of need.
- Initiate a new individual budgeting process for individuals, and incorporate methods into resource allocation strategies.
- Incorporate the final level-of-need assessment tool methodology and associated individual budgeting mechanisms in the preparation of an Independence Plus waiver application.

- Conduct meetings, informational sessions, and presentations for the grant's Steering Committee.
- Produce a level-of-need classification table and associated cost estimates, establish concurrent validity, and compute five final level-of-need models and cost models.
- Train staff to use the level-of-need and cost algorithm.
- Develop and implement an enhanced methodology to assist policy makers in assessing the support and funding needs of individual consumers.
- Develop the necessary level-of-need and individual budgeting methodologies to submit a second waiver application under the Independence Plus Initiative.

Abstract

The Connecticut DMR is engaged in discussions with the single state Medicaid agency, the Department of Social Services, to develop and submit a new Home and Community-Based Services (HCBS) Mental Retardation waiver using the Independence Plus template. The waiver, called the Individual and Family Support waiver, will introduce additional in-home, flexible services for children and adults. DMR is also preparing a second HCBS Mental Retardation waiver which will replace its Consolidated waiver, adding individual budgeting and flexible supports under a Comprehensive Support waiver.

The State has recognized that the flexibility and type of supports individuals and their families want from the DMR are not always best met under Connecticut's existing 1915(c) HCBS Mental Retardation waiver. Data gained from individuals using an Individual Support Agreement option are being gathered to prepare focus group meetings and to solicit Web-based input from individuals and families about preferred services and supports, current problems or barriers in obtaining the support they need, and barriers to self-directing their own support plans. Likewise, DMR has been rapidly developing new quality review and improvement methods and systems to ensure health, welfare, and positive personal outcomes for individuals supported in their personal or family homes. These efforts are all integral components for the State to prepare a new waiver under the Independence Plus Initiative.

To successfully apply for a second waiver, Connecticut must have a valid method to establish an individual's probable level of need. Completion of the Level of Need and Individual Budgeting Project will enable the DMR to amend both new waivers to clearly identify the support needs of individuals in Connecticut who are seeking services, and to fairly and equitably distribute resources across the State in the HCBS waiver programs. Grant products will include a database, a data entry program, an algorithm model, a training manual, an individual budget methodology, strategic plans and budget forecasts, policies and procedures, and a completed waiver application.

FLORIDA

Grant Information

Name of Grantee Agency for Persons with Disabilities

Title of GrantFlorida Freedom InitiativeType of GrantIndependence Plus Initiative

Amount of Grant \$501,801 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Project Coordinator to be decided.

Subcontractor(s)

Center for Self-Determination

Target Population(s)

Individuals with developmental disabilities, particularly those who earn income or wish to earn income, who are enrolled in Florida's Consumer-Directed Care Plus (CDC+) Program, as well as their families and circles of support.

- Secure a waiver from the Social Security Administration under 1902(a)(10)(c)(i) to allow individuals enrolled in the Consumer-Directed Care Plus 1115 waiver program to have increased levels of earned and unearned income and assets up to \$10,000.
- Develop statewide training based on principles of self-determination for supports brokers, consumers, families, and self-advocates.
- Evaluate the effects of the new waiver authority, including the cost-effectiveness of increased flexibility, the reduction in work disincentives, and the train-the-trainer system using self-advocates as supports brokers.
- Identify existing barriers and disincentives to employment, and address those issues as appropriate to effect broad system change.

- Identify and convene stakeholders to assist in the development of the waiver application.
- Develop and submit waiver application.
- Educate developmental disability districts, supports brokers, advocate groups, providers, and policymakers about consumer direction, self-determination, and the broad authority provided under 1115 waivers, with a specific focus on the waiver of the income and asset rule.
- Create/modify training and technical assistance to enhance utilization of existing work incentives (specifically 1619b) as well as to help participants understand how to integrate Florida Freedom Initiative (FFI) program features with existing work incentives.
- Develop training modules and resource materials to train Agency for Persons with Disabilities staff who coordinate FFI participants' services.

Abstract

Current income and asset limits for disability benefits and welfare programs often discourage beneficiaries from seeking employment because they fear losing their benefits. This grant will build on Florida's current 1115 Research and Demonstration waiver, Consumer-Directed Care Plus, a cash and counseling demonstration program approved to serve 50 to 100 individuals statewide. Considering the principles of self-determination, the grant will be used to explore opportunities to reform the system by working with the Social Security Administration to obtain a waiver to allow an increase in income and asset limits. Such an increase would enable individuals with developmental disabilities to work and to explore typical housing opportunities while maintaining their SSI eligibility despite asset development above current limits.

Intensive training on work incentives, supported employment, and benefits analysis will be provided to grant staff through a combination of general revenue and Medicaid Infrastructure grant funds. These staff members will provide direct support to participants and their circles of support.

This project is a cooperative effort of the Florida Agency for Persons with Disabilities, the Florida Developmental Disabilities Council, the Center for Self-Determination, the Department of Elder Affairs, the Department of Health, the Agency for Health Care Administration, and the Florida self-advocacy movement.

GEORGIA

Grant Information

Name of GranteeGeorgia Department of Human ResourcesTitle of GrantThe Georgia Independence Plus Initiative

Type of Grant Independence Plus Initiative

Amount of Grant \$432,108 Year Original Funding Received 2003

404-657-1138

Contact Information

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Subcontractor(s)

Atlanta, GA 30303

APS Healthcare Bethesda, Inc. 8403 Colesville Road, Suite 1600 Silver Spring, MD 20910

Target Population(s)

Individuals with disabilities (including those with physical disabilities, serious mental illness, developmental disabilities, and traumatic brain injury) and older adults.

- Develop a uniform methodology for calculating all individual budgets in the State.
- Adapt the Home and Community-Based Services (HCBS) waiver program quality assurance/quality improvement (QA/QI) system to ensure necessary safeguards for the health and welfare of participants in the self-directed service delivery system.
- Design key operational functions of the self-directed service delivery system.
- Develop a self-determination master plan that incorporates components of the self-directed service delivery system.
- Design a self-determination pilot for adults with serious mental illness utilizing peer supports.

- Develop uniform operational policies and procedures for individual budgets.
- Revise the current incident management system to serve a self-directed service delivery system.
- Develop individual and statewide emergency backup systems.
- Design a process for accessing the self-directed service delivery system.
- Develop a system for recruiting and training support brokers.
- Evaluate financial management services.
- Devise a self-determination pilot project for community mental health service delivery for adults with serious mental illness, which utilizes peer supports.

Abstract

Since the 1980's, Georgia has employed waivers to offer HCBS. Current HCBS, such as personal supports, day support, and natural support enhancements, lay a foundation for self-determination. Existing personal supports systems include a variety of services ranging from traditional services to individualized services designed to support people with disabilities in their growth, development, and inclusion in all aspects of community life. Day support services assist people with developmental disabilities through a combination of supports to address the multiple needs of an individual on any given day. Natural support enhancement services maintain and strengthen the natural support provided in individuals' homes. Georgia's system requires significant redesign to move the State toward self-directed services and supports.

To fulfill the State's commitment to self-direction, policies and regulations must change because the current regulatory system is designed to support traditional residential and personal care home services. Under this grant, self-advocates, family members, advocates, providers, and state agency representatives will work together with technical advisors to design a comprehensive, self-directed service delivery system. The system will provide needed supports, including budgeting support, financial management services, support brokerage services, and protections such as incident management and emergency backup systems.

The master plan for self-determination developed through this collaborative process will enable Georgia to address the increasing demand for community services through improved access to and enhanced flexibility of services tailored to individual and family needs. As a part of this project, Georgia will review its current regulatory system and determine actions needed to transform this system to be consistent with self-determination, including modifying existing and developing new state policies.

IDAHO

Grant Information

Name of Grantee Idaho Department of Health and Welfare, Division of Medicaid

Title of GrantIdaho Independence PlusType of GrantIndependence Plus Initiative

Amount of Grant \$499,643 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

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Target Population(s)

Adult individuals with developmental disabilities.

- Enable individuals with developmental disabilities to exercise personal choice and control over, and have access to, self-directed supports in their communities.
- Ensure that high-quality, individualized, flexible services and supports are available from a choice of service providers and are responsive to individuals' needs and based on their life goals.
- Increase the level of knowledge about the principles of self-determination statewide.
- Ensure continuous quality improvement in services across the system.

- Establish a service system infrastructure that effectively supports self-direction of Medicaid services. Include an enhanced person-centered planning process, individualized budgets, a new service brokerage role, a refined fiscal intermediary role, expanded community support and service options, and a fine-tuned quality assurance management system.
- Develop, submit, and implement a waiver for self-direction of Medicaid services.
- Increase provider capacity and capability through the use of flexible, individualized supports and services available from a variety of providers.
- Promote and support development of community resources in local and rural areas, and improve access to services through support brokerage services.
- Conduct a statewide self-determination educational campaign for all stakeholders.
- Develop and implement a person-centered, continuous quality management and improvement system.
- Develop and implement individualized emergency backup systems and enhance current protocols for incident management.

Abstract

Idaho currently serves over 1,300 individuals aged 18 and older with severe or intermediate levels of developmental disability through Home and Community-Based Services (HCBS) waivers that place some individuals in their own homes, while most are placed in the homes of paid caregivers. A total of 14 services are available under the Developmental Disability waivers but habilitation services, provided either by paid in-home caregivers or supported living caregivers, account for approximately 94 percent of Medicaid total waiver expenditures. Private Intermediate Care Facility populations in Idaho are for the most part static, capped at 486 by the Idaho Legislature in 2000.

Services to individuals with developmental disabilities in Idaho are affected by geography, cultural values, and system architecture. With only 15.5 residents per square mile and minimal public transportation services, individuals with disabilities may easily be isolated. The amount, type, and scope of services offered depends on local availability. By developing a self-directed system of supports and services, isolation will be addressed by a team of family, friends, and others to assist and support the person in developing a plan that best addresses their needs and goals.

A key issue that this grant will address is the need to educate consumers and providers about self-directed services. This project will also create change within the current system by developing and building a more flexible infrastructure to enable individuals with developmental disabilities to exercise more choice and control over the services they receive. To accomplish this goal, this project will (1) develop and implement a self-directed Medicaid services and supports waiver, (2) develop an infrastructure to support self-directed care, with more flexible provider options, (3) conduct statewide public education and training for consumers and providers, and (4) develop a system of quality management and improvement employing the CMS Quality Framework.

LOUISIANA

Grant Information

Name of Grantee Louisiana Department of Hospitals

Title of Grant Louisiana's Independence Plus Initiative

Type of Grant Independence Plus Initiative

Amount of Grant \$499,889 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

First Data Government Solutions ARC of Iberia

Target Population(s)

All individuals with cognitive and physical disabilities and older adults.

- Create an Independence Plus Advisory Committee.
- Create a long-term care system based on the principles of self-direction.
- Create an individualized backup system and emergency preparedness system for the three
 existing waiver programs (New Opportunities Waiver, Elderly and Disabled Adults, and
 Children's Choice) as well as for the Long Term Personal Care Services State Plan.
- Expand opportunities for waiver participants to earn income, own businesses, and increase participation in their cost of care.
- Expand opportunity for consumer direction in the Long Term Personal Care Services State Plan in Region 1 (New Orleans area) based on the system developed in the Real Choice Systems Change Grant.

- Increase stakeholder involvement.
- Survey recipients about barriers to self-determination/direction and apply identified changes to the State's programs.
- Analyze policies and procedures manuals and fiscal procedures for the three targeted waiver programs and the Personal Care Services State Plan, and recommend language revisions to incorporate the philosophy of self-determination.
- Train agency staff and stakeholders on the principles of self-determination.
- Identify best practices regarding backup systems and modify the State's backup system for all targeted waivers. Conduct training on the use of the revised backup support systems.
- Establish a revolving loan fund and policies and safeguards for the use of these funds.
- Conduct regional training for micro-enterprise developers, self-advocates and family members, providers, and case managers to help individuals determine what type of business they would like to have, develop a plan for that business, and explore resources for implementation.
- Recruit 15 waiver participants from the three targeted waivers and help them establish micro-enterprises, which will expand opportunities for them to earn income, own businesses, and increase their contribution to the cost of their care.
- Collect and analyze data to assess the impact of incorporating self-determination principles into the three target waivers.

Abstract

Louisiana's Department of Health and Hospitals, Office of Aging and Adult Services (formerly Bureau of Community Supports and Services [BCSS]) Independence Plus project will create a Home and Community-Based Services (HCBS) waiver system based on the principles of self-determination. The Office of Aging and Adult Services intends to develop a backup system, to expand opportunities for any interested waiver recipient to earn income by owning a microenterprise business (thereby generating personal income), and to create a consumer direction option within the Long Term Personal Care Services State Plan.

The current New Opportunities waiver will also be the catalyst for change in the Children's Choice and Elderly and Disabled Adults waivers. The Office of Aging and Adult Services will use the Independence Plus Advisory Committee to oversee this initiative.

MAINE

Grant Information

Name of Grantee Department of Health and Human Services, Adult Mental

Retardation Services

Title of Grant Supporting Choice and Control for Maine Adults with Mental

Retardation or Autism

Type of Grant Independence Plus Initiative

Amount of Grant \$500,000 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

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Edmund S. Muskie School of Public Service

The Center for Community Inclusion, University of Maine

The National Association of State Directors of Developmental Disabilities Services

STRIVE and Speaking Up For Us

Other consultants to be decided.

Target Population(s)

Adults with mental retardation or autism.

- Implement an Independence Plus Initiative waiver program for adults with mental retardation or autism.
- Assist consumers and families to understand their responsibilities and options within the Independence Plus Initiative waiver program.
- Provide consumers and families with tools and supports that help them make choices and participate actively in planning and managing their services.
- Assist support brokers to understand and perform their role consistent with the philosophy of self-determination.
- Adopt policies regarding the use of surrogates/representatives in self-direction, and people with surrogates/representatives participating in the Independence Plus Initiative waiver.

- Submit a 1915(c) Independence Plus Initiative waiver application and develop an implementation plan.
- Develop, test, and refine information and training material that employ universal design principles for full access for consumers and families that addresses options and responsibilities under the Independence Plus Initiative waiver program.
- Develop, test, and refine tools that consumers and families can use to self-direct their supports, including consumer-provider agreements and model job descriptions.
- Implement policy regarding the use of surrogates and representatives to ensure that self-direction can include persons who require regular assistance with their responsibilities.
- Develop, test, and refine training for support brokers, employing consumers as partners in a co-instruction model.
- Analyze national practices for establishing personal budgets and finalize an approach for Maine.
- Develop and implement a Fiscal Employer Agent position to support consumers with payroll and other administrative responsibilities.
- Assess consumer and family experiences in the new program and make changes as needed.
- Develop a sustainability plan that identifies resources and determines a sustainable growth rate in the waiver.

Abstract

Maine's Department of Health and Human Services is developing a new Independence Plus Initiative waiver program for adults with mental retardation or autism. The new program is intended to address the changing needs of people with mental retardation or autism in Maine by enhancing choice and control for consumers, and by offering different and more flexible supports within a philosophy of self-determination. The primary goal of the grant is to ensure that consumers and families have sufficient information, training, and support to manage their own services and supports as participants in the new program.

For consumers and family members to exercise greater choice and control, they must understand their options and responsibilities under the new Independence Plus Initiative waiver program, and must be given the tools and supports needed for successful self-direction. Likewise, people who have played traditional roles in the current system (i.e., case managers) must understand how roles change when consumers choose to direct their own supports.

This grant will support development and delivery of training and other supports to ensure that true system change occurs, initially in adult mental retardation services, and ultimately throughout the State's community-integrated services. Major partners include consumers, families, providers, and other state agencies.

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MASSACHUSETTS

Grant Information

Name of GranteeUniversity of Massachusetts Medical SchoolTitle of GrantMassachusetts Independence Plus Initiative

Type of Grant Independence Plus Initiative

Amount of Grant \$499,992 Year Original Funding Received 2003

Contact Information

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Subcontractor(s)

Kenneth Schlosser, LICSW

Target Population(s)

Individuals of all ages with all types of disabilities or long-term illnesses, including complex medical needs, developmental disabilities, cognitive disabilities, brain injury, sensory disabilities, mental illness, serious emotional disturbance, physical disabilities, and long-term disabling illnesses.

- Build upon the current self-directed program infrastructure to prepare for an Independence Plus model.
- Ensure meaningful involvement of people with disabilities and other potential stakeholders in the planning, design, and evaluation of grant activities.
- Apply for an Independence Plus Initiative waiver (or amend an existing waiver) no later than the third year of the grant.

- Adopt a person-centered planning (PCP) approach to service delivery that can be implemented in a flexible, self-directed program.
- Enhance the current Fiscal Management System to support the purchasing of goods and services and the tracking of individual budgets and budget expenditures.
- Ensure that an effective supports brokerage design is in place that will use facilitators and/or
 personal agents to assist participants in identifying, locating, and evaluating the services
 and supports the participant is directing.
- Enhance the system for participant protections in preparation for a flexible, self-directed program waiver, while building on existing methods used in the Personal Care Attendant Program.
- Ensure active and meaningful involvement of the Real Choice Consumer Planning and Implementation Group (RCCPIG) and other stakeholders in the waiver design and the development of tools.
- Complete the appropriate application for an Independence Plus Initiative waiver under the 1915(c) Home and Community-Based Services waiver program, or an 1115 Research and Demonstration waiver program, and/or enhance existing waivers.

Abstract

With this grant project, the State will design key components of the infrastructure necessary to allow individuals (and their representatives if appropriate) to have flexibility and control over their community services and supports. The State will build on the existing infrastructure to meet federal expectations for an Independence Plus waiver. With the creation of such a waiver, participants will have flexible use of the allocated funds to meet their needs in the community.

The State will address the following infrastructure areas in this project: (1) person-centered planning, (2) fiscal management, (3) supports brokerage, and (4) participant protections with a participant-driven continuous quality improvement system. Massachusetts will also design the waiver application and ensure meaningful involvement of consumers in all phases of the grant.

The University of Massachusetts Medical School, Center for Health Policy and Research (UMMS/CHPR) will subcontract with community partners to ensure that the tools and the program infrastructure created are applicable across all age, disability, and ethnic groups, and in all regions of the State.

MICHIGAN

Grant Information

Name of Grantee Michigan Department of Community Health

Title of Grant Michigan's Independence Plus Initiative

Type of Grant Independence Plus Initiative

Amount of Grant \$478,600 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

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Michigan Association of Community

Mental Health Boards

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Center for Outcome Analysis

ARC of Michigan 517-487-5426

Target Population(s)

Current or potential participants in state Community Mental Health Services Programs (CMHSPs), including adults with mental illness and persons with developmental disabilities (DD), and participants in the MI Choice waiver for elders and persons with physical disabilities.

- Implement a Project Work Group composed of a variety of stakeholders, with primary guidance from consumers and advocates experienced in Independence Plus design features to oversee all of the goals, activities, and products developed in the grant.
- Develop within the Michigan systems of mental health and DD services a comprehensive capacity for supporting arrangements that provide consumers/beneficiaries with a high level of choice and control over defining, selecting, directing, and purchasing needed services and supports, in accordance with Michigan's Self-Determination Policy and Practice Guideline.

- Strengthen knowledge, networking, and advocacy for consumers/beneficiaries, families, and allies concerning the tools and techniques inherent in the Independence Plus design features.
- Introduce into the MI Choice 1915(c) waiver the concepts, principles, and practices for supporting arrangements that provide consumers/beneficiaries with choice and control over defining, selecting, directing, and purchasing needed services and supports.
- Evaluate a best approach for requesting additional waiver or state plan amendments to expand self-determination via Independence Plus principles, utilizing a work group made up of consumers and their allies, advocates, and selected state resources.

- Determine best practices for self-determination activities used by CMHSPs.
- Develop written material that is specifically designed for consumers, families, and allies on the proper principles, practices, and methodological tools available to implement Independence Plus design features.
- Develop and deliver statewide training, and produce a variety of products to support Independence Plus principles, including (1) train-the-trainer programs, (2) collaborative identification of best practices and support for the person-centered planning (PCP) discovery process, (3) self-determination leadership implementation seminars, and (4) technical assistance and methodological guidance materials.
- Develop a specialty waiver or state plan amendment to provide flexibility in PCP and selfdetermination for a designated number of consumers from the MI DD and MI Choice programs.

Abstract

Michigan has adopted the principles and practices of PCP as the basis for planning and arranging consumer services. However, the adoption of these principles and practices throughout the State has occurred slowly.

This project will expand implementation of arrangements that support self-determination. It will identify and establish systemwide, self-determination options, creating effective and flexible consumer-controlled service arrangements in the Michigan mental health system. It will also incorporate the philosophy, information, methods, and practices of self-determination into the MI Choice Home and Community-Based Services (HCBS) waiver system and build in methods to make flexible, consumer-directed options available to beneficiaries who are elderly or disabled. The project will also develop the framework for the approval of a new waiver arrangement or state plan amendment to demonstrate, with a limited number of beneficiaries from the mental health and/or the long-term care systems, the option of receiving a cash allotment in lieu of formal Medicaid support services.

The project will involve consumers, advocates, and other stakeholders through a work group, which will guide the project. Specific accomplishments will include (1) the development of a standardized model for individual budget development and fiscal intermediary services, (2) the development and testing of models for using independent facilitators and support brokers in PCP and consumer-directed care, (3) the development of options for emergency backup systems, and (4) the establishment of incident management systems.

MISSOURI

Grant Information

Name of Grantee Missouri Department of Mental Health, Division of Mental

Retardation/Developmental Disabilities

Title of Grant Missouri Partnership for Self-Directed Support

Type of Grant Independence Plus Initiative

Amount of Grant \$427,461 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

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Project Coordinator

University Center for Excellence in Developmental Disabilities (UCE)

Additional consultants or small contracts may be needed.

Target Population(s)

Individuals with mental retardation and other developmental disabilities.

- Establish a statewide Self-Directed Planning Task Force that will plan for implementation of the Independence Plus Initiative activities.
- Plan and develop Missouri's self-directed choice system.
- Implement and evaluate a Missouri consumer-directed (CD) support program pilot.
- Ensure a Missouri self-direction system through continuance of successful, fiscally neutral activities and obtaining additional funding.

- Establish the Self-Direction Task Force and decide the final details of the CD model (e.g., how individual budgeting will be done; who will do person-centered planning).
- Develop a curriculum and resources about the CD model for person-centered planners and individuals with disabilities and their families.
- Recruit participants and conduct the Missouri CD support program pilot, and include ways to integrate the CD model into the current regional center backup system.
- Conduct training of consumers/families, trainers, and support brokers.
- Initiate evaluation (pilot) and conduct initial evaluation of the CD model.
- Develop a report on the full evaluation and decide what strategies will be adapted to the current system.
- Incorporate features of the independence plus model into existing waivers.

Abstract

The Missouri Division of Mental Retardation/Developmental Disabilities is seeking to enhance the choice and control individuals with disabilities and their families have over their lives. This project will allow the Division to make changes in its system so that it is prepared to implement self-directed support options associated with the Independence Plus Initiative model. The grant project will

- Implement a participant-directed person-centered planning system. Planning will be facilitated by persons outside the system, or by service coordinators with no gatekeeping responsibilities.
- Use MoCAN volunteers to train consumers and families to manage and self-direct supports.
- Explore how individual budgets can be controlled by service participants and be used to combine funding from different agencies in a more efficient manner.
- Examine the use of a more flexible fiscal intermediary system, the possible use of debit cards, and a mechanism whereby individuals can check their account balances.
- Develop and implement a participant-directed support brokering system.
- Review the current statewide emergency backup system and incident management system and adjust it to interface with the self-directed system.

A pilot incorporating the various aspects associated with self-directed support systems will be conducted with individuals with disabilities and/or their families. The pilot will be evaluated using several measures, including cost effectiveness, quality of life, incidence of abuse/neglect, and retention of personal care assistants. Successful components that are fiscally neutral will be implemented throughout the State under current laws. Documentation will be prepared for those that require legislative change. Pending state approval of funding through the appropriation process, features of the Independence Plus Initiative model, will be incorporated into existing waivers.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

MONTANA

Grant Information

Name of Grantee Department of Public Health and Human Services

Title of Grant Big Sky Bonanza—Montana's Independence Plus Initiative

Type of Grant Independence Plus Initiative

Amount of Grant \$499,963 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

Mountain Pacific Quality Health Foundation Summit Independent Living Center Carl Eby

Target Population(s)

Persons with disabilities and persons with long-term care needs.

- Develop an Independence Plus waiver.
- Implement and evaluate an Independence Plus waiver pilot program.

- Research best practices of cash and counseling models.
- Conduct forums and focus groups, and administer consumer surveys to inform the research.
- Complete a 1915(c) waiver to facilitate an Independence Plus program.
- Develop selection criteria for Independence Plus participants.
- Determine and audit process for individual cash allowance, and develop a method for compiling information on cash allowances to be available for public review.
- Establish financial management and support brokerage as Medicaid-reimbursable services, and solicit, enroll, and train potential providers.
- Develop a communication plan for consumers, bookkeepers, and brokers under the support brokerage component of the cash and counseling program.
- Establish a participant protection component to include an emergency backup system and an incident management protocol.
- Enhance the Job Service employer/employee job registry Web site. Develop a plan to facilitate caregiver background checks.
- Conduct and evaluate a pilot of the Independence Plus program in three counties.

Abstract

The anticipated outcomes of Montana's Independence Plus project are expanded options, increased consumer control, and effective consumer protections. The first two outcomes will be accomplished by establishing an Independence Plus Home and Community-Based Services (HCBS) waiver program for elderly and disabled persons. The third will be achieved through implementation of an emergency backup system, a disaster and emergency plan, caregiver background checks, and an improved incident management plan.

During the general grant activities, focus groups will be used to gather input regarding program design features. These group meetings will take place on Indian Reservations, in major cities, and in rural/frontier towns. Surveys will be mailed to collect data from those who do not attend the group meetings.

Consumers, advocates, family members, providers of services, and state agency partners will participate in the grant. Summit Independent Living Center will produce participant training materials and train participants, and Carl Eby, a Native American consultant, will spearhead outreach to Indian Nations and ensure cultural sensitivity in all phases of program development and implementation.

Montana's Quality Improvement Organization will collaborate in developing and implementing the capacity assessment protocol. Montana's Department of Labor will partner in developing a caregiver registry via the existing Job Service Web page. The Disaster and Emergency Services Division will collaborate on establishing the emergency backup system. The Montana Department of Justice will assist in implementing caregiver background checks.

OHIO

Grant Information

Name of Grantee Ohio Department of Mental Retardation and Developmental

Disabilities (ODMRDD)

Title of Grant Ohio's Self-Determination Project

Type of Grant Independence Plus Initiative

Amount of Grant \$500,000 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

Evaluation consultant to be decided.

Target Population(s)

Individuals with mental retardation and developmental disabilities (MR/DD).

- Develop and submit an Independence Plus waiver application.
- Assist individuals with MR/DD, families, and all other stakeholders within the demonstration counties to understand the alternatives available under the Independence Plus waiver and its implementation processes.
- Conduct an independent evaluation of the Independence Plus waiver and of the quality of life and satisfaction of individuals with MR/DD and their families.

- Identify barriers to implementing an Independence Plus waiver within the demonstration counties and develop methods to eliminate the barriers.
- Develop and submit to the Ohio Department of Job and Family Services (ODJFS) the information necessary for them to support submission of the waiver application to CMS.
- Draft language for the Independence Plus waiver application and submit it to CMS for approval as an Independence Plus waiver.
- Develop training and technical assistance materials, informational brochures, and a dissemination and implementation strategy.
- Establish a family information network to provide individuals with MR/DD and their families current information to help them maintain current skills and gain new skills needed for participation in the Independence Plus waiver.
- Produce routine reports of formative learning and develop tools and a strategy for obtaining baseline data of individuals prior to enrollment on the Independence Plus waiver.

Abstract

The overall goal of the grant is to obtain approval of an Independence Plus waiver, and to demonstrate successful implementation in at least five counties in Ohio. Grant funds will be used to obtain training, facilitation, and technical assistance related to achieving the expectations in the template for the Independence Plus waiver. Grant funds will also provide reimbursement/stipends to individuals with MR/DD and families to cover the cost of their involvement at three levels of policy work: (1) the stakeholder work team in each of the demonstration counties; (2) the collaborative group representing all demonstration counties; and (3) the advisory committee, which includes persons with expertise or positions of authority to eliminate barriers and establish the infrastructure needed to support implementation of the waiver.

Each demonstration county will use its experience from previous local and state selfdetermination efforts to identify barriers that must be reduced or eliminated and the infrastructure that must exist to achieve the major goals of person-centered planning, individual budgets, financial management services, support brokerage, and participant protections.

Several months following implementation of the Independence Plus waiver in the demonstration counties, an independent evaluation will be conducted on: (1) the use of services covered by the waiver; (2) system capacities to successfully implement the waiver; and (3) the outcomes and quality of life of individuals with disabilities, their satisfaction, and the satisfaction of their families and other stakeholders.

CALIFORNIA

Grant Information

Name of Grantee California Department of Health Services (DHS)

Title of Grant California Pathways

Type of Grant Money Follows the Person Rebalancing Initiative

Amount of Grant \$750,000 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

Regents of the University of California–Los Angeles (UCLA), Borun Center for Gerontological Research

Target Population(s)

Adult Medicaid-eligible nursing facility (NF) residents.

- Develop standardized protocols and processes for transitioning NF residents to home and community settings throughout the State.
- Develop financing models and systems that enable money to follow the person from a NF to home and community settings.

- Develop and field test a uniform assessment tool and protocol that can be used by care planners statewide to assess service needs and service availability to transition suitable residents from a NF to home and community settings.
- Develop and field test a standardized consumer-focused quality assurance model to enable the State to analyze the cost and quantity of services and consumers' self-report on quality of life.
- Develop and field test a standardized consumer-oriented NF transition care planning model that can be used statewide.
- Implement a pilot project to test the developed tools and protocols, with an estimated 440
 NF residents to be assessed in 12 months.
- Transition one-third to two-thirds of those assessed.
- Develop fiscal assumptions for care planners to manage costs across programs and services while maximizing independence in home and community settings.
- Make statewide policy decisions about a Money Follows the Person Initiative in California using individual and aggregate data and fiscal analysis based on case examples.

Abstract

The California Department of Health Services (DHS) proposes to develop a pilot project called California Pathways in one location in California. A pilot project community will be chosen based on its potential for successful transitions to community living; for example, the availability of an array of housing and service options. The pilot project will depend heavily on a lead contractor, with DHS retaining final approval of all deliverables.

The lead contractor will use public/private partnerships to develop and implement the pilot project. The Long-Term Care Council's Olmstead Advisory Committee will serve as a mechanism to obtain statewide stakeholder input, in addition to input from local stakeholders and potential consumers in the pilot project.

The federal grant funding will enable research and analysis on the following core questions:

- What are the options for reimbursement for one-time and ongoing services under a Money Follows the Person Initiative in California?
- What care planning process enables informed choice of Home and Community-Based Services (HCBS)? What infrastructure changes are needed?
- Of the other states' models, which Money Follows the Person model is most appropriate for application in California—cash and counseling, budget transfers, expanded HCBS waivers, or others?
- What financing and reimbursement systems changes are necessary to enable flexibility in covering an array of services at the state level? At the individual service level?

The pilot project will enable the State to map the assessment and transition process of NF residents by documenting transition cases, developing statewide protocols for future care planners, and costing out each element of the cases for the purpose of developing baseline data for Money Follows the Person models.

California Pathways will coordinate with other long-term care programs statewide that can benefit from the pilot project formative learning and outcomes, and will develop recommendations to build on the successes of the pilot project, including recommendations regarding care planning models and initiatives that enable the money to follow the person.

IDAHO

Grant Information

Name of Grantee Idaho Department of Health and Welfare, Division of Family and

Community Services

Title of Grant Idaho Money Follows the Person Project

Type of Grant Money Follows the Person Rebalancing Initiative

Amount of Grant \$749,999 Year Original Funding Received 2003

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Target Population(s)

People of all ages with physical, mental, developmental, or aging-related disabilities and long-term care needs.

- Facilitate community integration through a continuing anti-stigma campaign.
- Identify ways to reapportion and maximize funding for community services through a statewide service utilization and economic analysis.
- Examine the political and fiscal feasibility of increasing resources for community living and explore ways to create a more hospitable community through a community development project.
- Study ways to assist people with disabilities to reach their community integration goals through a community-based effectiveness study.

- Continue implementation of the existing anti-stigma campaign.
- Recruit selected communities to identify and develop supportive resources.
- Conduct a study of the effectiveness of an intensive anti-stigma campaign.
- Conduct an intensive economic and policy analysis of statewide service utilization since 1995.

Abstract

Under this grant, the State will build on work begun under the 2001 Real Choice Grant by completing a research-validated plan for community integration in Idaho. The project will (1) continue the anti-stigma campaign designed to reduce stigma and facilitate community integration, (2) continue the economic analysis of the current Medicaid system to identify ways to reapportion and maximize funding, (3) expand community development project efforts to examine the political and fiscal feasibility of increasing living resources and create a more hospitable community for people who wish to live in it, and (4) expand the ongoing effectiveness study to test what best helps people of all ages with any disabilities reach their community integration goals.

Consumers will also be involved in the project implementation. The Community Integration Committee, which will oversee the project, is made up of people with disabilities, family members, and representatives of private organizations and public agencies. Community-to-Community Coalitions will be established in the research sites to involve a broad base of community members.

This project will produce sustained change by identifying implementation strategies for cost-effective, community-based care. Activities conducted under this grant will demonstrate the feasibility of providing such services in a cost-neutral manner to the maximum number of individuals with disabilities in the most integrated settings based on their wants and needs. Products will include a research-based community integration plan, evidence-based protocols for anti-stigma campaigns, community development projects, and community integration planning.

MAINE

Grant Information

Name of Grantee Maine Department of Health and Human Services

Title of Grant Shifting the Balance: Individual Choice and Community Options

Type of Grant Money Follows the Person Rebalancing Initiative

Amount of Grant \$750,000 Year Original Funding Received 2003

Expected Completion Date September 2007

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Target Population(s)

Adults with mental retardation and autism, adults with brain injury, and persons with any type of disability in all age groups.

- Enhance individual choice and control by adopting a standardized assessment and budgeting process for mental retardation waiver services that results in consistent. predictable, and truly portable budgets.
- Create community options for persons with acquired brain injury by directing resources toward more person-centered, consumer-driven services offered in the most integrated and appropriate setting.
- Identify measures that enable the Department of Health and Human Services (DHHS) to assess its success at increasing community options and supporting consumer choice.

- Develop a published rate structure, rebalanced to enhance community integration goals.
- Establish procedures for assessing need and equitably allocating resources to individuals receiving waiver services.
- Pilot an individual budget tool and assess its impact on consumer satisfaction, providers, budget neutrality, staffing requirements, and Medicaid management information systems.
- Analyze service needs, identify best practices, and analyze funding constraints and alternative funding strategies for persons with brain injury.
- Design and implement a pilot for testing community service options for persons with brain injury who are transitioning to more integrated settings.
- Develop and field test consumer survey questions that measure stakeholder satisfaction with how well the Department's services support consumer choice and increase community options.

Abstract

With this grant project, DHHS will continue its current efforts to shift control to the consumer and to shift services to the community. Each of the grant's three goals responds directly to recommendations made by Maine's Work Group for Community-Based Living, a cross-disability, cross-age group consumer task force.

For persons with mental retardation and autism receiving waiver services, individual budgets are currently based on provider-negotiated cost reimbursement, answering the question "What does the provider need to support this individual?" rather than "What supports does the individual need?" To enhance individual choice and control, DHHS will adopt a standardized assessment and budgeting tool that will be used to produce consistent, fair, predictable, and truly portable budgets based on individual need rather than provider need.

For persons with brain injury, many of the services available are inadequate to make living in the community a meaningful option. DHHS will analyze and test the feasibility of offering cost-effective community options that redirect funding for individuals with brain injury to more integrated settings and develop strategies for stimulating new community service options to support such individuals.

DHHS will work with stakeholders to identify performance measures that will be used to evaluate the State's success at shifting the balance to increased consumer choice and greater community options.

Products will include feasibility studies, implementation plans, and sustainability plans. Major partners include consumers, families, providers, and other state agencies.

MICHIGAN

Grant Information

Name of Grantee Michigan Department of Community Health

Title of Grant Michigan's Money Follows the Person Rebalancing Initiative

Type of Grant Money Follows the Person Rebalancing Initiative

Amount of Grant \$746,650 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

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Target Population(s)

Elderly persons and individuals with disabilities and long-term illnesses.

- Give consumers and families a central role in defining and implementing the systems changes necessary to realize the principle of Money Follows the Person.
- Develop and establish within pilot sites a model for an integrated long-term care (LTC) system that supports Money Follows the Person.
- Develop strategies within the State Plan and the current MI Choice waiver that support the principle of Money Follows the Person.

- Establish a Community Consortium for Advocacy and Technical Assistance to provide advocacy for LTC system change.
- Establish an LTC Community Roundtable to facilitate stakeholder involvement in planning.
- Analyze barriers to Money Follows the Person and devise solutions, including waivers and state policy changes.
- Develop alternative uses for nursing facilities.
- Provide and support alternatives to traditional nursing care.
- Develop a model for nursing home transition and community-support development.
- Establish and implement the model at two pilot sites.
- Develop evaluation tools to measure the impact of services to support home and community long-term care.
- Develop policy and technical assistance materials to support systems changes promoting choices for consumers.

Abstract

This project will develop and implement systems changes to ensure that money follows the person, so that individuals' choices drive their services and that the aggregate choices of LTC consumers shape the State's use of resources. This work will be conducted by a partnership between state agencies and an LTC Community Roundtable, which will include consumers, families, advocates, and nursing facility and community providers. Consumer and family involvement will be supported by a Community Consortium for Advocacy and Technical Assistance. This support of and partnership with stakeholders represents a major commitment to inclusive planning for the development of LTC services.

At two local pilot sites, the project will develop an integrated model for LTC services, including nursing facility and home and community services. These pilot sites will establish integrated, capitated models and address barriers to Money Follows the Person in state regulations and financing. The pilot sites will adapt person-centered planning for LTC services and will have the flexibility to test strategies for (1) improving the direct service workforce, (2) developing housing options, and (3) meeting other challenges to providing effective community services.

Under this grant, the State will ensure enduring change through the work of the Community Consortium and the LTC Community Roundtable, through modifications to waiver programs and policy changes at the state level, and by developing and implementing changes to nursing home regulations and funding methods.

NEVADA

Grant Information

Name of Grantee Nevada Department of Human Resources

Title of Grant Nevada Money Follows the Person Rebalancing Initiative

Type of Grant Money Follows the Person Rebalancing Initiative

Amount of Grant \$749,999 Year Original Funding Received 2003

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Subcontractor(s)

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Target Population(s)

Nonelderly persons with disabilities served in nursing facilities or at risk of institutionalization in the absence of effective community services.

- Rebalance Nevada's long-term services programs so that community services and supports are the primary source of support for people with disabilities.
- Design and implement policies so that dollars spent on institutional services readily follow individuals from institutional to community services.
- Strengthen community services to reduce the use of institutional services.
- Expand options for individuals to direct their own services.

- Design a Nevada Money Follows the Person (MFP) mechanism that ensures funding for institutionalized individuals who want to return to the community.
- Prepare fiscal impact estimates and identify necessary changes to the Medicaid program.
- Collect Medicaid Statistical Information System (MSIS) information on costs and services.
- Identify 160 individuals for community integration, implement their transitions, and use peer advocates to assist individuals or families in the transition process.
- Establish a Housing Specialist at the Nevada Developmental Disabilities Council to help individuals locate affordable housing and access state and local housing assistance programs; revitalize the Nevada Home of Your Own program, an initiative to help people with disabilities secure housing; and develop, disseminate, and periodically update a registry of affordable, accessible housing in Nevada.
- Conduct research and investigations of state policies and home and community services programs. Prepare report of recommended policy and program changes in advance of 2005 and 2007 legislative sessions.
- Conduct research and investigations into self-directed care, and develop proposed design.
- Consolidate and improve consumer and family education activities across agencies.

Abstract

Rebalancing the State's system to avoid unnecessary institutionalization requires changes in its policies and programs so money can follow institutionalized persons into the community. It is also necessary to ensure that people with disabilities have ready access to effective, high-value services and supports in the community so that they need not seek institutional services. Another critical rebalancing dimension is to offer individuals with disabilities greater opportunities to direct their own services.

The Nevada Money Follows the Person Rebalancing Initiative is a collaboration of individuals with disabilities, advocates, Department of Human Resources agencies (Office of Disability Services, Division for Aging Services, the Division of Health Care Financing and Policy), the Nevada Developmental Disabilities Council, Nevada's two Centers for Independent Living, service providers, and community organizations.

The Initiative will link with other activities already under way to strengthen and improve community services for people with disabilities. The Initiative will

- 1. lead to fewer individuals served in institutional settings;
- 2. increase the number of people who are supported in the community;
- 3. pave the way for a solid, sustainable system of effective, high-quality community services;
- 4. improve individual and family access to information about community services; and
- 5. afford individuals with disabilities real opportunities to direct and manage their own services and supports.

PENNSYLVANIA

Grant Information

Name of Grantee Governor's Office of Health Care Reform

Title of GrantMoney Follows the Person Rebalancing InitiativeType of GrantMoney Follows the Person Rebalancing Initiative

Amount of Grant \$698,211 Year Original Funding Received 2003

Expected Completion Date September 2007

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Three Rivers Center for Independent Living

Target Population(s)

Persons with disabilities currently in a nursing home or other institution, paid for by Medicaid or state funds, who wish to transition into their own home in the community, and consumers in the community whose needs are not being met due to current state fiscal constraints.

- Plan and conduct a feasibility analysis that addresses both financing and service system objectives.
- Develop and begin to implement a long-term Money Follows the Person (MFP) strategy that will consolidate the state budget appropriation, and integrate the Medicaid appropriation for institutional and community long-term care.

- Conduct a feasibility analysis that addresses both financing and service system objectives.
- Establish three MFP demonstration sites, create local MFP Planning Groups, and conduct demonstrations under their direction.
- Develop and implement policies that increase the availability of affordable and accessible housing units; identify accessible housing units; and develop a mechanism for providing information regarding these units, as well as units being built or rehabilitated, to entities providing transition support.
- Encourage local housing authorities to apply for additional Section 8 housing certificates or vouchers and reserve them for persons with disabilities and long-term support service needs.
- Conduct outreach and education to community landlords focused on dispelling their misconceptions about accepting Section 8 housing people with disabilities and the benefits of home modifications.
- Create local MFP Planning Groups to carry out demonstrations.
- Present recommendations for long-term funding of MFP through the appropriations process.

Abstract

The Commonwealth of Pennsylvania is implementing the MFP Rebalancing Initiative project to examine the feasibility of the concept, and to demonstrate pooling of state long-term support service dollars to permit funding to follow consumers to the most appropriate and preferred setting. Grant funds will be used to engage consumers and providers in planning and implementing feasibility studies and three demonstration projects.

A statewide MFP Planning Group, comprising consumers and providers from the long-term care system, state staff, and aging and disability advocates, will (1) examine multiple issues related to reforming state financing and service design; (2) provide guidance to a contract consultant to conduct a feasibility analysis; and (3) finalize design, parameters, and location for three local demonstrations.

Local coordinators will assemble a local MFP Planning Group and coordinate the development and implementation of the three demonstration projects. The demonstrations will be located in one major metropolitan, one rural, and one suburban or small town setting. With the exception of the major metropolitan location, the demonstrations may be multicounty.

Projects will begin at the beginning of the third year. The State will appropriate a percentage of the overall long-term support service budget for the three demonstration projects.

TEXAS

Grant Information

Name of Grantee Texas Department of Aging and Disability Services

Title of Grant Promoting Independence

Type of Grant Money Follows the Person Rebalancing Initiative

Amount of Grant \$730,422 Year Original Funding Received 2003

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Subcontractor(s)

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Target Population(s)

Individuals of all ages residing in nursing homes who want to live in the community.

- Ensure that all community care programs are considered when an individual decides to transition to the community from the nursing facility.
- Develop local community care coordination work groups to help individuals transition from nursing facilities to the community.

- Develop and consolidate information concerning state- and federally-funded community care programs, including eligibility criteria, services offered, and a step-by-step guide to apply for services.
- Develop a training curriculum and a pre- and post-test evaluation form.
- Educate and train state office staff, regional staff who interact with consumers, Centers for Independent Living staff, consumer advocates, and other stakeholders about all community options.
- Evaluate training efforts and determine the need for follow-up training.
- Establish transition teams and educate members about transition problems, community programs and services for people transitioning, service coordination, and other activities needed to enable successful transitions.
- Transition teams will develop transition plans for individuals using a consumer-centered approach to ensure that consumer needs are addressed.
- Transition teams, which will include the consumer's individual case manager, will identify
 and secure resources needed for transitions and conduct a monthly assessment/evaluation
 using a person-centered approach to ensure that progress is made toward addressing client
 needs and resolving consumer problems.

Abstract

The purpose of this grant is to create a local system in each community that will allow the Texas Department of Aging and Disability Services (DADS) to more efficiently and effectively help clients transition from nursing homes to the community.

The DADS San Antonio Region has established a voluntary transition team of caseworkers, advocates, other agency personnel, local government employees, profit and nonprofit organizations, home health providers, housing authority representatives, and others to look at each individual requesting transition from the nursing facility to the community. The transition team looks at individual needs, establishes transition plans based upon those needs, offers technical assistance to group members and consumers, secures resources, and transitions individuals to the community.

A first step in replicating this model throughout the State is to educate DADS staff, consumers, advocates, and other stakeholders about the range of community care options available through DADS. Greater knowledge of the options available to enable people to live in the community will help transition individuals from nursing homes. The second step is to establish transition teams in the other 10 regions of the State.

Measurable outcomes include increased knowledge of community long-term care options available through DADS, community care coordination transition teams at the local level, and increased local resources to ensure a smooth transition and continued community supports.

WASHINGTON

Grant Information

Name of Grantee Washington State Department of Social and Health Services

(DSHS)

Title of GrantMoney Follows the Person Rebalancing InitiativeType of GrantMoney Follows the Person Rebalancing Initiative

Amount of Grant \$608,008 Year Original Funding Received 2003

Expected Completion Date September 2007

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Subcontractor(s)

Starling Consulting Laxmi Group

Target Population(s)

Adults and children with developmental disabilities.

- Develop accurate and valid assessment tools that will provide information on needs and natural and informal supports to help individuals make informed choices.
- Involve consumers, stakeholders, and public-private partnerships in planning activities.
- Improve collaboration with human services agencies and state agencies.
- Develop a quality improvement system that is consistent with consumer-based services.
- Rebalance the distribution of funding to give individuals choices about where they live.

- Involve stakeholders in the planning process for project initiation activities.
- Define assessment and service plan business requirements and program specifications for the new system.
- Design and code the assessment and related algorithms within the Comprehensive Assessment Reporting Evaluation (CARE) framework.
- Develop the system and unit test for the assessment and service plan.
- Pilot the system and involve stakeholders in testing the system for usability.
- Provide training to end users and implement the assessment and services plan system throughout the State.

Abstract

Through development of an automated comprehensive assessment and service planning tool, the Washington State Department of Social and Health Services (DSHS) will begin rebalancing its long-term support systems more evenly between institutional and community service options. This system will build on CARE, recently completed by the Department's Aging and Disability Services Administration (ADSA).

For this project, specific assessments will be developed within CARE.

- An Adult Assessment that will address the needs of adults with developmental disabilities
 to receive services and supports that will help individuals transition between institution and
 community settings.
- A Children's Assessment that will address the needs of children with developmental disabilities to receive ongoing services and supports to live successfully in the leastrestrictive setting.
- An Interactive Service Plan System to be used with each assessment that will promote
 maximum client participation in the detailed plan of resources and services tailored to meet
 the individual's needs.

Without an effective assessment tool it is not possible, in a systemic way, to give an individual with developmental disabilities the freedom to choose where he or she wants to live and for the funding to follow that choice. This Money Follows the Person Rebalancing Initiative will set the stage for rebalancing the currently-available funding and be linked with other major initiatives aimed at increasing options for self-directed services. The assessment tool will also be tied to a quality assurance process with automatic feedback, which is currently under development.

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WISCONSIN

Grant Information

Name of Grantee Department of Health and Family Services

Title of GrantWisconsin's Money Follows the Person InitiativeType of GrantMoney Follows the Person Rebalancing Initiative

Amount of Grant \$743,813 Year Original Funding Received 2003

608-266-3717

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Subcontractor(s)

County agencies
Consultants for training and consultation

Target Population(s)

Persons with developmental disabilities living in intermediate care facilities for persons with mental retardation (ICFs/MR) and persons with physical disabilities and frail elders living in nursing homes.

- Develop a new mechanism and supporting data systems to enable funding to follow individuals moving from ICFs/MR to homes in the community.
- Transition 200 individuals currently living in ICFs/MR, and their funding, to the community.
- Create a regional support system that will enable participants and their guardians, county administrators, and other key stakeholders to understand and choose alternatives to ICFs/MR.
- Determine the feasibility of a Money Follows the Person mechanism for individuals in nursing homes.

- Identify ICFs/MR to be downsized or closed.
- Develop a system so counties can track residents for whom they have responsibility on a person-by-person basis.
- Educate guardians and other judicial personnel about resources needed for community living.
- Conduct a feasibility analysis of proposed mechanisms for transferring nursing home funds.
- Work with the legislature to enact sponsoring legislation to implement the new funding mechanism.
- Work with counties to develop community resources for individuals transitioned.

Abstract

This grant will develop mechanisms and supporting data systems to allow institutional funding to follow persons transitioning from ICFs/MR and nursing facilities to homes in the community. Judges and attorneys serving as guardians ad litem will be educated about community living options and needed resources. Grant staff will work with county officials to identify ICFs/MR for downsizing or closure.

The Department of Health and Family Services (DHFS) will provide professional technical assistance for county boards/administrators and other decision makers as they create community care plans. Wisconsin will transfer 200 individuals to the community from private or county ICFs/MR, and the money will follow them for support in the community. This transfer will enable the closing of at least three ICFs/MR, and another seven will significantly reduce beds as people move to the community.

The State is currently developing a plan to establish a Money Follows the Person mechanism for individuals in nursing homes. As part of this grant, DHFS will conduct a feasibility analysis of proposed mechanisms for transferring nursing home funds, work with the legislature to enact sponsoring legislation, implement the new funding mechanism, and work with counties to develop community resources for persons transitioned from nursing homes.

ARIZONA

Grant Information

Grant information				
Name of Grantee	Arizona Department of Economic Security, Division of Developmental Disabilities			
Title of Grant	Arizona Human Service Cooperative Project			
Type of Grant	Community-Integrated Personal Assistance Services and Supports			
Amount of Grant	\$600,000	Year Origina	al Funding Received 2003	
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Target Population(s)

Medicaid-eligible persons with physical and developmental disabilities.

- Create a self-directed model in the current Home and Community-Based Services (HCBS)
 1115 waiver program through a user-owned and user-directed Human Service Cooperative (HSC).
- Develop the Federated Cooperative Development and Support Center (Federated HSC) that will provide technical assistance to HSCs in Arizona and other states.
- Prepare education, training, and outreach/marketing materials for developing HSCs.

- Plan and implement an HSC.
- Plan and implement an HSC targeted to the Spanish-speaking community.
- Plan and implement a Federated HSC.
- Develop support materials for HSCs, state agencies, and providers.

Abstract

For 15 years, Arizona has been operating its Long-term Care Service and Support System, including its HCBS program, under a Medicaid Section 1115 Demonstration waiver. Under this program, eligible elders and persons with physical and developmental disabilities have access to a comprehensive array of HCBS options. This project builds on existing options in determining the feasibility of the HSC as a model for addressing the need for self-determination and empowerment, and for implementing self-directed services for persons with disabilities in Arizona. Under an HSC, member/owners who are service users provide the policy direction and leadership to an incorporated cooperative that is recognized and does business as a state-certified service provider.

Development of this project will involve partnerships of several public and private groups: (1) a group of individuals who use services and their families will partner to form an HSC, (2) the State of Arizona will partner with the HSC to contract for services, and (3) a service provider will contract with the HSC to provide funding for development and professional services. The University of Colorado Health Sciences Center will provide research expertise for the endeavor, and a consultant will provide HSC business development and implementation assistance and partnership coordination. With this HSC as a base, a Federated HSC will be created to assist other groups in developing additional HSCs, in particular one that addresses the needs of the Spanish-speaking population. The project will also provide education, training, and outreach/marketing materials for developing future HSCs.

Along with an implementation and sustainability plan and implementation of the first HSC and the Federated HSC, the primary outcomes/products of this project will be the information and experience obtained to guide public policy staff and private organizations regarding HSC planning and development techniques, education and training materials for HSC leadership, and planning for future contracting systems. The development process will also stimulate new and creative service delivery options such as individual asset development and micro-board support and assistance.

As an independent organization, the HSC will operate after the grant ends, continuing to provide state-funded, long-term care self-directed services. Grant activities will transition to the Federated HSC, which will be incorporated and will provide ongoing assistance to cooperatives and professionals throughout Arizona and potentially in other states.

CONNECTICUT

Grant Information

Name of Grantee Department of Social Services

Title of Grant CHOICE, Connecticut Has Opportunities for Independence,

Choice and Empowerment

Type of Grant Community-Integrated Personal Assistance Services and

Supports

Amount of Grant \$595,349 Year Original Funding Received 2003

860-424-4864

860-679-500

Expected Completion Date September 2007

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Mary Beth Bruder, Principal Investigator

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 A.J. Pappanikou Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD)

Media consultant to be hired.

Target Population(s)

People with disabilities and long-term illnesses.

- Develop a single-point-of-access recruitment tool to recruit personal assistants (PAs) for permanent and backup employment.
- Create and implement a strategic marketing plan to recruit PAs for permanent and backup employment.
- Develop and implement management training for employers of PAs.
- Develop and implement a voluntary professional development program for PAs.

- Identify current recruitment efforts and registries, and conduct focus groups to inform the development of an interagency collaboration agreement and a Web site for matching PAs with employers.
- Collaborate with the Connecticut Department of Labor to design a professional workforce development plan to include the production of brochures, advertisements, fliers, and a video focusing on the relationship between PAs and employers.
- Establish a Training Work Group to identify the specific training needs of PA employers, produce a handbook of training modules, and conduct at least 250 in-home trainings for employers.
- Design a training curriculum for PAs that will result in an individualized professional development program and a catalog of training modules.

Abstract

Although Connecticut has a long history of providing personal assistant services, not enough attention has been given to developing an adequate workforce. Currently, the demand for PAs in the State far exceeds the supply and recruitment efforts are fragmented. It is essential to the growth of self-determination initiatives in Connecticut that individuals and families have easy access to a pool of qualified staff who meet basic requirements. In addition, Connecticut needs an education and support system for employers of personal assistants that can prepare them to confidently direct and manage their services and supports.

The goal of this project is to develop an infrastructure and create products that will promote the effective recruitment and retention of personal assistants, and ensure that people with disabilities in Connecticut have the knowledge and resources to maximize choice and control in the use of personal assistance services.

Outcomes for the 3-year project include (1) a single-point-of-access recruitment tool, (2) a curriculum of training modules for employers on the management of personal assistant services, (3) provision of at least 250 in-home trainings for employers of PAs, and (4) development and implementation of a voluntary professional development program for PAs.

While the Connecticut Department of Social Services (DSS) will serve as the lead agency to administer the grant project, the application was developed collaboratively with various state agencies and the Real Choice Steering Committee, which comprises 15 individuals with disabilities, family members of persons with disabilities, and representatives of state agencies. These same state agencies and the Real Choice Steering Committee will continue to work collaboratively as a steering committee to design, implement, and evaluate grant activities.

DSS will subcontract with the University of Connecticut's A.J. Pappanikou Center for Excellence in Developmental Disabilities Education, Research, and Service (UCE) to implement grant activities. The UCE will supply the fiscal and administrative infrastructure for all project activities.

LOUISIANA

Grant Information

Name of Grantee Department of Health and Hospitals

Title of Grant Community-Integrated Personal Assistance Services and

Supports Project

Type of Grant Community-Integrated Personal Assistance Services and

Supports

Amount of Grant \$464,184 Year Original Funding Received 2003

Contact Information

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C-PASS Project Director/Grant Coordinator

Division of Program Development and Implementation

Louisiana Office of Mental Health

1201 Capitol Access Road Baton Rouge, LA 70802

Subcontractor(s)

Boston University

Target Population(s)

Persons with serious and persistent mental illness (SPMI).

- Develop a common definition and service model of personal assistant services (PAS) for persons with SPMI for use by the Medicaid Agency, the Office of Mental Health, and service providers.
- Develop and implement a training curriculum for all personal assistance providers based on the service model developed, and ensure adequate consumer participation and sustainability of training effort following the grant period.
- Increase effectiveness of provider training and PAS through evaluation.
- Develop and make available public education materials regarding consumer self-direction of PAS.

- Develop a common definition and service model of PAS for persons with SPMI.
- Develop an assessment tool, prior authorization processes, and other infrastructure supports as needed.
- Develop training curricula for direct service workers, supervisors, and administrators using a train-the-trainer model.
- Train provider staff in the curricula and train consumers to conduct training in self-direction for consumers and providers.
- Conduct pre- and post-training evaluation of knowledge and effectiveness of service delivery
 of the providers who serve SPMI.
- Conduct pre- and post-consumer satisfaction and service effectiveness evaluations with consumers of PAS.
- Develop educational materials on consumer-directed PAS for persons with SPMI and a presentation on self-direction.

Abstract

In Louisiana, persons with SPMI have received PAS (called service integration) as a part of their service package under the Medicaid Psychiatric Rehabilitation Option. On a more limited basis, the Office of Mental Health provides funding for PAS (known as Act 378 funds) as required on an individual basis. Medicaid has recently finalized rules for a new Personal Assistance Services Employment Support Option in association with Louisiana's Ticket to Work Initiative. While the State of Louisiana maintains a strong commitment to providing a comprehensive system of flexible supports for persons with mental illness to achieve and maintain community living status, the usefulness of PAS with this population has not been fully explored and developed within the existing treatment programs.

The Community-Integrated Personal Assistance Services and Supports Project will finance (1) the development of an appropriate service delivery mechanism to provide support services, (2) the development of infrastructure enhancements, and (3) the employment of trained consultants and experts to educate the service provider network regarding the use of PAS for persons with mental illness to help maintain a high standard of community living. Consumers who choose to self-direct their care will have access to information and education materials about consumer service control.

Consumers' needs will be assessed and their feedback sought in each component of the grant project, but particularly regarding training.

MASSACHUSETTS

Grant Information

Name of Grantee Massachusetts Department of Mental Retardation

Title of Grant MASS C-PASS

Type of Grant Community-Integrated Personal Assistance Services and

Supports

Amount of Grant \$579,178 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Integration

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Subcontractor(s)

The Arc of Massachusetts Multicultural Services Center of the Pioneer Valley Emily Laurer, Project Evaluation Consultant Jeffrey Keilson, Policy Development Consultant

Target Population(s)

Individuals of all ages with disabilities or long-term illnesses who are seeking personal assistance services and supports (PASS).

- Develop and test quality assurance and safeguard procedures to ensure that the scope and quality of PASS meet consumers' needs.
- Develop and test consumer-directed demonstration projects that provide maximum opportunity for self-direction and flexible use and allocation of supports.
- Identify and field test models to prepare, support, and empower consumers or surrogates to select from a menu of options allowing differing levels of self-determination.
- Evaluate the effectiveness of the pilot projects and the achievement of all grant goals and objectives, and develop a long-range plan for systems change to sustain successful approaches.

- Strengthen existing partnerships and promote interagency collaboration.
- Increase staff competency and develop new training modules.
- Increase consumer/caregiver input, control, and competency.
- Implement and evaluate new models of service quality that emphasize consumer satisfaction and consumer decision making.
- Develop safeguards and backup options for consumers and caregivers.
- Implement and evaluate new models of functional assessment alternatives, increased flexibility for service allocation, and increased consumer choice.
- Prepare concrete recommendations for cross-disability, cross-age, and cross-cultural systems change.

Abstract

Massachusetts C-PASS is a comprehensive cross-disability, cross-age model designed to overcome the barriers to flexible, consumer-directed supports faced by persons who are elders and/or persons with disabilities. The overarching goal is to develop sustainable mechanisms that ensure consumer choice and consumer direction of PASS. The grant manager is the Department of Mental Retardation.

MASS C-PASS builds on the work begun in two successful federally-funded CMS New Freedom projects designed to promote systems change in community-based long-term care. These two grants established an effective state-level interagency work group that identifies obstacles, develops strategies to overcome obstacles, and generates recommendations for long lasting systems change. This CPASS grant funds two pilot projects that will produce new models of quality assurance, flexible supports, and consumer direction. All of the work in this project is underscored by a multicultural, grassroots approach to deliberately include traditionally underserved and unserved racial/ethnic, cultural, and linguistic minorities, as well as to build the receptivity of local communities to consumer-directed, community living.

Benefits to consumers include an expanded menu of PASS options, increased flexibility of services, improved control and quality of life, increased self-direction, increased choice, and increased safeguards. Anticipated program outcomes include increased community capacity in long-term care, stable sources for personal assistance and supports, increased competency of assistants, a well-trained workforce, and technical assistance to providers. Benefits to society include new support networks and collaborations and a system for sharing information on available services and supports.

Through their membership in the grant's Coordinating Council—a collaborative partnership of consumers, Independent Living Centers (ILCs), advocates, agencies, and social service providers—consumers will participate in all aspects of project implementation, management, evaluation, and reporting. The grant partners will incorporate successful strategies into existing programs and will disseminate information to encourage replication. The project's Coordinating Council will draft changes in regulatory, budgetary, and policy language to sustain the project's successes. The Project Collaboration Model will establish ongoing communication among the current initiatives in the State, including Olmstead and New Freedom.

¹Real Choices Systems Change (10/01–9/30/04) & *Bridges to Community* Nursing Facility Transition Project (10/01–9/30/04).

NEBRASKA

Grant Information

Name of Grantee Nebraska Department of Health and Human Services

Title of Grant Quality Assurance and Improvement Application

Type of Grant Community-Integrated Personal Assistance Services and

Supports

Amount of Grant \$600,000 Year Original Funding Received 2003

Expected Completion Date September 2007

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Systems Change Grants Coordinator

Aging and Disability Services

The Nebraska Department of Health

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PO Box 95044

Lincoln, NE 68509-5026

Subcontractor(s)

University of Nebraska Medical Center Munroe-Meyer Institute 4242 Farnam Omaha, NE 68131

402-559-5765

Target Population(s)

Consumers from the aging population and adults and children with developmental disabilities, behavioral health needs, physical disabilities, and complex medical needs.

- Improve the delivery system for personal assistance services (PAS) directed by trained consumers in the management of their personal assistance needs, utilizing the self-direction philosophy.
- Enhance the capabilities of Adult Protective Services (APS) staff, law enforcement agents, and the judicial system in the delivery of services to vulnerable adults who are abused and neglected.

- Develop/purchase materials for consumers on managing PAS providers using the selfdirection philosophy.
- Develop/purchase materials for PAS providers on the philosophy of self-direction and its application in working with consumers.
- Conduct 2-day conferences for Medicaid eligibility staff, APS staff, and Aged and Disabled waiver staff to strengthen staff ability to assess PAS needs, understand the self-direction approach, evaluate quality providers, and support the consumer.
- Conduct training with providers to (1) strengthen skills needed in assessing client capability, and recognizing medical needs/neglect, and (2) enhance the clients' awareness of available support services and their ability to participate in community networking.

Abstract

The original intent for our CPASS grant was to modify our current PAS delivery system by developing an Agency with Choice model. Nebraska top administration is in a time of transition, which has impacted the focus of service provision. With the approval of CMS, we have regrouped our efforts to improve the existing PAS delivery system even though we are unable to complete the original design. From activities thus far, we believe the PAS service system will be more significantly enhanced by training consumers, providers, and related staff on the philosophy of self-directed, in-home services.

It is Nebraska's intent to

- ensure that workers with disabilities utilize the PAS program to its fullest potential;
- increase knowledge of the availability of PAS to support individuals in their home, community, and workplace; and
- instill the philosophy of client direction and responsibility in the delivery of PAS.

Medicaid eligibility workers, PAS clients, providers, and Medicaid Home and Community-Based Services (HCBS) waiver staff will be trained to accomplish these goals. Because APS workers are often called in to investigate cases of individuals with disabilities living independently, we have included them in this awareness and philosophical training to enhance their understanding of freedom of choice in self-direction for consumers.

OREGON

Grant Information

Name of GranteePortland State UniversityTitle of GrantOregon CPASS Project

Type of Grant Community-Integrated Personal Assistance Services and

Supports

Amount of Grant \$585,007 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Persons with psychiatric disabilities.

- Increase consumer knowledge about the Personal Care Services (PCS) Program.
- Increase the extent to which consumers are able to direct their PCS.
- Increase the knowledge of mental health case managers about the benefits of the PCS Program and how to support consumers' self-direction of their services.
- Promote the awareness and use of effective practices in consumer-directed personal assistance services.

- Identify barriers to using the PCS Program and strategies for successful use.
- Implement a comprehensive plan for marketing the PCS Program, including awarding minigrants to consumer drop-in centers for CPASS outreach.
- Carry out a statewide program of face-to-face and Internet-based training and technical assistance for consumers and case managers, including the development of CPASS training materials and a CPASS planning tool for consumers.
- Conduct a CPASS Best Practices Conference.
- Collect and analyze information related to the level of consumer direction demonstrated by PCS project participants in two counties—their use of PCS, institutionalization and hospitalization rates, and quality of life—comparing their outcomes to individuals who do not participate in PCS project activities in two other counties.

Abstract

In Oregon, a small percentage of eligible persons use the consumer-directed PCS Program, which funds up to 20 hours per month of personal assistance for eligible individuals in the mental health system. For many individuals with psychiatric disabilities, achieving increasing levels of community inclusion, independence, and self-sufficiency requires having access to quality, consumer-directed personal assistance services.

The Oregon CPASS Project is improving community-integrated services by promoting mental health consumer access to and successful utilization of the PCS Program. The project is implemented collaboratively by the Office of Consumer/Survivor Technical Assistance (OCTA) and Portland State University in partnership with the State Office of Addictions and Mental Health Services, consumer/survivor and family leaders and organizations, Centers for Independent Living, and regional and county mental health programs.

TEXAS

Grant Information

Name of Grantee Texas Department of Aging and Disability Services (DADS)

Title of Grant Community-Integrated Personal Assistance Services and

Supports Service Responsibility Project

Type of Grant Community-Integrated Personal Assistance Services and

Supports

Amount of Grant \$599,763 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

Rebecca Wright and Associates 207 Summerhill Court Clermont, FL 34711

Target Population(s)

Adults and children who are eligible for Medicaid State Plan personal assistance services. To be eligible, individuals must have health problems that cause functional limitations in their ability to perform activities of daily living.

Goal

To provide increased opportunities for consumers to exercise more choice and control in service management by implementing a service responsibility option (SRO), sometimes referred to as "agency with choice," in Primary Home Care services.

- Develop materials for statewide use to train consumers, providers, and Department of Aging and Disability Services (DADS) staff.
- Educate consumers about the options of service management, including consumer-directed, service responsibility, and agency.
- Train consumers selecting the SRO to perform activities under this option, such as selecting, supervising, and training their personal assistant.
- Train providers and DADS case managers and regional staff to implement and oversee all service delivery options: agency, consumer-directed, and service responsibility.
- Pilot the SRO in a rural and urban area of Texas.
- Calculate provider rates under the SRO.
- Add the SRO to the State's automated service authorization and billing system, and to its automated eligibility and referral system.
- Analyze the differences across the three options for managing personal assistant services (agency option, service responsibility option, and budget and service responsibility option).
- Assess the effectiveness of the SRO and recommend improvements based on the assessment.
- Expand the SRO statewide.

Abstract

While a consumer-directed services option has been available to individuals receiving Primary Home Care services since 2002, very few have exercised this option. The introduction of a SRO may increase the number of individuals exercising choice and control in the management of their personal assistance services. The SRO is a hybrid service management option that allows the consumer to select, train, and supervise his personal assistant but leaves the fiscal, personnel, and backup responsibilities with the provider agency. The option will be piloted in a rural and an urban region of the State prior to offering the option to Primary Home Care services consumers statewide.

The training for provider and DADS staff focuses on how to describe the differences among the service management options as well as how to discuss the benefits and risks of each. Pre- and post-training surveys are being used to assess the effectiveness of the training. Consumer training, which ensures that participants understand their roles and responsibilities as well as their part in quality services management, is a requirement of SRO participation. Consumer surveys will be conducted to develop an understanding of why consumers choose particular options of service management and their satisfaction with those options.

Outreach materials, including a brochure, self-assessment tool, and video, have been developed to assist providers and case managers to inform consumers about their choices. Key stakeholders, including consumers, providers, and advocates, provide invaluable input and guidance related to all grant activities. The effectiveness of the SRO will be assessed and used along with lessons learned about implementation in order to improve the option as needed prior to statewide expansion. The project is expected to increase the number of Primary Home Care services consumers who are offered the expanded service management choices, increase the number of those using consumer-directed options, increase the understanding of service management options among providers and DADS staff, and provide a blueprint for offering SRO in other DADS community-based programs.

VIRGINIA

Grant Information

Name of Grantee Partnership for People with Disabilities, Virginia Commonwealth

University

Title of Grant Increasing Understanding, Use, and Control of Consumer-

Directed Personal Assistance Services in Virginia's Waivers

Type of Grant Community-Integrated Personal Assistance Services and

Supports

Amount of Grant \$513,557 Year Original Funding Received 2003

Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

None at this time.

Target Population(s)

Recipients of services under three waiver programs: the Elderly or Disabled with Consumer-Direction, the Mental Retardation waiver, and the Individual and Family Developmental Disability Support waiver.

- Ensure that individuals who receive consumer-directed personal assistance services have the opportunity to express their satisfaction with services and with the process of obtaining services.
- Ensure that individuals with disabilities have access to information, tools, and resources to understand and effectively manage and use personal assistance services.
- Provide individuals, families, and providers with assistance in understanding and using consumer-directed personal assistance services through technical assistance provided by members of the Consumer-Directed Services Resource Network.

- Design, pilot, and refine an interview instrument and protocols that enable waiver recipients to provide routine feedback on consumer-directed personal assistance services.
- Develop and disseminate promotional materials on consumer-directed personal assistance services to waiver recipients.
- Develop and disseminate educational and technical assistance materials and resources based on promising practices, to increase the ability of individuals to direct their own services.
- Expand the resources of, and the number of individuals served by, the Consumer-Directed Services Resource Network.

Abstract

Although Virginia has taken steps to make consumer-directed personal assistance services available, individuals often need additional information about consumer-directed personal assistance services in order to make informed choices. Additionally, users of consumer-directed services do not have an opportunity to provide input on their experiences with obtaining and using consumer-directed services.

Through this grant, the Partnership for People with Disabilities will interview 150 waiver recipients who use personal assistance services, using a survey developed through the project, and seek active involvement from recipients, family members, case managers, and service facilitators to determine ways to increase knowledge about personal assistance services and options. This grant builds on the 2001 Real Choice System Change program, in which the Partnership designed and developed materials and resources about self-direction and consumer-directed services, and designed and implemented a technical assistance network to reach consumers on a statewide basis.

The project will (1) interview consumers of personal assistance services about their satisfaction with services; (2) develop educational and technical assistance materials and resources that promote awareness of the possibilities and options for personal assistance services, and that strengthen the ability of individuals to maximize the use of services and support; and (3) expand the existing technical assistance network by increasing the number of personal assistance services recipients and services facilitators in the network, providing additional information for members to share with consumers, and providing opportunities for members to increase their knowledge of consumer-directed services.

ALASKA

Grant Information

Name of Grantee Stone Soup Group

Title of Grant Alaska's Family-to-Family Health Information Center Project

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$149,991 Year Original Funding Received 2003

Supplemental Award \$50,000 Expected Completion DateSeptember 2007

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Subcontractor(s)

The Center for Human Development, University of Alaska Anchorage Governor's Council on Disabilities and Special Education

Target Population(s)

Children with special health care needs (CSHCN) and their families.

- Create a statewide advisory group of parents and professionals who serve CSHCN to guide implementation of the project.
- Create a statewide information clearinghouse to provide print and digital information on CSHCN.
- Create an interactive, statewide peer-to-peer network and support forum for families of CSHCN.
- Devise and implement a strategy to identify community and/or state resources to ensure the sustainability of the Family-to-Family resource center.

- Identify parents and stakeholders to serve on the advisory board.
- Identify gaps and need for revisions in information provided to families of CSHCN.
- Collaborate with agencies and organizations that may have materials, resources, or skills to contribute to the resource center.
- Conduct trainings and workshops for families of CSHCN.
- Develop a Web- and phone-based forum for families of CSHCN to allow them to interact and to provide support and feedback.
- Develop a marketing plan to advertise the Family-to-Family resource center.

Abstract

Within the last 10 years, Stone Soup Group, an Anchorage-based, nonprofit organization, has been a catalyst for much of the development that has occurred in Alaska's services for CSHCN. Despite the efforts of Stone Soup Group, Alaska still has a long way to go to ensure that families of CSHCN have access to information and training on the resources and supports available to them. Alaska's Family-to-Family Health Care and Information Resource Center will fill this critical gap in Alaska's service system for families of CSHCN.

The project will focus on three primary goals. First, it will identify and compile existing information resources that are relevant to the needs of families of CSHCN. Throughout this identification and compilation process, the staff will identify outdated resources and update or produce new educational resources in order to provide the most comprehensive and up-to-date information warehouse for families of CSHCN in Alaska.

The project will also implement a peer-to-peer interactive network for families of CSHCN. This interactive network will provide an opportunity for families across the State to share their stories and find support among a group of their peers. The network will also provide a forum whereby professionals and other experts may respond to questions and provide information or feedback to families of CSHCN. Efforts to locate additional funding to support the Family-to-Family Information and Resource Center will also be initiated.

COLORADO

Grant Information

Name of Grantee Family Voices of Colorado

Title of Grant Project CFTF

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2003

Supplemental Award \$50,000 Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

Colorado's Health Care Program (HCP) for Children with Special Needs

Target Population(s)

Families of children with special health care needs (CSHCN), service providers who work with them, policymakers, and other support/advocacy groups.

- Establish a statewide network of parent professionals whose role will be to (1) improve
 access to information about health care systems and community resources and (2) assist
 other parents to effectively navigate these systems and utilize these resources.
- Disseminate new and current information to families of CSHCN, service providers, and advocates.
- Evaluate access to, use of, and satisfaction with the quality of health systems information.

- Identify health access and information guides relevant to six Healthy People 2010 core outcome indicators.
- Train family consultants to disseminate information and provide subsequent trainings in their local communities on core issues impacting CSHCN.
- Develop culturally competent information packets and materials.
- Implement a statewide system for data retrieval and sharing.
- Conduct surveys of families to measure increases in the ease of navigating service systems by means of Family-to-Family Project services.
- Provide information to policy makers to improve understanding of the issues facing CSHCN.

Abstract

Project CFTF will organize its activities based on six core Healthy People 2010 outcome indicators: Family Participation and Satisfaction, Access to a Medical Home, Access to Insurance, Early and Continuous Screening, Easy-to-Access Community-Based Service Systems, and Services Necessary to Transition to Adulthood.

These indicators will guide the project to help Colorado CSHCN families (1) have access to a "medical home"; (2) secure health insurance coverage; (3) obtain early and continuous screening and intervention services for their CSHCN; (4) access public services and entitlements specific to Colorado and regions in Colorado; (5) participate, partner, and advocate at all levels of decision making; and (6) obtain guidance that promotes a seamless transition from youth to adult services in Colorado.

The project will coordinate information sharing with existing projects such as the Medical Home Initiative and statewide transition planning groups. By the end of the first year, Project CFTF will compile a compendium of resources that incorporates information relevant to the six core indicators. HCP Family Consultants will receive in-depth annual trainings (using a train-the-trainer model) on health care and related services systems and navigation of the systems. Other families, community members, and agencies will be invited to attend. Information distribution and outreach will be conducted through local communication mediums such as newsletters, listservs, Web sites, and other community networks. HCP Family Consultants will be prepared to disseminate information and provide trainings in their local communities on core issues impacting CSHCN.

HCP Family Consultants will help families access health care resources and information, including negotiating benefits in health payer systems, understanding changes to the State's delivery of services, participating in the Medical Home Model, and using effective communication mechanisms to bring about systems change. Many HCP Family Consultants serving large Spanish-speaking populations are bilingual and culturally competent; all consultants participate on multidisciplinary teams and receive access to key health care, nutrition, and social work professionals.

Project CFTF will also conduct a second and third year evaluation to determine its success.

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INDIANA

Grant Information

Name of Grantee About Special Kids, Inc. (ASK)

Title of Grant The Indiana Family-to-Family Health Care Information and

Education Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2003

Supplemental Award \$50,000 Expected Completion Date September 2007

317-257-8683

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Children with special health care needs (CSHCN) and their caregivers.

- Improve the ability of no less than 100 families each year in each of two Indiana regions (northwest Indiana and southern Indiana) to care for their CSHCN in the community.
- Improve the ability of no less than 20 health care professionals each year to provide a medical home for no less than 50 families of CSHCN.

- Develop the infrastructure to provide information, peer support, and education to families regarding health care financing issues.
- Produce a newsletter and information packets to provide information to families of CSHCN in the two identified regions.
- Conduct regional workshops on health care financing and provide technical and financial assistance to support family participation.
- Establish partnerships with professionals who work with families of CSHCN to provide information to families on childcare, community resources, health care financing, genetics, and education law.
- Plan and conduct regional workshops and/or in-service programs for health care professionals on the components of a medical home.

Abstract

Over the past 10 years, Indiana has expanded its use of Medicaid to pay for services for children with disabilities and long-term health care needs. This has been accomplished through the State Children's Health Insurance Program (SCHIP) and development of new Home and Community-Based Services (HCBS) waiver programs. To address the information needs of families of CSHCN, About Special Kids, Inc. (ASK) established The Indiana Family-to-Family Health Information and Education Center to (1) make information and materials available online; (2) establish two Parent Liaisons in two state regions; and (3) plan and conduct training statewide on health care financing issues.

Working with a Web design consultant, ASK will expand and improve its current Web site by updating its online resource directory, responding to individual inquiries via the Internet, and providing downloadable materials. To place staff in regional sites, an advisory committee will help ASK identify (1) target regions; (2) regional staff who are respected by families and professionals in their communities; (3) options for co-location with other community agencies or organizations; (4) critical issues facing families; and (5) possible clinic and/or hospital sites for partnerships to meet families' information, support, and education needs.

The Indiana Family-to-Family Health Information and Education Center will (1) improve access to accurate, timely information on health care financing options; (2) support both families and professionals through medical homes in local communities; and (3) provide additional opportunities for education and training for both parents and professionals. The advisory committee will help the project maintain links with other family-directed organizations, ensure communication with state agencies and others who make or implement policies affecting families of CSHCN, and help identify emerging issues that are affecting these families.

MARYLAND

Grant Information

Name of Grantee The Parents' Place of Maryland

Title of Grant Maryland Family-to-Family Health Information and Education

Center

Type of Grant Family-to-Family Health Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2003

Supplemental Award \$50,000 Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Individuals with disabilities and special health care needs and their families.

Goal

The goal of this project is to develop and implement statewide strategies to ensure that families of children with special health care needs (CSHCN) have access to accurate, timely, and culturally appropriate information, to enable them to make wise health care decisions.

- Establish and maintain a toll-free number and Family Resource Center to increase access to information on health care options available to families of CSHCN.
- Expand outreach programs to special populations and translate outreach and education materials into Spanish and other languages as needed to be responsive to the need for information.
- Develop and pilot workshops on accessing the health care system (public health, private health, and behavioral and mental health services) for families of CSHCN.
- Develop a Health Care Advocacy and Leadership course for families and professionals using the community workshops piloted under the project.

Abstract

The mission of Parents' Place of Maryland is to enhance the ability of persons with disabilities and special health care needs to participate as fully as possible in home, school, and community life by providing education, information and referral, technical assistance, and support activities for them and their families. The overall goal of this project is to ensure access to accurate, timely, and targeted information on health care options within the State of Maryland to enable families of CSHCN, including those from special populations, to make wise health care choices.

One project objective is to ensure that families of CSHCN better understand the home and community services and supports available in their communities. This will be accomplished through the provision of a toll-free number, the hiring of a part-time Family Health Partner, the training of staff and volunteers from the partnering organizations, the dissemination of health information, and other outreach activities.

The project will expand outreach for special populations, especially Spanish-speaking families of CSHCN, through training and translated materials developed by the project. In addition, a series of training workshops for families of CSHCN in three broad topic areas—Maryland's Public Health System, Private Health Insurance in Maryland, and Accessing Health Care for Children with Emotional and Behavioral Disorders—will be piloted, evaluated, and implemented. The resulting workshops will become an ongoing part of the Parents' Place of Maryland's workshop repertoire.

MONTANA

Grant Information

Name of GranteeParents, Let's Unite for Kids (PLUK)Title of GrantFamily-to-Family (F2F) Center Project

Type of GrantFamily-to-Family Health Care Education and Information CentersAmount of Grant\$150,000Year Original Funding Received2003Supplemental Award\$50,000Expected Completion DateSeptember 2007

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Adults and adolescents with special health care needs, and parents of children with special health care needs (CSHCN).

- Increase the capacity of Parents, Let's Unite for Kids' (PLUK's) existing infrastructure to enable family-to-family assistance regarding health care information and education to further the ability of CSHCN to live in the most integrated setting with appropriate supports.
- Increase collaborative efforts among public and private entities to insure that families with CSHCN are receiving from their peers accurate and timely information relevant to their current situation.
- Facilitate the sustainability of family-to-family activities by providing a means for ongoing education and support for families with CSHCN.
- Strengthen statewide support of CSHCN by increasing the presence of family advocates within the health care system.

- Develop a statewide inventory of children's health-related programs and add to an existing Web site.
- Evaluate the capacity of families to provide peer-to-peer assistance.
- Develop a peer database, and policies and procedures for assigning peers to families.
- Create an advisory committee to bring together public and private stakeholders to advise, guide, and oversee the project.
- Develop, test, evaluate, and implement family peer training.
- Survey families with CSHCN to identify information needs.
- Develop an outreach plan for providing training and disseminating information.
- Establish CSHCN advisors for newborns in Billings, Helena, Great Falls, and Missoula to increase the presence of family advocates within the health care system.

Abstract

Parents, Let's Unite for Kids (PLUK) is a nonprofit organization dedicated to helping CSHCN reach their potential by insuring fair and equitable access to the educational system. PLUK uses a statewide team of well-trained parent volunteers who assist families by providing support and skill building for positive interactions with the educational system.

PLUK will use its current infrastructure for providing training, data collection, and information services to a statewide constituency to create a Family-to-Family Health Care Education and Information Center. Grant funds will be used to evaluate the information needs of families with CSHCN, conduct peer training to facilitate family-to-family support to meet information needs, and conduct a statewide conference for families by families.

An advisory committee will be established to bring together public and private stakeholders to advise, guide, and oversee the project. PLUK will conduct a survey to identify families who are willing to participate in the project and to determine their interest and skill level in various areas. The information gathered will be used to create an inventory of parental expertise. Topic areas with insufficient capacity will be identified and PLUK will create a plan to remedy the deficit. PLUK will also conduct a survey to determine the information needs of families with CSHCN.

PLUK will develop, test, evaluate, and implement family peer training, and will develop an outreach plan for providing training and disseminating information. A self-advocacy training track, which will be provided in other venues, will be developed for a CSHCN conference. The grant will also be used to establish CSHCN volunteer advisors for newborns in Billings, Helena, Great Falls, and Missoula, to increase the presence of family advocates in the health care system.

NEVADA

Grant Information

Name of Grantee Family TIES (Training, Information and Emotional Support) of

Nevada, Inc.

Title of Grant Nevada's Family-to-Family Health Care Information and Education

Center Project

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2003

Supplemental Award \$50,000 Expected Completion Date September 2007

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Children and youth with special health care needs (CYSHCN) and their families.

- Increase the understanding of and utilization of appropriate health care resources for CYSHCN.
- Promote family-centered and consumer-directed health care services and support.

- Analyze existing consumer education materials and develop health care and consumer education materials for services and resources available in Nevada.
- Develop a clearinghouse of information about systems of care for CYSHCN.
- Identify unserved or underserved populations and conduct outreach activities to them.
 Develop and/or disseminate information on how to access quality health care services and home and community supports.
- Train staff on the new systems of care for CYSHCN and host educational forums for consumers and providers.
- Conduct a consumer satisfaction survey.
- Develop an intake report form to track client intake, services used, utilization, and costs.

Abstract

The overall goals of the project are to increase understanding of and utilization of appropriate health care resources for CYSHCN, and to promote family-centered and consumer-directed health care services and support. Family TIES' consumer-run organization, culturally diverse staff, and peer mentoring supports will educate, inform, and serve CYSHCN families and help create a network of informed consumers. By encouraging and developing family-friendly materials and approaches, and using peer counselors and parent leaders as mentors, culturally competent policies, practices, and values will become part of the health care system.

Health education and information sharing among families will help families understand the health care system and obtain referrals for early screening and information on how to find appropriate services. The development of self-advocacy skills will help families serve as a resource to other families and provide the center with a pool of consumer leaders who will continue to make significant improvements to the service system in the future.

A Web-based clearinghouse of health care information, being developed under the project, will make information, services, and supports more accessible to families who need them. Information will be translated into Spanish so that Spanish-speaking families will have a place to find quality health care information in their native language. Products developed for consumers will inform and assist CYSHCN families in their decision-making and advocacy roles and help them understand the need for future planning for adult life. Family TIES will also develop a data collection and reporting system that will directly link key constituencies to information regarding the project goals and family satisfaction with services received.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

NEW JERSEY

Grant Information

Name of Grantee Statewide Parent Advocacy Network of New Jersey, Inc. (SPAN)

Title of Grant Family-to-Family Health Center Project

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2003

Supplemental Award \$50,000 Expected Completion Date September 2007

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Southern Region Coordinator

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Northern Region Coordinator 35 Halsey Street

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Subcontractor(s)

None.

Target Population(s)

Parents of children with special health care needs (CSHCN).

Goal

The goal of this project is to improve access to quality care and supports for children with chronic and acute health conditions in their communities by empowering their families with information and advocacy skills.

- Conduct focus groups with families and evaluate information obtained from volunteers to determine best approaches to reach diverse families of CSHCN.
- Develop two regional and at least 15 county-based Family Health Resource Centers to provide training, technical assistance, and leadership skills development for families of CSHCN.
- Design educational materials, forums, and training sessions to supplement existing training and educational programs.
- Provide training and information-sharing opportunities to parents of CSHCN, providers, and stakeholders.
- Provide direct peer-to-peer technical assistance to expand the capacity to respond to technical assistance requests.
- Develop and disseminate materials, through methods such as an existing Web site and newsletter, to assist CSHCN, parents, providers, and stakeholders with information on topics such as home health care, and home and community services and supports.
- Collect and analyze data to identify measurable outcomes and effective strategies in serving CSHCN; determine satisfaction levels; and track intake, utilization, and costs.

Abstract

The overall goal of the project is to improve access to quality care and supports for children with special health care needs in their communities by empowering families with information and advocacy skills. The Family-to-Family Health Center will assist families to

- 1. ensure that their children with special health care needs live at home or in the most integrated community setting appropriate to their needs;
- 2. exercise informed choices about their children's living environment, service providers, types of supports, and manners in which supports are provided; and
- 3. obtain quality services for their children with special health care needs.

The center will provide education, training, and information to families and providers; collaborate with national, New Jersey, and community agencies that benefit CSHCN and their families; and promote the philosophy of individual and family-directed supports.

Project activities and collaboration will increase the percentage of children with special health care needs whose families partner in decision making at all levels and are satisfied with the services; have access to adequate private and/or public insurance and community-based service systems; and can secure coordinated, ongoing, comprehensive care within a "medical home." The project will also increase informed participation of parents in local, county, and state health systems change activities.

SOUTH DAKOTA

Grant Information

Name of Grantee South Dakota Parent Connection, Inc.

Title of Grant South Dakota's Family-to-Family Health Care Information and

Education Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2003

Supplemental Award \$50,000 Expected Completion Date September 2007

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Subcontractor(s)

None.

Target Population(s)

Families of children with special health care needs (CSHCN).

- Provide information, referrals, and education about health care and home and community services statewide to those caring for CSHCN.
- Build capacity to connect those caring for CSHCN with local training, information, services, advocacy, and other parents of CSHCN.
- Provide culturally competent training and information for the American Indian and Spanishspeaking families of CSHCN.
- Collaborate with existing Family-to-Family Health Care Information and Education Centers to consistently promote the philosophy of individualized, family-directed support.

- Develop workshops to train Regional/Reservation Coordinators to assist in assessing and responding to the community's need for information, and to assist project coordinators in conducting two trainings per year in their respective communities.
- Promote the training statewide through the use of stakeholder newsletters and Web sites.
- Train volunteer parent trainers to facilitate training and provide information in their respective regions.
- Convert training materials to accessible formats (i.e., Braille, large print, electronic) to ensure access by populations with special needs.
- Identify parents and families interested in mentoring and/or training other families caring for CSHCN.
- Establish a statewide Advisory Council that includes families and parents of CSHCN, Reservation Coordinators, and other tribal and Spanish-speaking leaders to examine and provide input on training materials to ensure cultural competence.
- Contact and establish a communication network with other Family-to-Family Health Care Information and Education Centers in the region.

Abstract

The South Dakota Family-to-Family Health Care Information and Education Center will operate within the South Dakota Parent Connection, Inc. organization. South Dakota Parent Connection serves as the State's only Parent Training and Information (PTI) Center. The overall goal of the project is to build on the current infrastructure to increase access and choice for families with CSHCN and to establish new capacity without duplicating existing services. Information developed under the project will be easily accessible to underserved populations living in a frontier state and will help children remain in their home communities.

Project activities are designed to reach families through comprehensive programs including peer-training, parent-to-parent linking, training available through a variety of distance-education mediums, and individualized technical assistance, all with a strong emphasis on cultural competence and sensitivity toward the State's underserved populations. Collaboration with state, private, and local stakeholders will be the key to the success of building this parent-professional partnership.

Project activities will assist the State in its efforts to improve access to community services for families with CSHCN. The South Dakota Family-to-Family Health Care Information and Education Center will rely on a combination of staff, parent trainers, board members, advisory council members, collaborative partners, and Reservation/Regional Coordinators to complete its activities and meet its goals.

WISCONSIN

Grant Information

Name of Grantee Family Voices of Wisconsin

\$142,959

Title of Grant Family Voices of Wisconsin Health Information Project

Type of Grant Family-to-Family Health Care Information and Education Centers Year Original Funding Received

Supplemental Award \$50.000 Expected Completion Date September 2007

Contact Information

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Amount of Grant

Subcontractor(s)

Parent consultants

Target Population(s)

Children with disabilities and/or special health care needs (CDSHCN).

- Increase coordination between existing, state-funded information and assistance activities, and increase the availability of health and community resources to CDSHCN.
- Increase the availability to families of information on accessing health and community-based services and supports for CDSHCN.
- Ensure the availability of resources and training so that parents of CDSHCN, including parents of under-represented segments of the community, can be knowledgeable and effective navigators of their child's system of care.
- Develop an infrastructure for a sustainable Family-to-Family Information and Training Center.

- Develop recommendations for policy that streamline access to information and assistance for families of CDSHCN.
- Publicize information and assistance availability through interagency network outreach.
- Identify and train community partners and people in each region who can participate in health benefits training.
- Develop new and revise existing fact sheets to ensure that (1) Hispanic and Native American families have access to information and (2) families understand their insurance coverage.
- Develop and implement a dissemination plan for sharing information materials and key resources with consumer groups, support programs, and health care providers.
- Implement a strategic planning process to establish a private, nonprofit, family-directed organization focused on improving health care for CDSHCN.

Abstract

Families in Wisconsin have consistently identified the need for access to timely, high-quality services and supports in the health and community system of care. The complexities of the current systems, multiple funding streams, and lack of coordination make it difficult for families to obtain the services their child needs. Families who have the information they need to support their child with a disability or special health care need are in the best position to ensure access to quality health and community supports for their child.

Key aspects of this project include involving families in leadership positions in all aspects of project design, implementation, and evaluation. Extensive linkages will be fostered with existing parent groups concerned with CDSHCN. Strategies for supporting and training a network of health benefits specialists will be defined and implemented. All materials and training will be offered to the existing information and assistance network. Project outcomes will be monitored and evaluated throughout the project period.

NEW HAMPSHIRE

Grant Information

Name of Grantee University of New Hampshire—Institute on Disability/University

Center of Excellence in Disability

Title of Grant Living with Independence, Equality, and Freedom Account

Feasibility Study and Implementation Plan for Self-Directing

Individuals and Families in New Hampshire

Type of Grant LIFE Accounts Feasibility and Demonstration

Amount of Grant \$100,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

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Southern New Hampshire University

School of Community Economic Development

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Target Population(s)

Children and adults with disabilities responsible for self-directing their own services under the Home and Community-Based Care waiver services through In-Home Supports, Consolidated Services, Elderly-Chronically III services, and Personal Assistance Services programs.

Goal

Develop an easy-to-use LIFE Accounts savings program that will address the needs of persons with all types of disabilities and their families.

- Assess the various factors that could influence the success of a LIFE Accounts savings program, including potential demand, potential and actual ability to save, and barriers to saving, and underutilized but available means for saving for individuals and families who self-direct Medicaid-funded services and supports.
- Sample and survey individuals who self-direct to obtain information about the characteristics
 of those interested in participating in the LIFE Accounts savings program and produce a
 report of the findings.
- Use the findings to inform a feasibility study and implementation plan and host a conference to elicit feedback on the plan.
- Develop an implementation plan for a sustainable LIFE Accounts savings program.

Abstract

Many people with disabilities are deterred from accumulating personal savings because doing so may disqualify them from essential public benefits, such as Medicaid and Supplemental Security Income (SSI). Recent changes in the Social Security Improvement Act of 2003, and the establishment of a Medicaid Buy-In program for adult workers with disabilities demonstrates policy innovation to allow for savings accumulation. However, there remain significant program and policy barriers to saving for children, people who are temporarily unable to work, and for caregivers of the same household to purchase items that could substantially improve independence and community participation among citizens with disabilities.

The purpose of this project is to conduct a feasibility study and develop an implementation plan for the establishment of a savings program for children (i.e., parents) and adults with disabilities who self-direct their own Medicaid-funded, community-based, long-term care services without disqualifying beneficiaries from necessary medical or public benefit programs.

WISCONSIN

Grant Information

Name of Grantee Wisconsin Department of Health and Family Services

Title of Grant LIFE Accounts

Type of Grant LIFE Accounts Feasibility and Demonstration

Amount of Grant \$100,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

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Madison, WI 53703

Target Population(s)

Individuals with disabilities.

Goal

Develop a feasibility study and implementation plan for a Wisconsin Living with Independence, Freedom, and Equality (LIFE) Accounts savings program.

- Identify an eligible population to participate in the LIFE Accounts savings program.
- Develop and implement a survey sent to approximately 5,914 Medicaid waiver participants to determine interest in program participation and identify barriers to employment, increasing savings, and financial independence.
- Facilitate focus groups to further inform the feasibility study.
- Establish linkages and coordinate with a stakeholder advisory committee to provide guidance on the development of the feasibility study and implementation plan for establishing the LIFE Accounts savings program.

Abstract

The LIFE Accounts savings program for Medicaid recipients allows individuals to keep savings they have accumulated by self-directing their care. The savings accounts can be used to purchase equipment or home modifications that promote independence. Savings can be enhanced by an individual's earnings or by matched contributions from others.

The purpose of this feasibility study is to determine the number of individuals who are (1) currently eligible and likely to enroll in the LIFE Accounts program through their participation in a self-directed option in the three Home and Community-Based Services (HCBS) waiver programs—Community Integration, Community Options, or Family Care—or (2) receiving personal care under the Medicaid State Plan through the Independent Living Center Model.

The grant will also be used to study systems and policy issues that may impact the implementation of a LIFE Accounts program and to develop guidelines regarding allowable purchases and required documentation.

Anticipated project outcomes include (1) greater consumer participation in self-directed care, (2) the creation of incentives for cost-effective use of consumer resources, and (3) the availability of more equipment and supports to assist consumers in maintaining their independence.

DELAWARE

Grant Information

Name of Grantee Department of Services for Children, Youth and Their Families,

Division of Child Mental Health Services (DCMHS)

Title of Grant Family Psycho-Education for Children and Their Families

Type of Grant Mental Health: Systems Transformation

Amount of Grant \$300,000 Year Original Funding Received 2004

Contact Information

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University of Delaware

Center for Disabilities Studies (CDS)

Target Population(s)

Families and children served by the State's 1115 Medicaid waiver's public-private partnership for managed children's behavioral health care.

Goal

Develop, pilot, and disseminate for state and systemwide use a manualized, consumer-driven family psycho-education program relating to children's mental illnesses and severe emotional and behavioral disturbances.

- Analyze focus group and consumer survey reports to assess family/child expectations of Family Psycho-Education for Children and Families.
- Integrate all assessments with research on materials, curriculum, and best practices to make a preliminary determination of key components for the manual(s).
- Conduct statewide conference for families/consumers, DCMHS providers and other community providers, state agencies, and advocates to reach consensus on key components of Family Psycho-Education for Children and Families.
- Produce a draft, manualized Family Psycho-Education for Children and Families program and develop an evaluation plan for the pilot with selected DCMHS providers and families.
- Report on pilot and complete the plan for statewide dissemination of training and materials.
- Complete manual content and training curriculum and conduct statewide training with all DCMHS providers and other community providers.
- Produce final report to include evidence of completion of statewide provider training and evaluation of the grant project.

Abstract

Under Delaware's 1115 Medicaid waiver, there is a public-private partnership for children's behavioral health; however, there is no structured or systematic approach to family psychoeducation, and families/consumers report that this is a critical service gap.

DCMHS (the lead agency) is the single statewide payor for Medicaid children's behavioral health extended services with a statewide provider network and a commitment to effective treatment in the least restrictive environment and the use of evidence-based practices. Family psycho-education is already a Medicaid-coverable service in Delaware. DCMHS will partner with Delaware Federation for Families for Children's Mental Health, a statewide family organization and the family voice driving development of this project. In addition, the University of Delaware Center for Disabilities Studies is a strong academic partner with relevant expertise and evaluation capability and has already partnered effectively with DCMHS to produce curriculum for functional behavior analysis. These three partners will collaborate with Delaware Medicaid and behavioral health treatment providers to create Family Psycho-Education to directly benefit Medicaid children and their families. Outcomes to be achieved include

- Children live in the most integrated community setting appropriate to their individual needs.
 Families will be better informed about their children's illness/problems to enable understanding of the disability, and will learn to use demonstrated, effective strategies and supports so the child can live and function to his or her fullest potential in the home, school, and community.
- Families become full partners with professionals. Families and children will have the knowledge and skills they need to become full partners with professionals in the child's behavioral health care, exercising meaningful decisions about the services/supports they receive and the manner in which they are provided.
- Improved functioning for children, easing the transition to adulthood. Family psychoeducation will reduce reliance on institutional care and services in the adult system by creating family supports and the ability to identify and deal effectively with relapses, advancing toward recovery. Quality services will be obtained in an integrated, community setting, preparing the child for transition to adulthood.

MAINE

Grant Information

Name of Grantee Maine Department of Health and Human Services, Adult Mental

Health Services

Title of Grant Maine Recovery Specialist Program for Consumer-Driven Mental

Health Systems Change

Type of Grant Mental Health: Systems Transformation

Amount of Grant \$262,318 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

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Center for Learning

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Target Population(s)

Adults with mental illness who are Medicaid eligible.

- Build capacity for quality peer supports, self-directed services, and other consumer-driven services and natural supports by developing a peer support Recovery Specialist certification program.
- Strengthen the consumer role in system and community agency governance, decision making, planning, and service delivery.

- Develop a state peer support Recovery Specialist training and certification program and conduct annual training to produce 60 Recovery Specialists.
- Align the community support section of the Medicaid State Plan with the new Recovery Specialist program.
- Develop improved consumer-provider-Medicaid relations and increase consumers' community inclusion through education and marketing strategies.
- Research the evidence base for, and evaluate the delivery of, consumer-directed recoveryoriented services, with focus on Assertive Community Treatment (ACT) teams, Wellness Recovery Action Planning (WRAP), and Recovery Workbook Groups (RWGs) through better tracking of Medicaid claims data for reimbursed services.
- Develop and adopt a list of core values to guide statewide development of a consumerdirected recovery-oriented service system.
- Identify consumer-directed recovery-oriented services and supports with the strongest evidence base and promise. Identify which should be reimbursable. Identify barriers to delivery and recommendations to overcome those barriers.

Abstract

The Maine Recovery Specialist program for Consumer-Driven Mental Health Systems Change project is guided by the view that effective implementation of recovery-oriented principles in a state mental health system requires a strategic catalyst, a top-down and bottom-up approach, and a collaborative approach with strategic partners. Maine Department of Health and Human Services (DHHS), Adult Mental Health Services, in cooperation with DHHS Bureau of Medical Services, will collaborate with the Maine Peer Support Workgroup and the Center for Learning, Institute for Public Sector Innovation of the Edmund S. Muskie School of Public Service, University of Southern Maine, to implement this grant project.

A Consumer Project Advisory Committee representing consumers, survivors, and former patients from across the State will advise the project and provide a communications link to consumer organizations statewide. This Advisory Committee will be an expanded form of the Peer Support Workgroup, which designed the premise for this project with the Office of Consumer Affairs to further mobilize consumers and families to move a recovery-based agenda forward.

The project focus on training consumers as Recovery Specialists will serve as a catalyst for promoting a recovery-based approach for increasing community integration and inclusion of consumers and transforming the overall level of recovery-orientation of Maine's mental health system. Adult Mental Health Services will strengthen its strategic alliance with MaineCare, the State Medicaid program, collaborating to ensure utilization of newly trained and certified peer support Recovery Specialists and WRAP and RWG facilitators and thereby enhance the recovery-orientation of Maine's mental health system. Concurrently, the Deputy Commissioner, Programs, Director of Adult Mental Health Services, and grant project staff in the Office of Consumer Affairs will work to permeate a recovery-oriented philosophy in policy and decision making and planning and evaluation processes of the state mental health agency.

MASSACHUSETTS

Grant Information

Name of Grantee University of Massachusetts Medical School Center for Health

Policy and Research

Title of Grant Massachusetts Mental Health Systems Transformation Grant

Type of Grant Mental Health: Systems Transformation

Amount of Grant \$300,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

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M-Power

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Consumer Quality Initiatives

197 Ashmont Street Dorchester, MA 02124

Target Population(s)

Mental health consumers, adults, adolescents, and children who are Medicaid-eligible, including mental health consumers with substance abuse problems and young adults transitioning out of the children's mental health system.

- Establish a formal network among all recovery-oriented activities that are also consumerdirected across the State.
- Assess the gaps in recovery-oriented and consumer-directed (ROCD) services throughout the State.
- Establish a state-level consumer-directed Recovery Center of Excellence (RCOE) that
 provides training and technical assistance to consumer-directed programs and traditional
 mental health providers and that impacts state policy regarding mental health services.

- Develop a database of all ROCD programs and efforts in Massachusetts and build relationships and communication mechanisms between ROCD programs and efforts statewide.
- Analyze programmatic, financial, geographic, and cultural opportunities and barriers that support or hinder needed ROCD services.
- Establish an administrative structure and governance procedures for the RCOE and develop the charter and a strategic plan.
- Establish connections between the RCOE and the State Mental Health Planning Council and identify potential funding mechanisms to sustain the RCOE.
- Develop training curriculum for consumers and/or providers on implementing effective ROCD services and conduct a small-scale pilot test of the curriculum.
- Develop a process for certifying peer specialists.
- Develop quality measurement tools to assess the effectiveness of ROCD services and conduct a pilot study with local model programs.

Abstract

Consumer-directed services have taken root in Massachusetts and are providing much-needed support and assistance to mental health consumers, especially those who tend to avoid traditional service providers. However, several barriers currently stand in the way of consumer-directed programs being able to fully impact services and policy, including the lack of systematic quality measurement tools and program evaluations, limited training and technical assistance, limited funding streams, and systemwide cultural inertia.

The ultimate aim of this grant is to address these barriers, developing the infrastructure needed to support and sustain effective ROCD mental health services in Massachusetts. This will be accomplished through the establishment of a state-level, consumer-directed RCOE that will address each of these barriers by focusing on training, education and advocacy, planning and program development, and policy development. The RCOE will integrate consumer leaders and organizations to develop a consumer center of gravity that will influence the Massachusetts Department of Mental Health and Office of Medicaid policy and practice, and will ultimately promote systems transformation throughout the State.

Although the RCOE will ultimately impact the overall mental health system, its primary focus will be on Medicaid-eligible mental health consumers of all ages. This will be accomplished by targeting training, technical assistance, and education efforts to consumer-directed programs and traditional mental health providers that serve MassHealth members. Additionally, the RCOE will aim its efforts at two specific populations that have struggled greatly with the traditional mental health system—mental health consumers with substance abuse problems and young adults transitioning out of the children's mental health system.

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MICHIGAN

Grant Information

Name of Grantee Michigan Department of Community Health

Title of GrantMental Health Systems TransformationType of GrantMental Health: Systems Transformation

Amount of Grant \$300,000 Year Original Funding Received 2004

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Subcontractor(s)

To be decided.

Target Population(s)

Adults with serious and persistent mental illness.

- Facilitate a consensus among consumers, professionals, and service system managers about recovery as a concept and the models and pathways that can be implemented in the state mental health system.
- Ensure that leadership within the State's Department of Community Health is consumercentered and informed of consumer experiences in order to support the direction of the Recovery Council with consumer perspectives and the development of products that are consumer-oriented.
- Establish locally-based models of recovery that can serve as learning environments for consumers, families, professionals, and service system managers.
- Ensure that the application of the principles of recovery as the basis of service delivery is extended across the public mental health system, through continuous learning and expanded partnerships between consumers, service managers, and professionals.

- Establish a Recovery Council to provide project oversight, direction, guidance, and leadership in all grant activities; to provide feedback to the Michigan Department of Community Health on technical advisories, practice guidelines, policies, and workgroups regarding the principles and practices of recovery; and to serve as expert resources to areas throughout the State.
- Develop a Recovery Policy and Practice Guideline that will be a requirement in Managed Care contracts with Prepaid Inpatient Health Plans (PIHPs).
- Publish and maintain a statewide list of experts/speakers bureau to give presentations on recovery.
- Establish three Recovery Centers of Excellence that will develop partnerships with additional stakeholders and increase the number of primary consumers as experts.
- Disseminate materials and resources developed by the Recovery Council and the Recovery Centers, including a recovery Web site, and conduct mental health training events statewide.
- Develop a consumer experience survey, assessment instruments to measure organizational change with regard to systems transformation to the recovery model, and specific outcome indicators to measure recovery through a site review process.

Abstract

Michigan has a strong history of promoting and supporting consumer choice and control in the delivery of mental health services and supports. The State has partnered with consumers and families in work groups to develop practice guidelines, technical advisories, and other communications to the field. Person-centered planning is included in the State's Mental Health Code and a Self-Determination Policy and Practice guideline became effective in October 2004. While these innovations have moved professionals and systems into a service delivery model of consumer choice and control, there have been pockets of success without significant systems change.

In recent years, the State has sought to bring the theme of recovery into the forefront of thinking among professionals, service system mangers, families, and consumers. However, infrastructure is needed to address systems barriers and accountability of recovery-oriented services. Recovery education, training, and support are needed to continue the evolution of supporting positive practices that are evidenced-based.

The grant project seeks to transform Michigan's public mental health system so that recovery is the foundation of the service delivery system. The Department of Community Health will lead a focused and intensive effort to instill the principles of recovery, to enhance the understanding of pathways to achieve recovery, and to support models that can be built upon to demonstrate these pathways. The infrastructure development will include peer supports, self-direction, and consumer-owned and -operated services. In Year 2, the project will focus on developing and supporting at least three Recovery Centers of Excellence to move recovery from a statewide leadership focus to a regional and local level.

Outcomes and products will minimally include a Recovery Council of experts; a recovery brochure and handbook; a Web site with links to national resources; a speakers bureau of recovery experts; contract requirements for managed care; and infrastructure development to support recovery-oriented, evidenced-based mental health services.

MINNESOTA

Grant Information

Name of Grantee Minnesota Department of Human Services

Title of Grant Using Evidence to Transform Systems: Science in Service of

Children's Mental Health

Type of Grant Mental Health: Systems Transformation

Amount of Grant \$300,000 Year Original Funding Received 2004

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National Alliance for the Mentally III,

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Target Population(s)

Medicaid-eligible children with serious emotional disturbance (SED).

- Expand and update scientific information available to providers and families for guiding decisions about children's mental health care.
- Improve the service quality of children's mental health systems of care through the development of an evidence-based practices (EBP) database.
- Establish a fully operational system that improves outcomes for children and families.

- Produce a document that defines high-level concepts to guide priorities and policies for systems development.
- Produce guidelines for diagnostic assessments and identified outcomes measures for children's mental health.
- Produce a document that details the specifications for the EBP database.
- Develop training manuals, Web site supports, and ITV and site trainings for families, parent advocates, providers, and county case managers.
- Import the modified Hawaii EBP database to an appropriate site and establish maintenance agreements/contracts.
- Develop software or other technology to support pilot projects to design and test the prototype system.
- Develop and test a provider performance system and produce service authorization guidelines.
- Produce an interim evaluation report on the pilot projects, and conduct beta testing of the claims and authorization systems.
- Develop a Continuous Quality Monitoring process that will start producing reports.
- Implement a fully operational EBP database system, continue to provide training on the system, and produce a final evaluation report.

Abstract

The Minnesota Department of Human Services will develop and implement an evidence-based practices database to function as a clinical decision-making tool for parents and providers. The project is designed to make the best possible use of structures and processes used by Hawaii to implement evidence-based interventions throughout its system of care, to determine modifications in those structures and processes needed to match Minnesota's unique assets and constraints, and to evaluate the effectiveness and cost-efficiency of these changes to Minnesota's children's mental health service system.

Based on Hawaii's approach, the project will join families and providers in a learning collaborative to build and implement a systematic approach to evidence-based services from published research and evaluation data. By the end of the project's first year, there will be a plan in place for technical systems changes that need to be made; evidence-based concepts will be familiar to a wide range of families, providers, and administrators; and Minnesota will be prepared to acquire and install the Hawaii-developed core practice elements database. In the second phase of the project, spanning most of Year 2, pilot projects will be developed, implemented, and evaluated. Pilot sites will be chosen regionally in order to ensure the applicability of the project to urban, rural, and frontier areas. At the end of Year 3, the State will have a fully operational EBP database accompanied by strengthened collaborative consumer/provider relationships, customized training materials, enhanced claims and authorization systems, a continuous quality monitoring system, and evaluation reports.

Ultimately, the outcome will be a statewide system that improves clinical and functional outcomes for children, and parents and providers will have more choices in treating children. These system changes will also result in less institutional treatment of children and greater efficiencies in the State's Medicaid system.

NEW HAMPSHIRE

Grant Information

Name of Grantee State of New Hampshire, Bureau of Behavioral Health (BBH)

Title of Grant Statewide Implementation of Illness Management and Recovery

(IMR) for Consumers with Severe Mental Illness (SMI)

Type of Grant Mental Health: Systems Transformation

Amount of Grant \$300,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

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NH-Dartmouth Psychiatric Research Center (PRC)

Target Population(s)

Individuals with severe mental illness (SMI).

- Implement Illness Management and Recovery (IMR) as an evidence-based practice (EBP) in a comprehensive manner throughout the Bureau of Behavioral Health (BBH) services structures to support consumers in their recovery process.
- Involve consumers and family members formally in the evaluation of IMR services by incorporating consumers and family members in the fidelity teams assessing the IMR practice at the community mental health centers.
- Develop an organizational structure that specifies IMR clinician specialist teams in each community health region to be responsible for delivering the services, as well as an IMR supervisor at each center and an IMR coordinator at BBH.
- Develop a credentialing process for IMR providers, including staff at community mental health centers and state psychiatric facilities.
- Explore the involvement of consumers in the provision of IMR to individuals receiving services at community mental health centers.

- Establish a permanent state IMR team, including a permanent liaison coordinator at BBH, to oversee and implement the grant project and to become the advisory board for an IMR Center of Excellence.
- Develop an IMR implementation plan, outcome measures, and a quality assurance plan.
- Establish IMR clinician specialist teams to train regional providers in IMR foundation principles, IMR overview, and IMR skills.
- Improve financial incentives for implementing IMR by restructuring Medicaid guidelines and by offsetting the cost of IMR training and supervision with grant funding.
- Establish a benchmark for the attainment of critical IMR workforce skills—including participation in training, knowledge base, observable skills, and supervised practice experience—as a foundation for a credentialing process.
- Establish an IMR Center of Excellence, to include partnerships with all stakeholders, that will become the State's focal point for providing technical assistance and training in IMR.

Abstract

The New Hampshire BBH will implement the EBP IMR program statewide to empower consumers to better manage their mental illness and reclaim their lives by supporting their pursuit of personal recovery goals. The critical ingredients of IMR are supported by multiple controlled studies and include psycho-education, strategies for improving medication adherence, developing a relapse prevention plan, and enhancing skills for coping with persistent symptoms.

Implementation analyses of the IMR program and other EBPs conducted in New Hampshire and across the country have identified barriers to accessing IMR, including lack of a coherent service structure for IMR, a mismatch between Medicaid-reimbursable procedures and some key components of evidence-based IMR interventions, lack of involvement of consumer providers, and the need for ongoing mechanisms to ensure access to training and to sustain high-quality services. The grant will be used to address these barriers to IMR in New Hampshire as follows: (1) establish a coherent service structure for delivering and monitoring IMR in every community mental health center/peer-support program region (and the two state-operated inpatient facilities) involving trained clinician IMR service providers at each site, a supervisor, and a state IMR coordinator; (2) provide training for IMR in each community mental health center/peer-support program region and state-run inpatient facilities, and consultation to center administrations; (3) develop recommendations for modifying Medicaid reimbursement guidelines to support provision of IMR services; (4) develop an IMR state team at the BBH level to lead, monitor, and continuously improve the system transformation; (5) develop credentialing procedures and standards to facilitate long-term Medicaid reimbursement capability; and (6) establish a Center of Excellence for IMR services that will provide training and consultation to both centers and the State to ensure sustainability of collaborative high-quality IMR services throughout New Hampshire.

BBH has already convened a multi-stakeholder EBP team comprising consumers, family members, community mental health providers, BBH, and NH-Dartmouth Psychiatric Research Center (PRC). This team has been meeting on a regular basis and has unanimously endorsed this IMR project.

NORTH CAROLINA

Grant Information

Name of Grantee NC Division of Mental Health, Development Disabilities, and

Substance Abuse Services

Title of Grant Real Choice Systems Change Grant—Mental Health Systems

Transformation

Type of Grant Mental Health: Systems Transformation

Amount of Grant \$881,307 Year Original Funding Received 2004

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Target Population(s)

Adults with mental illness.

- Achieve greater incorporation of evidence-based practices into the mental health system by assisting local management entities (LMEs) to develop the infrastructure necessary to support and sustain the implementation of evidence-based practices within their local communities.
- Conduct field testing, review results, and design an evaluation.
- Disseminate models by conducting training and technical assistance activities.

- Conduct a needs assessment based on identified LME functions.¹
- Develop a strategic action plan (i.e., objectives, activities, outcomes, deliverables, and timelines) based on the needs assessment.
- Implement the strategic action plan using targeted onsite training and technical assistance, and document implementation processes.
- Develop protocols, monitoring tools, assessment of implementation fidelity, quality measures, and other data collection forms so that other LMEs may replicate the infrastructure-building process.

Abstract

The goal of the grant project is to achieve greater incorporation of evidence-based practices into the mental health system by assisting LMEs to develop the infrastructure necessary to support and sustain the implementation of evidence-based practices within their local communities. To accomplish this goal, a project work group was established at each LME, consisting of administrators, managers, clinicians, providers, and Consumer and Family Advisory Committee (CFAC) members. During planning and development, the local work groups met once or twice a month until consensus was reached on the strategic action plan. Since LMEs are implementing the strategic action plan, the work groups are meeting monthly.

Representatives (i.e., LME coordinator, LME staff member, and CFAC member) of the four project work groups meet as a group quarterly to discuss implementation issues such as essential infrastructure elements for successful planning, purchasing of services, training, instrument development, barriers to implementation, monitoring of implementation fidelity, clinical supervision, and reporting. Two of the four meetings are held in tandem with the Steering Committee meeting so that progress at each site may be reported to the Steering Committee for constructive feedback and future planning.

At Steering Committee meetings, representatives of the state Division of Medical Assistance and Mental Health, Division of Developmental Disabilities, and Division of Substance Abuse Services, the NC Council of Community Programs, the four LMEs, and the MHST Grant project staff discuss the goals, proposed activities, and expectations at each level (i.e., state, Council of Community Programs, Institute, LME, and CFAC). These meetings ensure that all participants understand what the project is trying to achieve.

The first year of the grant focused on planning and development; and the second year focused on field testing, review, and documentation of the experience, and development of an evaluation design for dissemination efforts. The third year will focus on dissemination, training, and technical assistance to implement standardized infrastructure tools across the State. Efforts will include workshops, training materials, and considerable technical assistance provided primarily by individuals from the field sites and the grant work group.

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¹The responsibilities of the LME as they relate to system performance are as follows: (1) general administration and governance; (2) access, triage, and referral; (3) service management; (4) provider relations and support; (5) customer services and consumer rights; (6) quality management and outcomes evaluation; (7) business management and accounting; and (8) information management, analysis, and reporting.

OHIO

Grant Information

Name of Grantee Ohio Department of Mental Health

Title of Grant Incorporating Peer Support Specialists into Ohio's Assertive

Community Treatment (ACT) Teams

Type of Grant Mental Health: System Transformation

Amount of Grant \$300,000 Year Original Funding Received 2004

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Target Population(s)

Medicaid beneficiaries receiving mental health services from community mental health providers, including Assertive Community Treatment (ACT) services to aid recovery.

- Develop a workforce and support network for peer support specialists in the evidence-based ACT services for individuals receiving mental health services from a Medicaid-funded community health center.
- Provide technical assistance and training to county boards and providers of ACT services in order to facilitate the incorporation of peer support specialists into Ohio's ACT teams.
- Disseminate lessons learned and learn from others about peer support and ACT.

- Develop a systems transformation white paper, based on input from a facilitated group of constituents, that outlines the system changes necessary to promote peer support specialists.
- Develop training materials detailing how consumers can effectively and ethically serve as peer support specialists on ACT teams and use materials to train providers.
- Facilitate the development of mentor relationships and a network for peer support specialists.
- Provide technical assistance and training for systems change to county boards and providers of ACT services.
- Develop workforce capacity by training 80 consumers as peer support specialists in four 2week classes of 20 persons.
- Provide training for peer support specialists on how to be an active and effective member of an ACT team and provide training and staff assistance for ACT teams on how to utilize peer support specialists.
- Conduct an evaluation of peer support specialists' work and mentor experiences.
- Provide technical assistance and training by ACT center staff on how consumers may be incorporated as staff in community mental health centers.
- Participate in conferences, such as the National Assertive Community Treatment
 Association Conference, the Substance Abuse and Mental Health Services Administration
 (SAMHSA) Federal Mental Health Block Grant Conference, and the Alternatives
 Conference, to learn from others about evidence-based practices and to disseminate
 lessons learned.

Abstract

The Ohio Department of Mental Health (ODMH) is partnering with the State Medicaid agency and the Ohio Department of Job and Family Services, to incorporate the evidence-based practices ACT as a distinct Medicaid community mental health service beginning in July 2005. ODMH is working with consumer groups, providers, and county boards to incorporate peer support specialists into Ohio's ACT teams. The grant project will provide funding for training and technical assistance to realize the goal. This will increase Ohio's capacity to deliver evidence-based practices and recovery-oriented services to Medicaid consumers with mental health needs and will have a positive impact on Ohio's mental health system's ability to provide the same services for all mental health consumers.

The measurable outcomes and products of this grant will include a white paper on how to incorporate peer support into ACT, which will be disseminated at national mental health conferences. Eighty people will be trained as peer support specialists, and ACT training will be conducted for providers to support the employment of peer support specialists. In addition, training and/or technical assistance will be provided to 40 providers on how to effectively incorporate peer support specialists into their staff.

OKLAHOMA

Grant Information

Name of Grantee Oklahoma Department of Mental Health and Substance Abuse

Services

Title of Grant Oklahoma Evidence-Based Practices Implementation Project

Type of Grant Mental Health: Systems Transformation

Amount of Grant \$299,820 Year Original Funding Received 2004

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Subcontractor(s)

None.

Target Population(s)

Adults with mental illness or substance abuse who are eligible to receive Medicaid or state-purchased services.

- Develop policy and program framework for evidence-based practices.
- Develop policy and program framework for Recovery Support Network.
- Create Recovery Support Network.
- Develop a collaborative relationship with the behavioral health provider community that supports the continuing implementation of recovery-oriented and evidence-based practices.

- Identify clinical policies from Substance Abuse and Mental Health Services Administration (SAMHSA) Implementation Toolkits.
- Research evidence-based practice implementation and Medicaid coverage in other states.
- Create billing code and rate proposals for new services.
- Develop educational materials and provider trainings.
- Develop provider contract and credentialing process.
- Create service outcome monitoring mechanism.
- Identify operational procedures for Recovery Support Specialists.
- Create policy documents for the Medicaid and behavioral health state agencies.
- Develop a credentialing process, training modules, and training materials for Recovery Support Specialists.
- Train Recovery Support Specialists and administer and score credentialing exams.
- Conduct follow-up visits with Recovery Support Specialists and their supervising behavioral health clinician.

Abstract

The Oklahoma Evidence-Based Practices Implementation Project is an extension of the Recovery Collaborative of Oklahoma. The Collaborative is sponsored by the Oklahoma Department of Mental Health and Substance Abuse Services (ODMHSAS), which is the state Mental Health Authority, and the Oklahoma Health Care Authority (OHCA), the state Medicaid agency. The Oklahoma Department of Human Services and the Oklahoma Department of Rehabilitative Services also participate in activities of the Collaborative as needed.

The mission of the Collaborative is to implement modifications to the Oklahoma adult outpatient behavioral health delivery system that will enhance the quality of services provided, focus those services upon recovery and the needs of the consumer, and ensure that state- and federally-funded health care is purchased in the most efficient and comprehensive manner.

The Collaborative will implement two evidence-based practices: the Family Psycho-education Program and the Illness Management and Recovery Program. These initiatives fall within the purview of the Collaborative to implement the six evidence-based practices suggested by SAMHSA.

The Collaborative will use grant funding to add one full-time staff member at ODMHSAS and one full-time staff member at OHCA. These individuals will develop a statewide network of Recovery Support Specialists who will collaborate with the current network of behavioral health practitioners to form a multidisciplinary team that will serve as providers of Illness Management and Recovery Services and Family Psycho-education. The new staff members will develop policies, procedures, reimbursement strategies, credentialing standards, outcome measures, and provider contracts that will serve as the foundation for these two programs.

Network development and provider training activities will begin in late 2005 and will continue throughout 2006. It is anticipated that the practitioner training sessions conducted through the funding of this grant will continue developing a collaborative relationship with the behavioral health provider community that will serve as the foundation for this effort and the continued implementation of evidence-based practices in the future.

OREGON

Grant Information

Name of Grantee Portland State University

Title of Grant The Peer Expertise Network: Building Peer Operated Supports for

Recovery

Type of Grant Mental Health: Systems Transformation

Amount of Grant \$300,000 Year Original Funding Received 2004

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Subcontractor(s)

None.

Target Population(s)

Individuals with psychiatric disabilities.

- Develop and expand peer-operated programs and services from five to eight programs.
- Facilitate the incorporation of peer-operated programs and services as evidence-based practices.
- Identify collaboration strategies, funding mechanisms and policy improvements necessary to sustain peer-operated programs.
- Increase consumer participation and collaboration at all levels of service and policy design, implementation, and oversight.
- Document and evaluate the impact of incorporating peer-operated services on mental health systems transformation.

- Identify potential resources and mechanisms for leveraging funding (e.g., waiver or State Plan amendments or adding peer services as a rehabilitation option) and develop a specific plan for funding peer-operated programs.
- Increase the capacity of peer-operated programs to provide billable services.
- Assess consumer and agency perceptions of peer-operated programs.
- Develop guidelines, benchmarks, and a quality assurance process for evidence-based peeroperated services.
- Obtain input and recommendations from consumers on ways to provide outreach focused on consumer direction, resilience, and recovery.
- Provide training and technical assistance for eight regional peer-operated program consumer leaders to facilitate infrastructure development in their regions.
- Provide mini-grants to organizations that develop specific plans for enhancing their capacity to be peer-operated and to offer peer-to-peer services.
- Produce brochures and flyers about accessing local, regional, state, and national consumerdirected newsletters, discussion groups, and other peer networking initiatives.
- Develop train-the-trainer tools and approaches for peer-operated groups in areas such as networking, person-directed planning, and self-directed supported employment.

Abstract

The Peer Expertise Network (PEN) project is undertaking a series of interrelated activities designed to increase the utilization, validation, and sustainability of peer-operated services. Consumer leaders are involved at all levels of the project, leading design, outreach, policy, evaluation, and dissemination teams. Peer-operated services are being outreached through the development of a network that brings together groups and leaders already skilled in the delivery of peer-based services with groups committed to moving toward increased peer operation. Train-the-trainer tools and approaches for peer support, education, and advocacy are being infused as well as peer-guided methods for providing supports, such as person-directed planning and self-directed employment.

A PEN Leadership Conference is being conducted to promote knowledge exchange, to facilitate organizational planning for peer-operated services, and to establish network linkages that bring together consumer/survivor leaders to support one another's efforts. An ongoing collaborative planning effort by consumers, state, and local agencies, and other leaders is identifying policy improvements, collaboration strategies, and funding mechanisms for sustaining peer-operated programs and services.

Key outcomes include an increase in (1) the number of peer-operated programs, (2) the level of evidence-based peer services delivered within those programs, and (3) consumer/survivor involvement in the implementation and evaluation of other evidence-based practices. Products include evidence-based practice guidelines, benchmarks, tools for structuring and delivering peer-operated services, and a policy and funding framework for incorporating peer-operated services as a standard practice.

PENNSYLVANIA

Grant Information

Name of Grantee Pennsylvania Department of Public Welfare, Office of Mental

Health and Substance Abuse Services (OMHSAS)

Title of Grant Real Choice Systems Transformation Grant

Type of Grant Mental Health: Systems Transformation

Amount of Grant \$300,000 Year Original Funding Received 2004

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Target Population(s)

Persons with mental illness.

- Select, engage, and prepare counties in the northeast, central, and western regions of Pennsylvania to implement a Certified Peer Specialist (CPS) program.
- Conduct CPS training in the selected counties.
- Support and expand CPS activities.
- Develop a State Plan Amendment for Medicaid reimbursement of peer specialist services and to provide ongoing program support.

- Select counties for participation in a CPS program.
- Identify and educate local stakeholders, form local CPS planning teams in the selected counties, and determine opportunities to create CPS employee positions.
- Recruit consumer trainees to serve the county programs, train and certify peer trainers, and conduct regional CPS training programs in each of the three regions.
- Establish a CPS self-help network for CPS graduates.
- Draft State Plan Amendment language for Medicaid reimbursement of psychiatric and peer specialist services, conduct complete fiscal analysis, and submit for approval.

Abstract

Through the Office of Mental Health and Substance Abuse Services (OMHSAS), Pennsylvania develops programs and policies, allocates funds, and develops guidelines for county planning and outcome reporting. County government, through the Mental Health/Mental Retardation Act of 1966 and the Mental Health Procedures Act of 1976, has the responsibility to provide a full array of mandated services to its citizens within each county area. OMHSAS has a long-term commitment to the development of a comprehensive array of mental health and substance abuse services and supports.

The Mental Health Association of Southeastern Pennsylvania (MHASP), in partnership with the Montgomery County Office of Mental Health/Mental Retardation/Drug and Alcohol Services, local providers, consumers, and other stakeholders, has implemented in Montgomery County a CPS Program similar to those developed in other states. Through this program, current or former mental health clients are being trained and certified to function as Peer Specialists. These programs assist consumer trainees to better understand peer support, communication skills, cultural competency, outreach, engagement, conflict management, crisis intervention, setting up and sustaining mutual self-help groups, helping clients build their own self-directed recovery tools, and navigating the work place. In Montgomery County, a protocol has been developed for engaging community stakeholders to support this new recovery workforce, a recovery training curriculum has been produced, training strategies are finalized, and a class of 18 consumers is now certified and functioning as the county and State's first Certified Peer Specialists. Montgomery County is using these Certified Peer Specialists in various service settings, including Targeted Case Management, Community Treatment Teams, and Mobile Psychiatric Rehabilitation programs.

Based on this successful program in the Southeast region of Pennsylvania and the accolades Peer Specialist Certification programs have received in other states (e.g., Georgia, South Carolina, Arizona, Vermont, New Mexico), OMHSAS will use this project to introduce and support a Peer Specialist Certification program in the northeast, central, and western regions of the State. Under the grant, the program will be developed in selected counties and then expanded to the rest of the State. A support network will also be developed for CPS training program graduates. OMHSAS will simultaneously work on a State Plan Amendment to win approval to support a continuing program by Medicaid reimbursement of peer specialist services through the Mental Health Rehabilitation Option.

VIRGINIA

Grant Information

Name of Grantee Virginia Department of Mental Health, Mental Retardation and

Substance Abuse Services

Title of Grant Transforming Virginia's Mental Health Services System

Type of Grant Mental Health: Systems Transformation

Amount of Grant \$300,000 Year Original Funding Received 2004

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Subcontractor(s)

Virginia Organization of Consumers Asserting Leadership (VOCAL) Mental Health Association of Virginia

Target Population(s)

Adults with serious mental illness.

- Increase stakeholder knowledge to ensure that the State's mental health system transformation and restructuring are based on principles of self-determination, recovery, and empowerment.
- Align the State's existing Medicaid Rehabilitation Option mental health services with the
 evidence-based practices of Assertive Community Treatment (ACT), Illness Management
 and Recovery (IMR), and Supported Employment (SE) to the maximum extent possible.
- Maximize opportunities for peer specialists and consumer-operated programs to provide Medicaid reimbursable services and evidence-based practices, including a potential new adult peer support Medicaid service.

- Develop and implement an advanced consumer empowerment and leadership training (CELT) academy.
- Sponsor mental health consumer participation at major mental health system conferences and planning events.
- Develop a recovery Web site within the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) and Virginia Organization of Consumers Asserting Leadership (VOCAL) housing resources to educate stakeholders.
- Conduct surveys to evaluate the recovery orientation of mental health providers and staff.
- Provide training and technical assistance to community mental health staff, peer specialists, and other stakeholders on Medicaid reimbursement that supports the State's Programs for Assertive Community Treatment (PACT) expansion.
- Review and analyze federal and state regulations pertaining to vocational and employment services.
- Resolve inconsistencies, gaps, and potential barriers between the State's evidence-based practices of IMR and SE implementation toolkits and existing funding streams.
- Provide training to mental health and vocational rehabilitation partners, including consumers and other stakeholders, on the evidence-based practices of IMR and SE.
- Identify national models and state-specific information about peer specialist and consumeroperated programs, and their roles in the delivery of community mental health services.
- Resolve inconsistencies, gaps, and barriers to peer support and identify opportunities to provide peer specialist and consumer-operated programs in the State's existing Medicaid Rehabilitation Option community mental health services and evidence-based practices.

Abstract

The Virginia DMHMRSAS will use the grant project to strengthen the capacity of the State's mental health services system to provide integrated community services that embody self-determination, recovery, and empowerment. The project will focus on consensus and partnership building with multiple stakeholders and constituencies to develop (1) state-specific models of illness management and recovery and supported employment; (2) regulatory analysis and agency funding streams that will support programs on assertive community treatment, illness management and recovery, and supported employment services; (3) provider training, consultation, and technical assistance; and (4) process evaluation of project implementation.

Project activities are intended to increase the number of mental health consumers who assume policy, planning, evaluation, and leadership functions and roles at Community Services Boards and in mental health system transformation activities; provide Community Mental Rehabilitative Services (CMHRS) that include relevant components of IMR and SE; and are better able to access recovery-oriented and personalized supports leading to competitive employment and independence. The State estimates that approximately \$5 to \$10 million of existing CMHRS Medicaid reimbursement will ultimately be redirected to support more effective and efficient recovery-oriented community mental health services and supports.

Grant activities were developed collaboratively with consumers and are responsive to numerous recommendations in the President's New Freedom Commission on Mental Health Report and Virginia's *One Community*, the Olmstead Task Force Report.

ALASKA

Grant Information

Name of Grantee Department of Health and Social Services

Title of Grant Alaska's Comprehensive Quality Management System

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$417,849 Year Original Funding Received 2004

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Subcontractor(s)

None.

Target Population(s)

Participants in all the State's Home and Community-Based Services (HCBS) waiver programs.

- Develop a quality of life assessment tool and methodology to provide more accurate information on the effectiveness of the HCBS waiver programs.
- Assist in the implementation of a new quality management database system that will more effectively track complaints and incident reports across all state agencies and departments.
- Evaluate the project's effectiveness toward meeting the State's goals and objectives and implement necessary modifications to replicate activities statewide.

- Identify existing assessment instruments and methodologies that measure quality of life and conform with the HCBS Quality Framework to serve as a guide for developing a quality of life assessment tool.
- Implement a quality of life assessment tool, test the assessment tool with a sample of consumers, make revisions, and finalize the tool.
- Develop and disseminate information in multiple formats to waiver recipients and providers on the quality management system and how to access quality assurance information, give feedback, file complaints, and make incident reports.
- Prepare the quality assurance system to receive data, assist personnel to import existing data into the new system, and develop protocols for maintenance of the system.
- Train state agency and provider staff to use the new quality database system.
- Develop reports to be used in distributing quality assurance findings to consumers, families, and providers.
- Evaluate progress toward meeting goals and objectives and post quarterly progress reports and project evaluation reports on the State's Web site (http://www.hss.state.ak.us/dsds).

Abstract

The processes used by the State to assess needs for services, and to periodically review service plans already incorporates person-centered strategies. The purpose of the grant project is to expand the ability of the Division of Senior and Disabilities Services (DSDS) to provide more comprehensive quality management.

In Year 1, consumer partners (Alaska Commission on Aging, Alaska Mental Health Trust Authority, Governor's Council on Disabilities and Special Education, and State Independent Living Council) will examine instruments and methodologies for assessing quality of life on an ongoing basis and make recommendations to the DSDS Quality Improvement Steering Committee. An assessment will be implemented with a small sample of waiver recipients and, after review by the partner organizations, any problems will be addressed. In Years 2 and 3, this assessment will be implemented with larger samples and expanded to other regions of the State, becoming an ongoing part of Alaska's Quality Management System.

Simultaneously, in collaboration with the Alaska Mental Health Trust Authority, the project will assist in the implementation of an already existing data management system that can integrate quality of life data with other data, such as eligibility assessments, case management, service delivery, program provider performance, complaints, and incident reports. This will make it possible for Alaska's Quality Management System to become more data-driven in ongoing monitoring and improvement activities. It will allow DSDS to provide data-supported information that will be accessible to consumers and families as a tool for making informed choices, to providers as a tool for making their own quality assurance decisions, and to other stakeholders.

ARIZONA

Grant Information

Name of Grantee State of Arizona, Department of Economic Security, Division of

Developmental Disabilities

Title of Grant Empowering AriZona's Individuals with developmental disabilities

(EAZI)

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$500,000 Year Original Funding Received 2004

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Project Manager

Policy, Planning and Special Projects

Subcontractor(s)

Thomas Uno, Ed.S., Assistant Director Northern Arizona University/Institute for Human Development

Target Population(s)

People with developmental disabilities and their families.

Goal

Develop and test a consumer-to-consumer strategy for gathering quality assurance (QA) data and identifying quality improvement (QI) needs.

- Develop a compendium of quality characteristics, under the direction of a consumer-led steering committee, based on a literature review and consumer focus groups.
- Develop a training curriculum for peer quality reviewers and data gathering procedures and tools.
- Develop a database for storing and analyzing information.
- Produce technical reports on pilot and demonstration projects.
- Develop a model consumer-to-consumer QA/QI plan.

Abstract

The goal of this project is to develop and evaluate a consumer-to-consumer strategy for gathering QA data and identifying potential QI needs. To ensure the project is consumer/family driven, a consumer steering committee will be created to oversee all aspects of the project. The Grantee will first conduct small pilots and later a larger demonstration to evaluate and refine the model.

The Division of Developmental Disabilities will administer the project and coordinate with the Northern Arizona University, Institute for Human Development, to conduct the initial design and discovery tasks to create the model and engage in evaluation activities. Other partner agencies (Administration on Aging and Department of Health Services) will help review the project, identify ways to ensure that the model is sustainable, and implement model components as appropriate in their quality management systems.

Measurable outcomes and products of this project include (a) a consumer-run steering committee with a direct connection to the quality management system, (b) a set of consumer-identified characteristics of quality services, (c) a training curriculum for consumer-to-consumer assessment, (d) a cadre of peer quality reviewers, (e) pilot study and demonstration reports, and (f) a consumer-to-consumer model plan.

Ultimately, the project will help to improve services provided to people with disabilities in Arizona by offering a consumer perspective on the quality of services provided to individuals and families in their own homes. This new source of information will aid continuous quality improvement efforts for the target population.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

ARKANSAS

Grant Information

Name of Grantee Department of Human Services, Division of Aging and Adult

Services (DAAS)

Title of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$500,000 Year Original Funding Received 2004

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Subcontractor(s)

Contractor to be determined through RFP in first year of the grant.

Target Population(s)

Persons who participate in Arkansas's 1915(c) Home and Community-Based Services (HCBS) waivers.

- Develop a systemwide quality management (QM) strategy that will fulfill the State's commitment to ensure the health and welfare of HCBS 1915(c) waiver participants by implementing the CMS Quality Framework design features and quality functions.
- Develop an integrated data system that collects, analyzes, and generates relevant, useful, and timely QM information and activity.
- Design and implement a methodology to secure participant feedback information to apply quality assurance and quality improvement strategies for the State's HCBS waivers.

- Develop a comprehensive systemwide QM plan for all HCBS that can be replicated for all department services.
- Design and implement a single, automated data collection and analysis system for all HCBS waivers that generates reliable and timely reports to allow for informed program decisions and establishment of performance standards.
- Provide a framework for developing a comprehensive incident reporting system to determine trends and patterns of complaints, investigations, and outcomes.
- Design and implement participant feedback mechanisms to assess satisfaction with waiver services, identify participant outcomes, and assist the State in designing quality assurance and improvement strategies.
- Disseminate educational materials to support participants in directing their own services.
- Implement a peer-counseling and mentoring program for participants in consumer-directed HCBS waivers.

Abstract

The grant project represents a commitment by the Arkansas Department of Human Services (DHS) to (1) ensure the quality of the State's HCBS waivers, (2) develop quality management strategies for waiver services, and (3) produce a QM strategy for home and community services that address quality issues in each of the seven focus areas of the HCBS Quality Framework. At present, the State's HCBS quality assurance initiatives are unevenly developed across waiver programs with varying levels of automated data collection and tracking. The overarching goal of the project is to move HCBS quality assurance and improvement activities from the project or program level to a collaborative, interdepartmental commitment to ensure the health and welfare of all Arkansas waiver participants. DHS, with the Division of Aging and Adult Services as lead agency, will update and standardize quality assurance procedures across programs through the Quality Assurance and Quality Improvement (QA/QI) grant project.

Successful implementation of this project will result in the following measurable outcomes or products: (1) a sustainable systemwide QM Strategy that meets the requirements of the CMS Quality Framework; (2) a single, automated data collection system for all HCBS waivers that generates reliable and timely reports to allow for informed program decisions; (3) a QA/QI Task Force to provide consumer input on HCBS participant-defined measures of quality (in both services and service delivery) and participant outcomes; and (4) shortening of the response time between identification of quality problems and issues and their remediation.

FLORIDA

Grant Information

Name of Grantee Agency for Persons with Disabilities (APD)

Title of Grant A Customer Approach to Quality Management

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$475,000 Year Original Funding Received 2004

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Target Population(s)

Individuals with developmental disabilities (DD) and other stakeholders.

- Establish statewide quality management and leadership capacity.
- Improve organizational practices through proven effective quality improvement (QI) steps linked directly to organizational principles that support outcome achievement for service recipients.
- Ensure continuity and sustain achieved quality management practices.

- Establish statewide leadership capacity (trained consultants in each district) to assist with organizational change by (1) establishing and training district steering committees made up of key stakeholders to oversee and advise local QI initiatives; (2) providing consultation and technical assistance to services providers in revising organizational practices that best promote achievement of customer outcome expectations; and (3) providing education, consultation, and assistance to consumers, their families, and other stakeholders related to self-determination and customer satisfaction.
- Expand current quality assurance (QA) activities and capacity by training reviewers to use a
 consultation model for organizational change that will assist service providers to develop
 focused QI plans to enhance organizational practices targeted at achieving outcomes
 desired by people receiving services.
- Create organizational change for the Agency for Persons with Disabilities (APD) to operate and direct policy based on self-determination principles.
- Create district staff capacities for technical assistance and follow up on providers' organizational practices and overall quality management roles.
- Collaborate with the existing DD program structure in the use of Personal Outcome Measure (POM) Core Trainers and strengthen oversight.
- Sustain the initiative after the 3-year grant cycle through APD funding for ongoing consultation and measurement for a continuous QI cycle.

Abstract

The grant project involves a partnership effort between the APD (formerly the Department of Children and Families, Developmental Disabilities Program), the Council on Quality and Leadership, Delmarva Foundation, and the Agency for Health Care Administration. All four organizations have been involved in providing direction and resources for project development as well as identifying resources that will be dedicated to its implementation. The grant provides an opportunity for the newly established APD to institute quality management and service delivery structures consistent with the principles of self-determination. The overall goal for this project is to achieve, through improved quality management, a more person-directed service delivery system that will result in increased achievement of desired outcomes for people receiving services.

The focus of Florida's initiative will be to enhance the use of data from existing QA activities and realign district functions to build QI and quality management capacities throughout the service system. This effort will improve abilities at all levels of the system, including local service providers and stakeholders, district operational management, and state-level policy and funding partners. The project will specifically target QI and ongoing quality management for organizational change that supports self-determination and meeting customer expectations through the project's goals, activities, outcomes, and products.

Project funds will be spent at a higher rate early in the grant cycle to establish a strong infrastructure and as capacity is established, a smaller percentage of the grant will be spent each year with an expectation that sustainability is facilitated by a growth and shift in funding through both state and local DD program offices.

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MASSACHUSETTS

Grant Information

Name of Grantee University of Massachusetts Medical School

Title of Grant New England Quality Improvement Collaborative

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$499,226 Year Original Funding Received 2004

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National Association of State Directors of Developmental Disabilities Systems

Target Population(s)

People with mental retardation and/or developmental disabilities (MR/DD).

- Develop a common subset of standards, indicators, measures, and benchmarks to evaluate quality in New England state Home and Community-Based Services (HCBS).
- Increase access to information and resources regarding HCBS quality, best practices, and quality improvement for MR/DD system stakeholders in New England.
- Increase knowledge and skill in using objective and quantitative information as a quality management (QM) and quality improvement (QI) tool.
- Improve communication and collaboration to promote oversight of HCBS programs between state MR/DD agencies, state Medicaid agencies, and the CMS regional office.
- Develop and pilot methods for sharing system and provider quality indicators and performance with consumers and families to promote informed choice.

- Develop a series of reports, including (1) best practices, current gaps, and recommended standards and indicators for measuring and promoting quality in HCBS; (2) common measures and a proposed quality report format; (3) written guidelines for collecting a subset of objective quality data; (4) tools and methods, including a database for collecting and organizing the data; (5) a revised set of indicators and measures for participating states; (6) a standard database and accompanying instructions and guidelines; (7) quality reports with common elements and benchmarks across a minimum of five states; and (8) formal state policies, procedures, and protocols.
- Establish a virtual library of quality resources and tools available to New England stakeholders (consumers, families, providers, and personnel).
- Conduct teleconferences for New England state personnel and annual meetings for New England state MR/DD leaders, QM Committee representatives, and QA/QI personnel.
- Conduct training workshops for state staff on use of quantitative information and develop a resource workbook on effective use of objective and quantitative information for evaluating and improving the quality of HCBS.
- Establish a Quality Council in Massachusetts and conduct two annual conferences on QM.
- Conduct meetings for New England state MR/DD leaders and joint meetings with state Medicaid leadership; invite participation of CMS regional office personnel in development of standards, indicators, and measures; and to participate in training sessions.
- Develop prototype risk-adjusted performance/benchmark measures and reports.
- Develop consumer-friendly performance profiles and prepare a report for MR/DD leadership with recommendations on information consumers/families find most useful and on full implementation of provider performance profiles for use by consumers.

Abstract

The Commonwealth of Massachusetts, through the University of Massachusetts Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research, will develop a unique QI collaboration between the New England MR/DD state systems. The major outcomes for this grant project include the development of a set of common quantitative standards and quality indicators, comparative interstate benchmarks, standard algorithms for trend and pattern analysis of quality data, standardized evidence for use by the CMS Regional Office, National Core Indicators (NCI) enhancement, coordinated resource sharing, multistate training and learning opportunities regarding QI and the use of objective data and analytic methods of performance evaluation, increased partnership between the state Medicaid directors and the MR/DD system leadership, and improved methods for federal oversight of HCBS supports.

Consumers, families, service providers, and CMS regional personnel will be invited to participate with state personnel in the initial identification of standards and indicators to ensure that the design reflects what is important to HCBS participants, providers, and federal monitors. In addition, grant funds will be utilized to establish methods to facilitate the sharing of resources regarding quality and QI across the participating states and the training of stakeholders in the use of quantitative information and methods for consumer use of objective quality information, including prototype provider profiles.

NEBRASKA

Grant Information

Name of Grantee Nebraska Department of Health and Human Services

Title of Grant Quality Assurance and Quality Improvement System in Home and

Community Based Services

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$470,000 Year Original Funding Received 2004

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Target Population(s)

Consumers receiving services through the Aged and Disabled Home and Community-Based Services (HCBS) waiver, which covers populations across the lifespan.

- Develop an integrated and comprehensive quality management (QM) system (at state and local levels) based on the CMS HCBS Quality Framework incorporating expanded consumer involvement.
- Implement a tool mirroring the CMS Participant Experience Survey to assess children's families' satisfaction with services.
- Implement risk assessment tools/process to ensure consumer health and welfare while allowing self-direction and consumer decision making.

- Establish a Quality Council that includes consumers to serve as an advisory group.
- Create data collection protocols for quality monitoring.
- Develop written protocols for consumer participation in the Participant Experience Survey.
- Develop, implement, and analyze results of a Family Participant Experience Survey.
- Establish a Web-based feedback and incident reporting system, with accompanying reports and protocols for linking information with the regulation and licensure system.
- Develop and implement a medication risk process including a pharmacist referral protocol and corrective action process.
- Implement the MDS-Home Care instrument as a level-of-care evaluation and care planning tool for aged persons and persons with disabilities.

Abstract

The purpose of the grant project is to develop a system of supports and services that builds quality into the design of program operations, including a QM strategy that involves real-time methods of feedback and information gathering; involves consumers, families, and advocates in active roles; and makes effective use of QM processes to guide system improvement. This grant will target consumers receiving services through the Aged and Disabled HCBS waiver, which covers populations across the lifespan.

This project will integrate and enhance current quality assurance efforts into a coordinated, comprehensive QM system that is aligned with the CMS HCBS Quality Framework. Three key issues will be addressed to improve current processes:

- Consumer roles will be expanded using innovative strategies to increase their participation in all stages of the QM process.
- QM analysis, reporting, and follow-up processes will be enhanced, resulting in effective reporting and responsive actions on improvement recommendations.
- A medication assessment process and a Family Participant Experience Survey will be developed.

NEW HAMPSHIRE

Grant Information

Name of Grantee New Hampshire Department of Health and Human Services

Title of Grant Enhancing New Hampshire's Quality Assurance and Quality

Improvement System

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$498.988 Year Original Funding Received 2004

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Subcontractor(s)

To be determined.

Target Population(s)

Individuals with physical or mental disabilities, chronic illness, or older adults.

- Design and implement a participant-centered and participant-directed interdepartmental quality assurance (QA) and quality improvement (QI) infrastructure for waiver programs and other Medicaid and state-funded services under the long-term care (LTC) system.
- Adopt a structured waiver operations business plan to streamline processes, expand clinical expertise in community-based support programs, and increase the level of quality services provided to waiver participants.
- Develop an automated system that will perform multiple clinical management tasks and interface with the State's Medicaid reimbursement system.
- Engage Home and Community-Based Services (HCBS) participants and include their perspectives in active development, evaluation, and monitoring of the HCBS and system.
- Adopt a formal plan for a risk management and incident reporting system that serves Home and Community Based Care-Elderly and Chronically III (HCBC-ECI) waiver participants.
- Adopt a systematic approach to measure participants' satisfaction with services and system performance at regular intervals to guide improvements for the HCBC-ECI waiver program.

- Design and implement standardized quality management for all HCBC waivers and throughout the Department of Health and Human Services (DHHS), Division for Community Based Care Services (DCBCS), that includes vision and mission statements; principles, goals, and objectives; operating and system performance standards; a training curriculum and evaluation; and a DHHS, DCBCS quality Web site.
- Improve internal processes and response to consumer eligibility, assessment, and service provision that includes a list of competencies for nurse and case manager roles, protocol manuals, and a training matrix.
- Develop an automated clinical assessment and management tool and customized training manuals to improve system performance.
- Improve services provision and HCBC-ECI participant satisfaction, as determined by internal measures, claims data, and a Participant Experience Survey, and establish a formal complaint process.
- Establish a Quality Council that will form work groups to address specific issues, and design and produce an HCBC-ECI Consumer Handbook, a consumer/professional Web site, and fact sheets for specific information.
- Develop a formal risk management protocol and training module and develop a critical incident tracking and review system.

Abstract

The New Hampshire DHHS, through the Bureaus of Continuous Improvement and Integrity (BCII) and Elderly and Adult Services (BEAS) proposes to institutionalize a continuous QI culture and management system at the department level that impacts all HCBS waiver programs as well as other Medicaid and state-funded services for those citizens who have a disability or long-term illness. Additionally, DHHS proposes to initiate selective QA/QI activities that are specific to the HCBC-ECI waiver program that is administered by the BEAS and transfer the knowledge and products to other waiver programs.

These two-tiered goals provide an opportunity to advance the department's new leadership and reorganization efforts that are aimed at generating operational and fiscal efficiencies, increasing program integrity, and building a permanent system of ongoing program monitoring and continuous QI. All of these efforts involve enhanced collaboration with community stakeholders, with the foremost challenge of expanding the role of participants and family representatives in designing, developing, and evaluating the system and its performance.

The project will enable the State to create a fundamental change in the DHHS quality management system and to develop or improve community-based services for the HCBC-ECI waiver program in multiple ways. A participant-centered and participant-directed departmental quality management infrastructure will be secured. This will include a continuous QI culture and department-wide standards for quality management. The HCBC-ECI program will realize operational efficiencies; improved assessment and service planning; an ongoing method for capturing participants' level of satisfaction with services and supports; and the active, meaningful involvement of participants at all levels of system planning and evaluation.

NEW JERSEY

Grant Information

Name of Grantee New Jersey Department of Human Services, Division of

Developmental Disabilities (DDD)

Title of Grant Building a Quality Management Infrastructure for New Jersey's

Division of Developmental Disabilities HCBS Waiver

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$475,000 Year Original Funding Received 2004

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New Jersey Association of Community Providers

Target Population(s)

Persons with developmental disabilities (DD).

- Develop an interactive training CD that helps Home and Community-Based Services (HCBS) providers to build quality management (QM) systems.
- Create an integrated QM system based on the CMS HCBS Quality Framework that is consistent with Division of Developmental Disabilities (DDD) information technology (IT) strategy.
- Expand the DDD Web site to involve the entire DD community in using timely and accurate information for QM.

- Design and implement an interactive training CD comprising three training lessons. Lesson 1 teaches providers how to create a Continuous Quality Improvement (CQI) Plan; lesson 2 teaches providers how to use the Plan, Do, Check, Act cycle, following the development of their CQI Plan; and lesson 3 introduces CMS's HCBS Quality Framework and provides specific examples on how to achieve the impending quality expectations.
- Restructure the Quality Improvement Steering Committee system to enhance family and participant involvement in program planning.
- Create a Web-based system of data collection to meet the Interim Procedural Requirements and the Division's quality expectations through browser-based interfaces with a single integrated database to support an integrated QM system.
- Develop new business processes to ensure that providers and DDD staff are accountable for timely and accurate quality assurance/quality improvement (QA/QI) data collection and entry, including a revised and more meaningful data reporting format.
- Identify and implement a consumer satisfaction survey instrument.
- Expand the DDD Web site to provide enhanced support for the Quality Improvement Regional and Central Steering Committees and for browser-based surveys to facilitate consumer input.

Abstract

The New Jersey DDD has been serving developmentally disabled persons through the Community Care HCBS waiver, relying heavily on group homes and day habilitation programs as its primary service models. Since September 2002, DDD has been pursuing a broad program of system change and planning to expand choices with a community-based, self-directed services option called "Real Life Choices," which uses an objective assessment to allocate an individual budget based on support needs and a person-centered planning model built on Essential Lifestyle Planning to assist participants to purchase supports they choose to achieve desired personal outcomes. DDD has expanded the array of supports for individuals living at home and added resources for participants transitioning from special education.

The current DDD QA/QI program for the Division began in 2001 with the creation of an Assistant Director position in the central office to oversee and coordinate quality enhancement activities and the development of a QA/QI staff. The quality program has been involved in planning QM systems for Real Life Choices, helping to develop a new model for the plan of care.

However, the quality program has been hampered by several barriers, including (1) the language and models of facility-based services that dominate the culture of most DDD staff and providers, (2) QA/QI activities that are fragmented and rely on paper systems for data collection and analysis, and (3) a need for broader family and participant involvement in QM. This grant project aims to upgrade the QA/QI system in a manner consistent with the CMS HCBS Quality Framework by changing the existing culture to support person-centered community-based service models, instituting an integrated QM system supported by browser-based data management, and revamping the existing Quality Improvement Steering Committee system to provide more consumer and family input.

VERMONT

Grant Information

Name of Grantee Agency of Human Services, Department of Disabilities, Aging, and

Independent Living (DAIL)

Title of Grant Quality Assurance and Quality Improvement in Home and

Community Based Waiver Services

Type of Grant Quality Assurance and Quality Improvement in Home and

Community Based Services

Amount of Grant \$499,709 Year Original Funding Received 2004

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Target Population(s)

Persons with disabilities who are eligible for Home and Community-Based Services (HCBS) waivers within the Department of Disabilities, Aging, and Independent Living (DAIL).

- Develop a Quality Management Plan (QMP) addressing all HCBS waiver programs.
- Include consumers, their families, and community members as active participants in Vermont's quality management activities.
- Develop and implement quality management activities to improve supports and services to Vermont's elder citizens and those with disabilities.
- Develop a technology-based system to manage and analyze critical incidents.
- Develop an ongoing system of technical assistance to all providers of services across age and disability and provide training to service recipients and relevant staff.

- Assess the current quality management systems within the HCBS waivers, develop new service standards, and implement the strategies outlined in the QMP within the HCBS waivers.
- Develop quality indicators with consumers and families, and contract with consumer and family advocacy organizations to convene focus forums to seek feedback on the quality indicators.
- Develop methods to directly engage consumers and their families in a discovery process that elicits their experiences with the services.
- Include direct consumers on state quality review teams; recruit, hire, and train two 0.5 FTE consumers; and evaluate effectiveness of consumers in assessing the quality of services for other consumers.
- Develop methods to include consumer and family involvement in the development of service provider remediation plans, and utilize consumers and families to provide training during implementation of the QMP.
- Research promising quality assurance practices and methods of gathering data to determine viable methods, develop and implement multiple methods of discovery, develop technical assistance manuals for information gathering activities, and implement service provider agreements.
- Develop and implement relevant and timely methods of remediation, design a system with participant safeguards, and develop formats for remediation plans that include consumer and family input.
- Research, develop, and implement methods of public reporting on the quality of services and develop information that includes data from existing sources and methods developed as a result of grant activities.
- Research Web-based methods of tracking and reporting critical incidents, train all relevant providers on the uses of the system, and develop reporting and follow-up formats and protocols for critical incidents across all waivers.
- Assess the training needs of stakeholders involved in the implementation of the new QMP, develop an initial training plan to "roll out" the plan, and provide training to stakeholders on the plan.
- Develop a system of technical assistance to service providers in the delivery of quality services and identify training needs and develop training plans with service providers.

Abstract

The grant project will develop a comprehensive quality management system across the HCBS waivers within DAIL. This system will be based on the expectations contained in the CMS Quality Framework. These home and community services are provided to individuals with developmental disabilities, elders, individuals with physical disabilities, and individuals with traumatic brain injuries.

The goals of the project are to effect enduring systems change that fulfills Vermont's commitment to ensure the health and well-being of individuals receiving an HCBS waiver within Vermont's community-based, long-term care system.

ARKANSAS

Grant Information

Name of Grantee Department of Human Services, Division of Aging and Adult

Services (DAAS)

Title of Grant Affordable Housing with Long-Term Supports

Type of Grant Integrating Long-Term Supports with Affordable Housing

Amount of Grant \$900,000 Year Original Funding Received 2004

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Subcontractor(s)

NCB Development Corporation (NCBDC)

University of Arkansas at Fayetteville

School of Architecture

Target Population(s)

All persons who are currently residents of nursing facilities and those at risk of nursing facility placement.

- Establish an affordable housing with long-term supports (AHLTS) workgroup consisting of consumers, providers, and stakeholders to guide grant activities.
- Develop a needs and resource analysis for AHLTS.
- Create and implement an adult foster care (AFC) initiative and an affordable assisted living (AAL) expansion initiative.
- Develop tools and technical assistance for the AFC and AAL initiatives and implement demonstration projects.
- Develop and implement universal design standards for state implementation to promote housing accessibility statewide.
- Provide training and dissemination on grant activities to consumers, providers, developers, and state staff to transfer knowledge and create sustainable capacity.

- Develop state infrastructure to support innovative settings offering high levels of care that are sustainable, easily integrated into neighborhoods, and viable in small, rural markets.
- Formulate efficient business models to foster the rapid development of innovative AFC and AAL initiatives.
- Implement development financing, demonstration projects, and a registry of affordable supportive housing to promote access to a wide variety of community-based options.

Abstract

The overall goals of this project being administered by the Division of Aging and Adult Services (DAAS) under the Arkansas Department of Human Services will be to (1) partner with persons with disabilities of all ages and other stakeholders in a workgroup to identify current and innovative models of AHLTS, create a short-term and a 10-year plan to meet Arkansas's needs, and implement the plan; (2) conduct a county-level needs and resource analysis for community-based care options to direct state activities and provide planning estimates; (3) address the immediate need for affordable AFC and assisted living options by implementing and modifying policy, program, and development infrastructure to facilitate their creation; (4) create universal design standards for state implementation to promote housing accessibility statewide; (5) provide financial and development tools (including universal design standards), technical assistance, and financing to create and help replicate demonstration projects; (6) provide training and dissemination on grant activities to consumers, providers, developers, and state staff to transfer knowledge and create sustainable capacity; and (7) develop and maintain a housing registry to facilitate linkages to community-based sheltering arrangements.

Some of the major outcomes include meaningful consumer involvement in state planning efforts leading to improvement in consumer satisfaction; development of state infrastructure to support innovative settings offering high levels of care that are sustainable, easily integrated into neighborhoods, and viable in small, rural markets; formulation of efficient business models to foster the rapid development of these innovative models; and implementation of development financing, demonstration projects, and an affordable supportive housing registry to promote access to a wide variety of community-based options.

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DISTRICT OF COLUMBIA

Grant Information

Name of Grantee District of Columbia Department of Mental Health

Title of Grant Building Capacity to Integrate Access to Housing Supporting

Home Ownership in DC's Medicaid Programs Serving Individuals with Mental Illness. Mental Retardation and Developmental

Disabilities

Type of Grant Integrating Long-Term Supports with Affordable Housing

Amount of Grant \$812,004 Year Original Funding Received 2004

202-673-7597

Contact Information

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Subcontractor(s)

HCBS Strategies and Marialice Williams

Target Population(s)

Persons dually diagnosed with mental illness and mental retardation/developmental disabilities (MR/DD) and youth with severe mental illness that are transitioning from foster care.

- Integrate access to Medicaid-funded supports with access to housing.
- Revise Medicaid regulations that prevent the sharing of staff in supportive living arrangements.
- Identify individuals with dual diagnoses of mental illness and developmental disabilities, and match them with potential homes.
- Identify individuals with severe mental illness who are transitioning from foster care, and match them with potential homes.

- Develop and implement a system of procedures to integrate access to Medicaid-funded supports with access to housing.
- Develop and secure approval for modifications to the MR/DD waiver to pay for the transition costs of individuals moving out of an Intermediate Care Facility for Mental Retardation to community housing.
- Design and implement a system of mechanisms for matching individuals who can jointly live together in community-based housing.
- Develop and secure approval for revised regulations for Medicaid-funded services to allow the pooling of supportive living services.
- Develop and implement a program to assist individuals in purchasing a home, including credit counseling, assistance in locating property, securing supportive services, moving, and training in the responsibilities of home ownership.

Abstract

The Department of Mental Health (DMH) will establish a mechanism to link an application for mental health services funded under the District's Mental Health Rehabilitation Services with an application for housing from the DC Housing Authority. DMH will also work to remove the barriers in current regulations regarding shared housing.

The grant will involve two parallel pilot demonstration programs. DMH has entered into an agreement with the DC Housing Finance Agency that has resulted in the identification of a substantial number of housing units that can be used for this effort. The addition of identified housing units greatly increases the likelihood that the proposed demonstrations will be successful. The two pilot demonstrations will function as follows:

- The Grantee will identify 90 consumers who are enrolled in both the Department of Human Services/Mental Retardation and Developmental Disabilities Administration and DMH. The demonstration will move at least 5 of these individuals into independent housing options.
- The grant will also be linked with the DMH's Real Choice Systems Change EPSDT Portals Grant that has the goal of improving supports to youth with mental health issues who are transitioning out of foster care. The EPSDT Portals Grant has succeeded in establishing collaboration between DMH and the Child and Family Services Agency to identify barriers to adequately support these vulnerable individuals. By combining the efforts of these two grants, a pilot program will be established to support independent living arrangements for approximately 10 to 15 transition-age people ready to leave the foster care system.

For both these demonstrations, the grant will fund the following activities: (1) the recruitment of pilot participants, (2) the identification of the housing needs of the program participants, (3) the identification of housing, (4) the payment of costs associated with transitioning to an independent housing option, and (5) the establishment of mechanisms that will allow the pilot program participants to own their homes.

MISSISSIPPI

Grant Information

Name of Grantee The University of Southern Mississippi, Institute for Disability

Studies

Title of Grant Project BRIDGE

Type of Grant Integrating Long-Term Supports with Affordable Housing

Amount of Grant \$720,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Medicaid-eligible individuals with disabilities and/or long-term illnesses requiring long-term supports and housing services.

- Prepare consumers and other key shareholders to set an agenda by developing a comprehensive plan for systems change resulting in the building of an infrastructure that integrates and coordinates long-term supports and housing services.
- Adopt an action plan that will guide systems change efforts to develop the State's infrastructure in meeting the needs of individuals requiring long-term supports.
- Field test the action plan by supporting two community-based pilot demonstration projects.
- Design and implement a program and outcomes-based evaluation system for defining data needs and purpose; defining audiences for data reports; identifying sources of data; defining research methodology and instrumentation for both quantitative and qualitative measures; establishing a data storage system; and collecting, analyzing, and reporting data.

- Establish a statewide BRIDGE Action Council to guide the development of an agenda for systems change.
- Provide ongoing training and technical assistance to members of the BRIDGE Action Council regarding best practices on affordable and accessible housing, long-term support, the coordination and integration of long-term support and housing, community inclusion, quality-of-life issues, self-determination and person-centered planning, transition, and exemplary models of community housing programs from across the United States that provide for long-term support.
- Conduct a statewide focus group with Medicaid-eligible consumers from each region to determine the performance of Mississippi's current system in meeting the needs of individuals with disabilities requiring long-term supports who want to live in their community in the housing arrangement of their choice.
- Analyze information from the statewide focus group.
- Develop a statewide action plan that outlines recommendations for interagency coordination of policies, resources, and services that result in the development of infrastructure in meeting the needs of individuals.
- Select two regional communities to serve as model sites to test the action plan and serve as
 office locations for housing support coordinators.
- Develop local action plans (that support the statewide plan) that result in the development of local infrastructure that meets the needs of individuals requiring long-term supports.
- Transition individuals from institutional settings to affordable housing and stable long-term supports in the community by implementing the Home of Your Own (HOYO) model.
- Develop and implement program evaluation measures to ensure the effectiveness and efficiency of Project BRIDGE in meeting designated goals and objectives.
- Design a quality of life, outcomes-based evaluation system.

Abstract

The Institute for Disability Studies (IDS), Mississippi's University Center for Excellence located at the University of Southern Mississippi, has been endorsed by the Executive Director of the Governor's Office, Division of Medicaid for the State of Mississippi as the lead agency for the Real Choice Systems Change Grant in the area of integrating long-term supports with affordable housing. IDS will work with the Division of Medicaid and other key stakeholders, including Medicaid-eligible individuals with disabilities (and their families) requiring long-term supports who want to live in their community in the housing arrangement of their choice.

Project BRIDGE is designed to prepare consumers and other key stakeholders to set an agenda through the development of a comprehensive plan for systems change resulting in the building of an infrastructure that integrates and coordinates long-term supports and housing services.

NEW HAMPSHIRE

Grant Information

Name of Grantee University of New Hampshire, Institute on Disability

Title of Grant Home Care Connections

Type of Grant Integrating Long-Term Supports with Affordable Housing

Amount of Grant \$899,954 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

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Target Population(s)

Older adults with disabilities who are Medicaid-eligible, especially those with mental illness/dementia/Alzheimer's disease.

- Increase access to affordable housing and the supports needed to ensure that older adults reside in the community or in the housing arrangement of their choice.
- Bridge the gap between housing and community-based support providers by increasing communication in order to implement a seamless system of care.
- Develop and implement a comprehensive, statewide training and education initiative for housing and service providers that ensures the integration of affordable housing and longterm supports.

- Develop a planning and implementation process and a data collection and evaluation tool, and collect baseline data for progress measurement.
- Develop a detailed System of Care Operations Manual to include core values, guiding principles, partnerships, governance and accountabilities, policy and procedures, and evaluation and outcomes.
- Identify a "best practice" demonstration project through an RFP process that will be developed with one of the 19 local housing authorities to integrate housing and long-term supports for 10 individuals with mental illness/dementia/Alzheimer's disease.
- Develop formal partnerships between housing and service providers and state agencies resulting in a Memorandum of Understanding (MOU) that will outline the commitment to work collaboratively on the system of care for older adults.
- Develop a project Web registry thereby enhancing, updating, and maintaining the Accessible Housing Registry Web site created by Granite State Independent Living and providing a Web-based resource network.
- Develop a Senior Guide for People with Mental Illness and/or Dementia/Alzheimer's Disease to include regional housing and long-term supports information.
- Identify knowledge gaps; design a cross-training curriculum; produce and disseminate training materials in written, DVD, and other formats; and provide statewide and regional training based on identified needs of housing and service providers.

Abstract

The overall goal of the project is to develop a system that encourages and fosters the collaboration and cooperation of existing housing and support networks. An infrastructure will be established that represents two levels of input and collaboration—one for resource and policy development and a second to coordinate hands-on delivery of services. Both should reflect the ethnic and cultural diversity of the community. The process will include six key areas:

- Development of Partnerships—including the involvement of a Consumer Advisory Council in the planning, implementation, and evaluation of the project and the development of an MOU between housing partners and the Divisions of Elderly and Adult Services and Behavioral Health.
- Development of a System of Care—to include four regional collaboratives comprising consumers, housing and service providers, and other community organizations; natural supports; and a state-level, older-adult supported housing collaborative composed of state agencies, housing organizations, and advocacy organizations.
- Coordination Activities—including the hire of two housing support coordinators, one to be located with a housing partner and one with a state agency that coordinates service delivery.
- Education and Training—development and implementation of a cross-training initiative targeted to housing providers and service providers.
- Implementation of Specific Demonstration Projects—including working with identified public housing site(s) to develop a replicable model that permits elderly residents to age-in-place and avoid or delay the need for institutionalization.
- Evaluation and Quality Assurance—including the development of effectiveness and
 efficiency goals and indicators, qualitative and quantitative measures of improved access to
 and capacity of accessible and affordable housing and long-term care supports, and
 measurement of evidence of infrastructure changes at the state and local levels.

NORTH CAROLINA

Grant Information

Name of Grantee North Carolina Department of Health and Human Services

(DHHS)

Title of Grant Integrating Long-Term Supports with Affordable Housing in North

Carolina

Type of Grant Integrating Long-Term Supports with Affordable Housing

Amount of Grant \$775,123 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

School of Government (formerly Institute of Government), University of North Carolina at Chapel Hill

Center for Urban and Regional Studies, University of North Carolina at Chapel Hill

NC Housing Coalition, Raleigh, NC

NC Justice and Community Development Center, Raleigh, NC

Target Population(s)

Low-income adults with disabilities and long-term illnesses who would benefit from access to supportive housing.

- Develop infrastructure for cross-agency collaboration within the human services system.
- Implement the Demonstration Rental Subsidy Program.
- Develop infrastructure for efficient working relationships between local services agencies, consumers, and housing providers.
- Educate partners on legal rights and responsibilities of tenancy, fair housing, and reasonable accommodations.
- Integrate long-term supports.
- Expand housing expertise among consumers, advocates, and local human services agencies.

- Map local and regional service areas of the North Carolina Department of Health and Human Services (DHHS) agencies to identify responsible parties.
- Organize local Housing Support Committees and develop materials and provide training on existing low-income housing tax credit developments.
- Develop written policies, procedures, and documentation for a Demonstration Rental Assistance Program.
- Develop protocols for sharing information on tenants for the purpose of establishing eligibility, while at the same time ensuring confidentiality.
- Develop handbooks and conduct training on fair housing and reasonable accommodations for persons with disabilities for housing providers, human services agencies, and consumers.
- Develop local Support Resource Guides for consumers, service providers, and housing providers.
- Develop local housing needs assessments; compile and update annually to document statewide need.

Abstract

DHHS will partner with the NC Housing Finance Agency (HFA) to work with consumers, housing providers, and local service providers to build infrastructure between the affordable housing system and the human services system to integrate long-term supports with affordable housing by accomplishing the following goals:

- Develop processes, procedures, and monitoring mechanisms to operationalize the DHHS and HFA partnership in the Low-Income Housing Tax Credit (LIHTC) program, including implementation of a state-funded rental assistance program demonstration.
- Develop positive working relationships between housing providers and local service agencies to reinforce the shared goal of assisting tenants to access and maintain affordable housing.
- Ensure access to the array of available community services and long-term supports, including both Medicaid and non-Medicaid funded services, that individuals may need to live successfully in the community.
- Maximize this opportunity to expand the housing knowledge of the human services system
 to improve collaboration with the other components of the housing system to better serve
 persons with disabilities.

The grant project will help the State bring needed staff capacity to local communities to organize a collective response to the LIHTC opportunity and expand the housing knowledge and capacity of the local human services system. At the end of the grant, local cross-agency Housing Support Committees will be working in local communities to ensure that persons with disabilities have access to the LIHTC units and to services they may need to live successfully in the community. Housing needs of persons with disabilities will be documented and represented in local and state affordable housing activity. The demonstration rental subsidy program will provide assistance to qualified tenants, and its findings will be documented. In addition, a minimum of 45 individuals will have successfully transitioned from institutional settings to affordable housing in the community.

OREGON

Grant Information

Name of Grantee State of Oregon Department of Human Services (DHS)

Title of Grant Expanding Housing and Supports for Oregonians

Type of Grant Integrating Long-Term Supports with Affordable Housing

Amount of Grant \$828,232 Year Original Funding Received 2004

Expected Completion Date September 2008

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Subcontractor(s)

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Target Population(s)

Medicaid-eligible individuals of all ages with physical, developmental, and psychiatric disabilities.

- Integrate the use of assistive technology in affordable housing to enable people with physical and developmental disabilities to live more safely and achieve greater independence.
- Reform outdated service financing infrastructure to enable individuals with psychiatric disabilities to obtain the supports they need to live more safely and successfully.
- Research and address assistive technology barriers concerning Oregon Administrative Rules and Statutes for affordable housing programs.

- Produce a report on available assistive technology, systemic barriers, and a blueprint for system change.
- Establish a resource clearinghouse on assistive technology.
- Produce a resource manual to be distributed to at least 200 service and housing providers statewide on integrating long-term supports with affordable housing for people with psychiatric disabilities.
- Create a new Medicaid funding mechanism for "supportive housing services" for people with psychiatric disabilities within existing State Plan services.
- Develop at least five test sites implemented for persons with psychiatric disabilities to demonstrate strategies outlined in the new resource manual and reforms, and at least three demonstration sites using assistive technology.
- Provide training at regional sites to 500 participants.
- Initiate at least 12 affordable housing projects by the end of the grant term that use developed strategies to integrate supports with housing.

Abstract

Over the years, Oregon has exhibited leadership in providing community-based services to Medicaid-eligible people with disabilities. Oregon's achievements in implementing assisted living for seniors are well recognized. Similar shifts to community-based care for people with developmental and psychiatric disabilities have occurred, and impressive partnerships among service and housing providers are well established. However, there is a need for infrastructure mechanisms that incorporate both (1) systematic consideration of consumers' assistive technology needs in individual planning related to housing and long-term supports, and (2) avenues to effectively connect consumers, technical assistance providers, and property managers who implement long-term supports in housing.

Expanding Housing and Supports for Oregonians will implement infrastructure improvements to remove barriers that prevent people with physical, developmental, and psychiatric disabilities from residing in the community housing of their choice. The lead agency for the project is the Oregon Department of Human Services (DHS). DHS is the single state Medicaid agency and manages the State Section 1915(c) Home and Community-Based Services (HCBS) waiver and the Section 1115 Managed Care waiver. The project is a collaborative effort of two offices within DHS—the Office of Mental Health and Addiction Services (OMHAS) and Seniors and People with Disabilities (SPD)—which will bring people together on a cross-disability basis to formulate ways to integrate supports with housing. The Oregon Housing and Community Services (OHCS) Department will actively participate in the grant, and meaningful involvement by consumers and other key stakeholders will be ensured through the Stakeholders Coordinating Council.

Grant activities include completing analyses of existing and proposed resources and strategies, planning and implementing identified infrastructure changes, developing resource materials to support changes, providing training and technical assistance, and transitioning the grant accomplishments to insure sustainability. The successful systems reforms will be accompanied by modifications of service financing systems that reimburse desired services. Evaluation will include both ongoing formative evaluation throughout the project to ensure timely completion of project activities and summative evaluation of project impact and effectiveness.

PENNSYLVANIA

Grant Information

Name of Grantee Governor's Office of Health Care Reform

Title of GrantIntegrating Long-Term Supports with Affordable HousingType of GrantIntegrating Long-Term Supports with Affordable Housing

Amount of Grant \$893,340 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

Pennsylvania Housing Finance Agency

Diana T. Myers and Associates

Target Population(s)

Persons of all ages with disabilities.

- Create state and local infrastructures and systems that will increase access to affordable, accessible housing currently available for consumers with long-term care (LTC) needs.
- Expand the supply of affordable and accessible housing available to persons needing LTC services and facilitate the allocation of new units for local nursing home transition programs and diversion processes such as Community Choice.
- Develop an inventory of publicly funded accessible housing and a real-time listing of vacant, affordable, accessible housing.
- Complete a needs assessment of present and future accessible and affordable housing stock for persons with LTC support needs to be able to live in the community.
- Develop a state strategic plan for the development of affordable, accessible housing and mechanisms to connect such housing with persons needing LTC during the next decade.

- Identify, design, and test interventions to address organizational, programmatic, and institutional barriers that prevent access to affordable and accessible housing for persons needing LTC services.
- Work with the Pennsylvania Housing Finance Agency (PHFA) to encourage developers to allocate 10 percent of units as accessible housing and conduct demonstration projects in HUD-funded housing complexes that will identify best practices in providing LTC services.
- Work with PHFA and local housing authorities to provide Section 8 vouchers that will make accessible housing units available to nursing home transition and diversion clients.
- Develop specifications for an inventory of publicly funded accessible housing, contact all HUD-funded housing authorities and PHFA-financed units for information, and compile and post the inventory on the PHFA Web site.
- Develop and post a database system on the PHFA Web site that will allow housing managers to update housing vacancy information in real time.
- Develop specifications for a needs assessment of accessible and affordable housing stock for the next fiscal year and the next decade and conduct the assessment at the county level.
- Develop specifications for a state strategic plan for the development of affordable, accessible housing after review of the inventory and needs assessment, hold five regional meetings to procure local input, and draft plan and finalize after public comment.

Abstract

Pennsylvania is a large, populous state with the second highest percentage of elderly of any state. In 2003, 72 percent of Pennsylvania's long-term care Medicaid budget went to nursing homes, while Pennsylvanians rated nursing facilities as the last place they wanted to receive LTC services. In order to provide housing to support this preference, the State faces a number of challenges, the foremost being the lack of a statewide system to ensure coordination between LTC supports in the community and accessible, affordable housing. Other challenges include an inadequate supply of affordable and accessible housing, the lack of a single entity that systematically addresses the barriers people with LTC support needs face in finding accessible and affordable housing, and the lack of effective mechanisms to connect persons needing LTC supports with the accessible housing that exists. A statewide needs assessment of the amount, location, and rental subsidy needed to provide affordable, accessible housing in the State is also needed.

The State has begun to address these issues through Regional Housing Coordinators in five regions and Local Housing Options Teams in 18 locations helping to identify, develop, and facilitate access to housing options for people with disabilities. In addition, a state-funded nursing home transition program is already in operation. The grant project will extend these efforts into a statewide initiative by (1) creating state and local infrastructures to help link consumers of LTC supports to affordable, accessible housing options and eliminating the barriers that prevent them obtaining such housing; (2) working with public housing authority partners to expand the supply of affordable and accessible housing and to connect those units to nursing home transition and diversion project clients; (3) developing an inventory of Pennsylvania's publicly funded accessible housing, including a real-time listing of vacant, affordable, accessible housing; (4) performing a needs assessment of present and future accessible and affordable housing stock; and (5) developing a state strategic plan for the development of affordable, accessible housing for the next decade.

VERMONT

Grant Information

Name of Grantee Agency for Human Services, Department of Disabilities, Aging and

Independent Living (DAIL)

Title of Grant Integrating Long-Term Supports with Affordable Housing

Type of Grant Integrating Long-Term Supports with Affordable Housing

Amount of Grant \$900,000 Year Original Funding Received 2004

Contact Information

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Real Choices Supportive Housing

Project Director

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Real Choice Systems Change Project Director VT Department of Disabilities, Aging and

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Subcontractor(s)

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Target Population(s)

Elders and adults with disabilities who require long-term supports coordinated with affordable and accessible housing and are dually eligible for Medicare and Medicaid.

- Improve access to housing by preserving, developing, and enhancing supportive housing projects.
- Establish medication assistance best practices to support critical early aging in place for elderly or disabled adult residents in unlicensed congregate housing.
- Determine viability and complete planning to co-locate two Program for All-Inclusive Care for the Elderly (PACE) sites with affordable housing.

- Provide consultation services through Cathedral Square Corporation (CSC) to a minimum of ten supportive housing projects that can or will serve a significant number of Medicaid beneficiaries and medically needy persons.
- Build the knowledge base of CSC regarding issues that challenge the development or operation of affordable supportive housing settings.
- Provide early planning and service development support to an affordable assisted living demonstration project sponsored by a public housing authority.
- Establish medication assistance best practices for unlicensed supportive housing.
- Implement pilot studies of medication assistance best practices and conduct evaluations.
- Through training, provide housing, service, and care providers with the information and skills they need to implement medication assistance best practices.
- Transfer enduring knowledge and resources of medication assistance best practices to programs and partnerships that will sustain the work after the life of this grant.
- Conduct planning activities, including a feasibility study, to coordinate PACE sites within affordable and accessible housing in the greater Burlington and Rutland areas.
- Collaborate with the Religious Hospitallers of Saint Joseph-Vermont (RHSJ) to determine the feasibility of co-locating the PACE site at its convent and, if feasible, convert the existing convent into affordable housing.

Abstract

The Department of Disabilities, Aging and Independent Living (DAIL) has been designated by the Vermont Agency for Human Services and its state Medicaid Director to lead the grant project. DAIL is the state department charged with accomplishing the shift of nursing home resources to community services. Each of the grant project initiatives is strongly supported by public/private partnerships and will benefit from the guidance and technical assistance of a workgroup that shall include partners, stakeholders, and consumers.

DAIL has contracted with CSC, as lead developer, management, and operations consultant to the housing network, regarding elders and adults with disabilities and will work with community housing partners including the Vermonters Coming Home partnership.

JSI Research & Training Institute has been retained by DAIL to research, analyze, recommend, help establish, and evaluate medication assistance best practices to be implemented within unlicensed congregate housing to support aging in place and consumer satisfaction for residents of those settings.

Vermont PACE will lead focus groups with seniors to evaluate proposals that plan for two PACE sites that will coordinate services with supportive housing to meet later, high care needs.

The grant project's measurable outcomes include (1) the number of housing sites and Medicaid beneficiaries assisted (and potentially assisted); (2) a public housing agency plan for a first demonstration of affordable assisted living in public housing; (3) adoption by the State of medication assistance best practices in unlicensed housing sites; (4) consumer satisfaction with the suggested best practices; (5) provider satisfaction that they have the knowledge, skills, and coordination with others to do their part to support medication assistance; and (6) feasibility studies for two sites completed by PACE.

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ILLINOIS

Grant Information

Name of Grantee Illinois Department of Aging

Title of Grant Illinois' Initiatives to Increase Community Services for Frail Elderly

Type of Grant Rebalancing Initiative

Amount of Grant \$300,000 Year Original Funding Received 2004

312-814-4179

Contact Information

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Subcontractor(s)

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University of Illinois at Chicago, Institute for Disability and Human Development

Target Population(s)

Seniors residing in nursing facilities who are eligible to reintegrate back into the community, seniors wanting to remain in the community but need additional support, and caregivers in need of information or services in order to help the senior remain in the community.

- Determine the capacity of the current long-term care (LTC) service system to identify deficiencies and any barriers to filling gaps.
- Identify consumer needs and preferences for LTC services.
- Develop a quality assurance strategy and tools to ensure the quality of LTC services.

- Clarify roles and responsibilities of existing aging network providers participating in the transition process.
- Create an inventory and analyze services available by county and by Chicago neighborhood.
- Create an inventory and analyze available, affordable, and appropriate housing options by county and by Chicago neighborhood.
- Assess the level of funding or lack of funding to provide services to transitioning seniors.
- Develop a strategy to address funding needs for transitioning seniors.
- Convene focus groups of seniors and caregivers to identify and prioritize additional service needs.
- Convene forums of the Illinois Department of Aging Consumer Direction Stakeholder Network to develop a strategy to meet consumer needs and preferences.
- Establish uniform quality assurance standards that are benchmark performance, person centered, data driven, and focused on consumer direction.
- Conduct comparative analysis of the actual costs associated with community residency on behalf of nursing facility residents returning to their homes and communities.

Abstract

The Illinois Department on Aging is leading the Rebalancing Initiative to address the planning capacity needs associated with designing a framework for the retooling of Illinois' LTC system. This will enable elderly nursing facility residents the opportunity to choose to return to their homes and communities.

Illinois' seniors have identified that the inaccessibility of some services hinders their ability to remain in their homes or transition from nursing facilities. Seniors and their caregivers have also indicated that obtaining information regarding service availability is difficult and confusing.

Illinois' existing provider network provides a strong foundation and community presence to implement LTC reform. The additional tools and resources developed through this initiative will enhance Illinois' capacity to develop a community reintegration program for the frail elderly. In addition, the project will create an effective quality assurance and improvement framework for evaluation and monitoring of the program.

LOUISIANA

Grant Information

Name of Grantee Louisiana Department of Health and Hospitals

Title of Grant Louisiana Department of Health and Hospitals Real Choice

Rebalancing Initiative

Type of Grant Rebalancing Initiative

Amount of Grant \$300,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

Oregon Technical Assistance Corporation 3886 Beverly Avenue NE, Building 1, Suite 21 Salem, OR 97305

Target Population(s)

People with developmental disabilities living in Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) with 16 or more beds.

- Develop a transition plan to increase the number of individuals with developmental disabilities transitioning to the community though rebalancing of the State's long-term care services programs.
- Enhance community-based services and supports for persons with developmental disabilities according to the pattern of their needs.
- Transition at least 270 persons with disabilities living in large ICFs/MR to community living options by the end of the grant period.
- Improve the quality of supports and services included in the transition plan.

- Identify states with successful rebalancing initiatives and review their programs to identify best practices and develop policies and procedures necessary to implement a comprehensive transition plan.
- Develop a framework for increasing consumer-directed community-based services and supports.
- Develop a transition guide to help identify needed transition services together with a plan for transitioning consumers from institutional settings to the community.
- Develop a list of minimum needs that must be met when a person with developmental disabilities transitions from an institutional setting to the community.
- Develop a flowchart of steps necessary to transition consumers to the community.
- Create tools (e.g., satisfaction and outcome surveys) to measure the quality of supports and services included in the transition plan.

Abstract

The purpose of the grant project is to develop a comprehensive plan that addresses the pattern of need for people with developmental disabilities to transition from large ICFs/MR to the community-based living options.

To accomplish this goal, the project will establish an Advisory Board comprising people with developmental disabilities and their families, advocates, professionals who provide supports and services, public and private policymakers, and others to steer the project. In collaboration with the Advisory Board, Regional Workgroups comprising people with developmental disabilities and their families, case managers, advocates, agency personnel, and others will examine the needs of consumers who wish to transition. The Regional Workgroups will also examine the pattern of needs exhibited by consumers and establish an action plan to obtain community services and supports for individuals wishing to transition to the community.

A consultant experienced in transition issues will be hired to assist with the development of the statewide transition plan. The consultant will work with Regional Workgroups and the Advisory Board to develop an ongoing system of supports that is based on best practices and provides increased, high quality community-based living options. The consultant will provide assistance in the implementation of these newly established practices to Department of Health and Hospital staff, consumers, advocates, and other stakeholders.

The grant will fund the development and implementation of both a guide to transition for people living in large ICFs/MR facilities and an accompanying community resource guide to adequately equip consumers and providers with the information necessary to ensure that consumers with developmental disabilities can control and direct their own services and supports in a way that enhances their participation, choice, and autonomy in community living.

The project intends to transition 10 percent of the number of persons with developmental disabilities currently living in large institutional settings. Additional measurable outcomes include a quality framework to accompany the comprehensive transition plan and increased local resources to provide transition services and community supports.

MISSISSIPPI

Grant Information

Name of Grantee Mississippi Department of Mental Health

Title of Grant Mississippi Statewide Coordinated Transportation System

Type of Grant Rebalancing Initiative

Amount of Grant \$282,700 Year Original Funding Received 2004

Contact Information

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MS Department of Mental Health Division of Community Services

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Division of Community Services, DMH 239 North Lamar Street, Suite 1101

Jackson, MS 39201

Subcontractor(s)

Community Mental Health Centers in Region 4, Corinth, MS (North) and Region 15, Vicksburg, MS (Central)

Jan Larsen

Global Strategies Incorporated

Target Population(s)

Adults, adolescents, and parents of children with disabilities.

- Develop a model for a statewide coordinated transportation system for Mississippi that will
 ensure self-directed access by adults and children with a disability to community-based
 services that will provide them with long-term support, thereby reducing or eliminating their
 need for institutional services.
- Develop a financing plan for the statewide coordinated transportation system that will ensure its long-term sustainability.
- Develop a comprehensive plan to monitor the operation of the statewide coordinated transportation system for quality, reliability, cost effectiveness, and stakeholder satisfaction.
- Develop a plan for the implementation of the model for the statewide coordinated transportation system in one or more test sites.

- Review transportation service models currently in operation in the State to determine models or components of these models that may be appropriate for the statewide system.
- Identify and summarize strengths and weaknesses of models in other states or countries that may be appropriate for Mississippi's system.
- Finalize a model design for Mississippi's system.
- Identify all funding sources for transportation that are currently being used, as well as funding available but not being used by the State, and any other possible options.
- Prepare a summary report of the financing options for a coordinated transportation system in Mississippi, identifying the strengths/weaknesses and benefits/disadvantages of each, and include recommendations for optimal funding options.
- Establish performance standards and a monitoring schedule for the system to ensure that system stakeholders are satisfied, that the cost of the system is reasonable compared to similar systems, and the design of the system incorporates best practices.
- Develop criteria to monitor health status changes in beneficiaries who access services through the coordinated transportation system and develop cost comparison criteria to review the cost of services provided compared to the cost of services provided through systems of similar design and funding sources.
- Prepare a written report establishing a monitoring and evaluation plan for the coordinated transportation system.
- Develop criteria for the selection of model sites and to determine the number of sites to be established.
- Develop criteria to establish (1) a schedule for the monitoring and evaluation of the system at the test sites and (2) the composition of the evaluation team to conduct the monitoring and evaluation activities.
- Develop a written plan and schedule for the implementation of the statewide coordinated transportation system at the test sites.

Abstract

The Mississippi Department of Mental Health, in partnership with the Mississippi Division of Medicaid and other consumer and stakeholder organizations, will develop a plan for the design and implementation of a system of statewide, coordinated transportation services for adults and children of all ages with a disability. This system will provide accessibility by these persons to long-term support services anywhere in the State. This comprehensive accessibility to community-based services will give them a full range of noninstitutional options for care based on service choices they make for themselves.

NORTH CAROLINA

Grant Information

Name of Grantee North Carolina Department of Health and Human Services

Title of GrantRebalancing ProjectType of GrantRebalancing Initiative

Amount of Grant \$249,500 Year Original Funding Received 2004

Contact Information

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NC Division of Vocational Rehabilitation

Services (DVRS)

Community Services Section 2801 Mail Service Center Raleigh, NC 27699-2801

Subcontractor(s)

William Lamb 919-966-9444

UNC Institute on Aging

Marian Hartman Project Coordinator

Target Population(s)

Medicaid-eligible adults with significant physical disabilities who have applied for admission to, are waiting to enter, or reside in institutions such as nursing homes.

- Develop a targeted Rebalancing Plan to prevent and correct inappropriate placements of adults with significant physical disabilities in institutions such as nursing facilities.
- Test and revise the Rebalancing Plan based on formative evaluation data gathered in the pilot phase of the project.
- Write and publicize a 5-year Implementation Plan.

- Develop profiles on the types of people with significant physical disabilities (at risk) for whom institutionalization has been reversed.
- Identify and select rebalancing strategies that would be most effective for the targeted population.
- Identify administrative and programmatic policy and procedural changes required to implement the selected rebalancing strategies.
- Conduct rebalancing pilot study with people with significant physical disabilities and their families.
- Conduct quality management activities to monitor participants and interview placement workers about their experiences.
- Finalize and disseminate Rebalancing Plan.
- Prepare a 5-year schedule for implementation statewide.

Abstract

The North Carolina Department of Health and Human Services (DHHS) will develop a targeted rebalancing plan to prevent and correct inappropriate placements of adults with significant physical disabilities. The project will target those Medicaid-eligible adults with significant physical disabilities who have applied for admission to, are waiting to enter, or reside in institutions such as nursing homes.

The Rebalancing and 5-year Implementation Plans will describe the target population, the nature of the diversion/institutionalization services, the role of key stakeholders, the policies and procedures governing service priorities, and the schedule of events. The project will be implemented based on input from a broadly based local Rebalancing Team consisting of consumers, state and local agency representatives, and service providers. Its work will be reviewed by the DHHS Long-Term Care Cabinet headed by the DHHS Assistant Secretary for Long-Term Care and Family Services.

NORTH DAKOTA

Grant Information

North Dakota Department of Human Services

Title of Grant Choice and Self-Directed Community Resource Delivery for the

Elderly and People with Disabilities in North Dakota

Type of Grant Rebalancing Initiative

Amount of Grant \$300,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

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Minot State University

North Dakota Center for Persons with Disabilities

500 University Avenue West

Minot, ND 58707

Target Population(s)

Persons who are elderly (60+) and adults with disabilities.

- Increase access to and utilization of home and community services for elderly people 60+ and people with disabilities.
- Revise the finance mechanism for home and community-based programs and services.
- Increase choice and self-direction for elderly people 60+ and people with disabilities.
- Decrease reliance on institutional forms of care.
- Develop quality management mechanisms for service delivery.

- Establish a stakeholder consultation process to create a rebalancing plan that will develop and implement a single-point-of-entry mechanism, develop and implement a state financial distribution mechanism for home and community services, and create and implement quality management mechanisms.
- Use the consultation process to develop a set of draft bills for consideration by the North Dakota Legislative Assembly that will direct the implementation of the rebalancing plan.
- Develop public information services regarding the long-term care (LTC) continuum of services available for the target population and utilize various media for maximum impact, including television, radio, Web sites, brochures, and posters.
- Develop and disseminate informational materials that will include practical self-assessment guidelines and checklists for assessing the appropriateness of LTC services in institutional settings and in home and community-based settings.

Abstract

The Rebalancing Initiative Grant project will improve community-integrated services by providing a forum for all constituencies to participate in a new mechanism for funding home and community services, and by providing full consultation with consumers and stakeholders in building a lasting agreement on the direction of LTC services in the State. The project will also enhance coordination of all LTC services through a single point of entry for home and community services and institutional services.

The stakeholder consultation process will develop a "roadmap" or strategic plan for the development and implementation of a single point of entry, and direction and recommendations for continued efforts to balance the system of LTC services in the State. In addition, incentives will be considered for enabling and supporting the leadership of the existing infrastructure of nursing homes to participate in providing home and community services. The grant project will also conduct research regarding choice and access to all LTC services in North Dakota and disseminate these findings statewide. This research information, along with past studies and best practices, will be used to guide the development of a single point of entry and the rebalancing initiative roadmap.

The stakeholder consultation process will produce a comprehensive set of legislative proposal(s) for consideration in the 2007 session of the North Dakota Legislative Assembly. These proposals will provide clear mandates and the financial support for their implementation.

The development of public information services through the grant project will strengthen the current trend in public thinking toward rebalancing resources for institutional and home and community services, and can provide the foundation for future significant initiatives for rebalancing. The Department of Human Services is committed to seeking appropriate Medicaid waivers to support implementation of the recommendations that are identified in the Stakeholder Consultation Process and to ensure sustainability of the initiative.

TENNESSEE

Grant Information

Name of Grantee Tennessee Department of Finance and Administration's Bureau of

TennCare

Title of Grant Improving Access to Community-Based Care with a New

Comprehensive Client Assessment Instrument

Type of Grant Rebalancing Initiative

Amount of Grant \$291,382 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

Pacific Health (Andy Cohen)—Health care consulting firm

Target Population(s)

Medicaid-eligible, long-term care applicants and recipients who qualify for nursing home admission and who would be served typically in Level 1 nursing facilities.

- Improve client access to community-based care by implementing a new comprehensive client assessment instrument and process.
- Develop the comprehensive client assessment instrument and the process for using it.
- Develop procedures and create and pass rules for adoption.
- Implement the comprehensive client assessment instrument and process statewide.
- Conduct operations monitoring, evaluating, and reporting activities.

- Conduct a needs assessment.
- Review potential comprehensive client assessment instruments and process options and select or create a replacement assessment instrument and process.
- Design and conduct a parallel test between the current and proposed client assessment instruments and refine as indicated by the test results.
- Train and certify assessors on use of the new comprehensive client assessment instrument and process.
- Draft rules to implement the new process and procedures and secure approval by the State.
- Commence use of the new comprehensive client assessment instrument and process.
- Conduct a project review and write a final report containing information on stakeholder satisfaction, lessons learned, and progress on the goals/outcomes of the project.

Abstract

The goal of the project is to improve client access to community-based care by implementing a new comprehensive client assessment instrument and process. Tennessee needs a comprehensive assessment instrument and process, designed for facility and community-based care, which supports consumer choice. Such an instrument could help consumers make more informed choices, make the process more predictable for providers, improve the operation of the evolving long-term care system, and allow the system to function in a more fiscally responsible and accountable manner.

A new comprehensive client assessment instrument and process will (1) be more objective, (2) help consumers identify the program that best meets their needs, (3) be more respectful of applicants' time, and (4) reduce the financial risk of providers by providing more timely decisions. Faster eligibility determination will increase the likelihood of appropriate community-based placement, while a future computer-based comprehensive client assessment instrument will provide administrators with a broader scope of information to more efficiently manage programs and quality.

This project consists of five primary activities: (1) project start-up; (2) needs assessment, comprehensive client assessment instrument selection, and parallel testing to calibrate the instrument; (3) regulatory approval; (4) statewide implementation; and (5) operations monitoring, evaluation, and reporting. Several intermediate products will be produced by the grant project. A requirements report will be produced from the needs assessment activity, a new comprehensive client assessment instrument will be selected, and a process will be defined. Parallel (new instrument compared to current instrument) test results will be used to create a final comprehensive client assessment instrument, and rules approval will lead to statewide implementation of the new instrument and process.

With the overall goal of improving access to community-based care, the State expects to produce the following outcomes: (1) improve access to services, resulting in a decrease in eligibility decision time from 7 days to 1 to 2 days; (2) improve client choice of services, resulting in a higher proportion of consumers choosing and being served in community-based care; (3) rebalance long-term care expenditures, resulting in expenditures growing less rapidly as clients are served in lower-cost settings; and (4) improve public accountability through more objective, reliable, and consistent long-term care admission criteria.

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VIRGINIA

Grant Information

Name of Grantee Partnership for People with Disabilities, Virginia Commonwealth

University

Title of Grant Increasing Person-Centered Planning, Informed Choice and Self-

Direction

Type of Grant Rebalancing Initiative

Amount of Grant \$300,000 Year Original Funding Received 2004

804-828-3879

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Individuals with intellectual disabilities, as well as individuals with other developmental and physical disabilities who may also benefit from materials being developed.

- Provide tools, information, and resources to individuals with disabilities, their families, case
 managers, and providers to assist them in designing person-centered service plans and to
 maximize informed choice in the selection of supports and services.
- Maximize opportunities for individuals in state training centers and individuals currently on the statewide urgent waiting lists to choose, design, and manage needed community supports and services.
- Develop definitions, processes, and procedures that can be used to identify additional services that can become consumer-directed within Virginia's Mental Retardation/Developmental Disabilities (MR/DD) waiver programs.

- Implement a person-centered service planning awareness program to renew interest in and increase knowledge of person-centered planning principles and practices.
- Develop local systems change processes and materials that organize person-centered thinking, planning, and service options.
- Create a Web page on the Partnership for People with Disabilities Web site and post person-centered planning information and resource materials.
- Provide information and resources on person-centered services planning, informed choice, and service options to individuals who will be returning to the community and individuals who will be moving from the urgent waiting list into slots in the MR/DD waiver.
- Assess strengths and challenges of pilot demonstrations (including financing of services and quality management) and use results to refine materials and processes.
- Identify strategies to ensure that the processes developed (e.g., financing across settings and providing quality in all supports) are used with individuals who receive waiver slots.
- Identify barriers that limit the number and types of consumer-directed services that are offered in the State and the strategies to overcome them.
- Develop definitions for additional consumer-directed services and identify strategies and processes for including the services in current state waiver programs.

Abstract

The Rebalancing Initiative will build the infrastructure to allow individuals with disabilities to plan, select, and manage their own services by focusing its work strategies in two areas that will increase access to and the availability and diversity of home and community-based long-term services and supports. The first area involves the design, development, and piloting of materials and processes in selected pilot localities to increase the use of person-centered thinking, planning, and services for individuals who are targeted to receive new waiver slots, including the development of resources that explore multiple options for support. A subset of the materials will be designed with a specialized focus on person-centered discharge planning for individuals transitioning from state training centers and who are targeted to receive new waiver slots.

The second area examines mechanisms and strategies for determining how additional services can become consumer-directed in the State's current waiver programs. This is a step toward greater self direction of key supports and will benefit all waiver recipients, including those leaving institutions. The selected areas have the potential to expand community options for supports and shift the balance in the State by focusing on the individual's preferences and choices rather than on the service systems' programs and requirements.

Several products will be developed as part of the project. These include (1) local systems change process and materials that organize person-centered thinking, planning, and services in formats useful for individuals, family members, case managers, providers, and other supporters; (2) resource documents that explain informed and meaningful choices and provide an array of options for community support and service possibilities; (3) a report that describes the pilot demonstration, including methods, findings, and results; (4) a report listing the findings of research from other states and outlining additional prospective consumer-directed services and definitions for services; (5) a rebalancing plan to be submitted to key state agencies and leaders; and (6) an implementation plan that addresses how the State can integrate and continue the work of this initiative, including how these efforts will eventually become a part of a greater reform effort.

DISTRICT OF COLUMBIA

Grant Information

Name of Grantee District of Columbia, Department of Mental Health (DMH)

Title of Grant Supporting Transitions for EPSDT Eligible Children in Foster Care

with Mental Health Disorders in the District of Columbia

Type of Grant Portals from EPSDT to Adult Supports

Amount of Grant \$499,649 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

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Georgetown University

School of Nursing and Health Studies

Steven Lutzky, President 202-558-2176 Steve@hcbs.org

HCBS Strategies, Inc.

Target Population(s)

Children in foster care with mental health issues, who are transitioning into adult mental health care.

- Examine and refine current mechanisms for identifying and referring early and periodic screening, diagnosis, and treatment (EPSDT) children in foster care with mental health issues to ensure that they are referred to appropriate supportive services within and after they leave the foster care system.
- Examine and refine current regulations, policies, and programs related to offering mental health assessment and supports to foster care children to identify gaps and eliminate duplicative service.

- Review program regulations, policies, and procedures and recommend alterations to current protocols and/or the creation of new protocols to ensure that EPSDT children in foster care with mental health issues have access to mental health supports.
- Assess actual and potential services looking at their standards of care, practices, protocols, policies, and data-sharing methods.
- Based on systems assessment, identify provider training needs, legal/ethical impediments and safeguards to data sharing, efficient referral mechanisms, and service gaps for the identified population.
- Design and implement monitoring tools and develop reports to establish continuous quality monitoring.

Abstract

The roughly 3,000 children in foster care in the District are at high risk of having mental health disorders. The District currently lacks mechanisms to assist these children to receive the supportive services they need as they age out of the foster care system. If these children do not receive mental health supports, they are dramatically more likely to experience homelessness, substance abuse, and criminal behavior. Although the District has made strides in improving mental health services for EPSDT-eligible children in foster care, the system is complex and lacks linkages to mental health services offered under the Medicaid Rehabilitation Option, locally known as Mental Health Rehabilitation Services (MHRS).

The Department of Mental Health (DMH) has worked closely with Children and Family Services Administration (CFSA) to redesign services to children in foster care and improve pathways for these children to access services as they age out of the program. Both agencies have recognized the pivotal role played by Medicaid in this endeavor. The grant will further this work toward reviewing current regulations and program operations for Medicaid-funded mental health services to improve coordination across the range of services and ensure that as foster care children with mental health disorders age out of the system, they are still able to access the supportive services they need.

Grant funds will be used to hire District staff to conduct much of the work of this initiative. Georgetown University will supply policy and programmatic guidance and will conduct a process evaluation of this major systems change effort. This grant represents the strong collaboration that has been formed as a result of CINGS (Children Inspired Now Gain Strength), the District's System of Care initiative being implemented by DMH, CFSA, Medical Assistance Administration (MAA), and other partner agencies. This collaboration among District government agencies, with strong consumer input, has made it possible to have dramatic and sustainable improvements in Medicaid services for foster care children with mental health disorders.

NEBRASKA

Grant Information

Name of Grantee Nebraska Department of Health and Human Services

Title of GrantPortals from EPSDT to Adult SupportsType of GrantPortals from EPSDT to Adult Supports

Amount of Grant \$500,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

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University of Nebraska Medical Center

Munroe-Meyer Institute

The Parent Training Institute will be a subcontractor under the UNMC-MMI subcontract.

Christine Reed 402-556-5509 breed@mitec.net

Family Voices 800-284-8520

Easter Seals Nebraska 800-471-6425 bkoehler@ne.easterseals.com

Target Population(s)

SSI-eligible youth with physical disabilities or medically complex health needs receiving services from the Aged and Disabled waiver, youth served through the Medically Handicapped Children's Program and SSI-Disabled Children's Program, and parents of these youth.

- Increase the effectiveness of the Aged and Disabled waiver to transition youth served by the program to more appropriate adult medical care services.
- Increase collaboration between tertiary and specialty care providers and community providers in the pediatric and adult health care fields.
- Increase the capacity of school districts that incorporate medical transition planning into their formal transition process.
- Increase the capacity of other youth-serving disability programs that provide medical transition services.

- Develop an amendment to Nebraska's Home and Community-Based Aged and Disabled waiver to modify the assessment process used for persons transferring from children's services to adult services, to include a medical transition component.
- Coordinate training for general practitioners so they are ready to serve young adults on the waiver and cultivate relationships between them and pediatric specialists who have been serving these persons in their youth.
- Implement a pilot project with a rural school district that will integrate medical transition assessment and planning into required transition plans for employment preparation and expand the resulting program statewide.
- Create a statewide system of transition clinics as part of the Medically Handicapped Children Program's specialty clinics, specifically for SSI-eligible youth as they age out of children's services.

Abstract

The Nebraska Health and Human Services System (NHHSS) will develop a transition project for young adults with disabilities with the ultimate goal of improving access to adult-focused tertiary and specialized medical care for SSI-eligible youth transitioning from early and periodic screening, diagnosis, and treatment (EPSDT) to adulthood.

In Nebraska, the Home and Community-Based Aged and Disabled Medicaid waiver is a lifespan waiver, serving children age 0 to 18, adults age 19 to 64, and elderly persons age 65 and above, with services coordination provided to eligible persons by a different provider for each of the categories described above. For children and youth through age 18, services coordination is provided internally by the Nebraska Department of Health and Human Services, which has local offices around the State. For adults through age 64, services coordination is contractually provided by two regional Centers for Independent Living. Grant activities are focused on the transition between services for these two age groups.

Partners that will work with NHHSS on the project include Nebraska's Medicaid staff working with EPSDT, administrators and staff of the Aged and Disabled waiver, Centers for Independent Living, the University of Nebraska Medical Center Munroe-Meyer Institute, Creighton University, Easter Seals of Nebraska, the Nebraska Department of Education Vocational Rehabilitation Program and Special Education Program, the Social Security Administration, and the North Platte Public Schools.

An infrastructure of training, clinics, and assessment will be developed through this grant that will be sustained as a result of the investment of these partners, creating measurable improvements in the lives of the young adults who will receive their services. Consumers and their families, pediatric specialists and general practitioners, and other relevant youth-serving programs will all be impacted by sustainable changes that will ultimately result in better, more cost-effective care and a higher quality service system for adults with disabilities.

VERMONT

Grant Information

Name of Grantee State of Vermont

Title of Grant Vermont Real Choice Systems Change Comprehensive Systems

Reform

Type of Grant Comprehensive Systems Reform

Amount of Grant \$2,089,863 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

To be determined.

Target Population(s)

Frail, vulnerable, and chronically ill elderly and physically disabled adults.

- Form a core planning team to develop a model integrated care organization to serve frail, vulnerable and chronically ill elderly and physically disabled adults.
- Improve access to services through integrated care organizations by using an interdisciplinary team and a single care plan.
- Develop a reimbursement system for integrated care organizations.
- Improve services and supports provided by integrated care organizations.
- Ensure that services are available that match consumer's needs and preferences, and that sufficient workers are available to provide services.
- Build quality management systems.

- Define target population and develop initial policies around legislative changes, service provider licensure, and risk-based entity licensure.
- Develop policy and procedures for administration, care delivery, and enrollment, and solicit and select provider organizations.
- Create a business plan that outlines the feasibility of creating integrated care organizations for the defined target population.
- Define core interdisciplinary team members, define relationship of primary care provider to the team, and define role of the consumer in planning and evaluating care.
- Define services to be provided and contracted by team members, develop an operational structure to promote collaboration and care integration, and develop a single care plan.
- Research spending by the target populations in various state Medicaid programs and identify services currently being reimbursed by Medicaid.
- Develop a Medicaid Capitation Rate; research current regulations from CMS for an 1115 Medicaid waiver or Medicare Specialty Plans; and develop a strategy for integration of funding, seeking CMS approval as appropriate.
- Develop guidelines for creative solutions for care, increased payment flexibility, and the involvement of consumers in identifying their treatment goals.
- Develop feedback loops and incentives to ensure best practices, develop support systems to increase retention and job satisfaction of the interdisciplinary team members, and develop funding integration to pay higher or different rates for needed services.
- Develop clear definition of consumer-centeredness that is incorporated into the program, conduct and review research on consumer preferences in Vermont, and research and develop a guide to be used for initial program development.
- Design systems to solicit ongoing participation from consumers in both planning and evaluation of care and quality service, and develop systems to ensure high technical standards of care.

Abstract

Under the umbrella of Vermont's Agency of Human Services, the Office of Vermont Health Access and the Department of Disabilities, Aging and Independent Living will collaborate to redesign a system in Vermont to coordinate both primary/acute and long-term care services for elderly and physically disabled adults. A commitment to integrated care is the starting place for the reform. Separation between health care and long-term support systems and the discontinuity across service delivery settings and providers will guide the development of the reform. The State will build upon the lessons learned from the Vermont Independence Project's Care Partners program (e.g., physical co-location of case management in a primary care setting) and the planning for the Program for All-Inclusive Care for Elderly (e.g., coordinated care delivery at an adult day/health care clinic by an interdisciplinary team).

To address identified problems, the project will undertake strategies to integrate funding streams for Medicaid, commercial health insurance, and Medicare; develop a community advisory committee, including consumers and other stakeholders, to develop policies and procedures; and use an interdisciplinary team to manage the long-term care and health care needs of adults with physical disabilities, chronic illnesses, and challenging life issues.

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WISCONSIN

Grant Information

Name of Grantee Wisconsin Department of Health and Family Services

Title of Grant Comprehensive Systems Reform Effort

Type of Grant Comprehensive Systems Reform

Amount of Grant \$5,500,000 Year Original Funding Received 2004

608-267-4896

Contact Information

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Family Services

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Subcontractor(s)

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University of Wisconsin—Cooperative Extension

Target Population(s)

Older adults and persons with disabilities who are Medicaid eligible.

- Develop and implement a comprehensive plan for statewide expansion of long-term care (LTC) reform by applying managed care strategies in new and expanded programs facilitated by public/private partnerships to be implemented in at least one-half of the State by 2007.
- Provide timely information to Wisconsin citizens to facilitate informed decisions about LTC service options as well as information about prevention strategies and financial planning to delay the need for publicly funded LTC services.
- Improve management of where, when, and how people access the LTC system.
- Develop systems and processes that will enhance the availability of service options.
- Develop strategies to improve the quality, consistency, and cost-effectiveness of LTC services in Wisconsin.

- Support local partnerships to undertake a 1-year planning process for local reform.
- Create Web-based content for consumer links to information and other service systems and design an effective multimedia campaign.
- Create full-service aging and disability resource centers (ADRCs) statewide and pilot a dementia screening process in an ADRC.
- Improve the functional eligibility screen and develop tools and supports for local use.
- Establish a pilot program that will allow qualifying facilities to reduce nursing facility beds while developing affordable assisted living.
- Develop nursing facility reimbursement incentives and facilitate downsizing and development of regional specialty facilities.
- Develop technical assistance content on consumer direction and develop a Web site with access to consumer direction information.
- Develop strategies to retain people in the direct care workforce.
- Develop a training curriculum for options counseling workers and a comprehensive consumer-centered curriculum that can be utilized by nurses and social workers.
- Implement the outcome tool in all waiver programs and compile and analyze results across programs.
- Pilot the encounter reporting tool used in the Family Care program in participating counties and conduct pilot post-implementation analysis.
- Research and analyze issues related to expanding access in the encounter reporting data.

Abstract

The Comprehensive Systems Reform Effort project will plan for, design, and begin to implement reform activities during the 3-year grant period. The Department of Health and Family Services and its partners will develop a strategic implementation plan to utilize the learning and key principles from Family Care and Partnership managed care programs statewide and address key barriers to statewide reform. In the reformed system, (1) LTC funding will be available without a bias in favor of institutional care, (2) community resources and LTC options will be developed to respond to consumer choices and managed for cost-effectiveness, and (3) system management tools that have been developed in Family Care and Partnership pilots will be put into use in regionally and locally developed implementation plans.

Major products and outcomes include

- a preadmission assessment and consultation process to prevent unnecessary institutional admissions:
- local collaborative reform models that build on Wisconsin's existing reform efforts and build on local energy and capacity;
- a "virtual resource center" providing comprehensive information on aging and disability topics, including long-term care;
- enhanced tools to provide an infrastructure for comprehensive statewide reform;
- a comprehensive strategic plan to achieve reform statewide in 6 to 10 years; and
- process and outcome evaluations that will guide the State in future implementation activities.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

ARIZONA

Grant Information

Name of Grantee Raising Special Kids

Title of GrantFamily-to-Family Health Care Information and Education CenterType of GrantFamily-to-Family Health Care Information and Education CentersAmount of Grant\$150,000Year Original Funding Received2004

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Children and youth with special health care needs and their families.

- Create a coordinated Family-to-Family information system to support children and youth with special health care needs and their families.
- Provide families and consumers with access to information about health care financing systems, community resources, and state programs that serve children and youth with special health care needs and their families.

- Provide education and training about options in health care financing, state systems, and state Medicaid requirements to enable parents of children and youth with special health care needs to obtain needed services.
- Provide information, training, and support to children and youth with special health care needs and their families to help them develop self-advocacy skills, understand relevant legislative and policy issues, and participate in all levels of decision making.
- Develop new community partnerships and strengthen existing partnerships to promote family-centered practice within a statewide system of health care information and education.
- Provide appropriate levels of staffing, training, and resource materials to serve Spanishspeaking families and families who reside in rural areas of the State.
- Develop initiatives to expand relationships between state agencies, parent organizations, and local community groups in order to (1) provide information, education, and support for understanding services and supports and (2) promote access to health care in rural and underserved areas.
- Promote knowledge and understanding of the Medical Home concept among families and professionals.
- Educate health professionals about Family-to-Family supports and referral systems.

Abstract

The primary goals of this project are (1) to create a coordinated Family-to-Family information system that will support children and youth with special health care needs and their families and (2) to bring about enduring improvements in understanding and access to community resources and systems of care.

The project will focus on activities to meet families' need for information and education about a wide range of issues related to their children's health needs. It will also provide skills training to (1) enable families to become effective participants in advocacy and community development activities and (2) improve communication among parents, youth with disabilities, and health professionals.

Other grant initiatives will focus on (1) expanding relationships between state agencies, parent organizations, and local community groups to provide information, education, and support to families in rural and other underserved areas and (2) educating health care professionals about Family-to Family supports and referral systems.

Grant funds will be used to assess the effectiveness of education and training methods. The Grantee will partner with Arizona's Office of Children with Special Health Care Needs (OCSHCN) in the Department of Health Services in several initiatives, including an evaluation of grant activities.

KENTUCKY

Grant Information

Name of Grantee The Arc of Kentucky, Inc.

Title of Grant Kentucky's Family-to-Family Health Information and Education

Initiative

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2004

Supplemental Award \$50,000

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Children and adults with disabilities or long-term care illnesses and their families.

- Empower families of children with special health care needs (CSHCN) to make sound choices about services and supports based on accurate up-to-date information.
- Enable children and adults with disabilities or long-term illnesses and their families to live in an integrated community setting; make decisions about their supports, services, and living environment; and consistently obtain quality services.
- Promote the philosophy of individual- and family-directed supports through advocacy and self-determination training.

- Develop a user-friendly network to collect and deliver information and provide technology for Internet access.
- Coordinate, facilitate, and provide training sessions to provide information and education on health care and home and community services and supports for families with CSHCN, providers, and stakeholders.
- Provide information about and referrals to programs that can help children remain in the community.
- Help families assess their potential eligibility for public long-term care benefits and services.
- Collaborate with existing projects that benefit CSHCN to learn and share best practices.

Abstract

The Arc of Kentucky, Inc. will establish a statewide Family-to-Family Health Care Information and Education Center that will (1) provide education and training opportunities for families with CSHCN, (2) develop and disseminate information about health care and home and community services to families and providers, (3) collaborate with existing Family-to-Family Health Care Information and Education Centers, and (4) promote the philosophy of individual- and family-directed services.

The Arc will collaborate with existing programs to prevent duplication of efforts.

LOUISIANA

Grant Information

Name of Grantee Family Voices of Louisiana

Title of Grant Louisiana Family-to-Family Health Care Information and

Education Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Children with special heath care needs (CSHCN).

- Strengthen collaboration between families, health care, and other service providers to enhance the care of all CSHCN.
- Provide information, education, and training about a range of topics and issues relevant to families with CSHCN.
- Increase parental involvement in program development and service delivery.

- Provide CSHCN and their families with timely, relevant, and useful information about navigating and participating in the complex health and related systems in Louisiana.
- Engage families and key stakeholders in discussions to identify ways to improve and coordinate public and private health systems and ensure that these systems are responsive to the needs of the families and children they serve.
- Provide education and training opportunities on an array of issues and topics relevant to families with CSHCN.
- Develop a standard data collection method to identify service gaps.
- Collaborate with Family Voices of Louisiana, Inc. to establish and expand the network of parents and parents' associations that consult with and provide support to families of CSHCN.
- Collaborate with key health care providers, policy makers, and public and private partners to encourage additional funding for services for families of CSHCN.
- Develop a user-friendly information collection, storage, and retrieval database for working with and providing services to partners, providers, and families of CSHCN.

Abstract

The grant will be used to create the Louisiana Family-to-Family Health Care Information and Education Center under the umbrella organization of Family Voices of Louisiana, Inc., a nonprofit organization and chapter of Family Voices National. The new Center will be a statewide, family-run, home and community-based, culturally competent, health care, education, and information center.

The Center is designed to strengthen collaboration among families, health care providers, and other stakeholders to enhance the care of CSHCN, especially underserved and minority children. The project's primary activities are to (1) provide CSHCN and their families with timely, relevant, and useful information about navigating and participating in Louisiana's complex health and related systems; (2) engage families and key health care stakeholders in discussions to identify ways to improve and coordinate public and private health systems and ensure that these systems are responsive to the needs of the families and children they serve; (3) provide education and training opportunities on an array of issues and topics relevant to families with CSHCN; (4) develop a standard data collection method to identify service gaps; (5) collaborate with Family Voices of Louisiana, Inc. to establish and expand the network of parents and parents' associations that consult with and provide support to families of CSHCN; and (6) collaborate with key health care providers, policy makers, and public and private partners to encourage additional funding for services for families of CSHCN.

Family Voices of Louisiana, Inc., will begin work to ensure the sustainability of the Center by writing grants, raising funds, and developing fiscal partnership contracts.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

MASSACHUSETTS

Grant Information

Name of Grantee Massachusetts Family Voices @ Federation for Children with

Special Needs

Title of Grant Massachusetts Family-to-Family Health Care Information and

Education Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2004

Contact Information

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Dr. Richard Robison, Project Manager 617-236-7210 rrobison@fcsn.org

Federation for Children with Special Needs

1135 Tremont Street, Suite 420

Boston, MA 02120

Subcontractor(s)

None.

Target Population(s)

Families of children and youth with special health care needs.

- Increase the number of families with children with special health care needs (CSHCN) who
 receive information about services and supports that will enable their children to be active
 participants in their communities.
- Increase the number of families with CSHCN who receive services for which they are eligible, particularly traditionally underserved families.
- Increase the number of families with CSHCN who have access to training, leadership, and peer support opportunities.

- Provide training opportunities to parents and parent groups on advocacy strategies for achieving quality care for their CSHCN through workshops, conferences, conference calls, and access to training materials.
- Provide education and technical assistance to families as they navigate health care service systems and advocate for their CSHCN.
- Act as a clearinghouse for specialized information and support related to eligibility, enrollment, benefits, and services available under Massachusetts and federal public benefits programs for families of CSHCN, parents, parent groups, providers, and others.
- Develop and distribute brochures and materials in Spanish, Portuguese, and for those with limited English proficiency, describing the Center's services for families of CSHCN.
- Collaborate and coordinate with organizations and agencies to develop and expand statespecific health information and support resources for parents and parent groups.
- Collaborate with existing and new Family-to-Family Health Care Information and Education Centers to provide input and feedback to CMS and the State on training and technical assistance activities.
- Unite parent and agency initiatives so families and others will have a central location for information and support around health care services, Home and Community-Based Services (HCBS) waivers, referrals and other available services and supports for families of CSHCN.

Abstract

The goals of this grant are to increase the number of families with CSHCN who (1) receive information about services and supports that will enable their children to be active participants in community living; (2) receive services for which they are eligible (particularly traditionally underserved families); and (3) have access to training, leadership, and peer support opportunities.

Massachusetts Family Voices, housed at the Federation for Children with Special Needs, will create and operate a statewide, parent-run Family-to-Family Health Care Information and Education Center. The Center will offer health care information and support to families of CSHCN, and others, as they negotiate various systems to enable their children to live in the community and be active participants in the decision-making process.

The Center will unite parent and agency initiatives in Massachusetts so families and others will have a one-stop shopping source for information and support related to health care services, Medicaid home and community services, and other services and supports available to families with CSHCN. The Center will also provide referrals for needed services.

The Center will collaborate with state agencies and programs to develop family-friendly training materials so families will have information on state and federal public benefits programs.

NEW MEXICO

Grant Information

Name of Grantee Parents Reaching Out

Title of Grant Family Health Information Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Families of children and youth with special health care needs.

- Build the capacity of families of children with special health care needs (CSHCN) to understand, access, and choose health care services, including home and community services, and support for their children through the development of educational materials and opportunities and the collection, cataloguing, warehousing, and dissemination of information on health care topics and issues.
- Develop family-to-family networks around New Mexico for families who have CSHCN by assisting them to serve as mentors and resources to new families entering or those having difficulty navigating the health care system and accessing information and services.

- Develop and conduct training for families of CSHCN, health care professionals, and other stakeholders on a range of relevant topics, including public benefit programs and Medicaid home and community services.
- Develop and disseminate accessible, family-friendly guidebooks on self- and family-directed services and how to navigate the Supplemental Security Income system, handbooks on the waiver program for persons with developmental disabilities and other Medicaid waivers, and the Step-by-Step Guide to New Mexico Health Care Services for Children in both English and Spanish.
- Expand the resources of the Parent Reaching Out resource center by (1) purchasing, cataloguing, and disseminating relevant periodicals, audio, and videotapes, and (2) increasing the amount and variety of information on the Web site.
- Identify, recruit, and train family members throughout the State to become Health Information Parent Specialists.
- Provide technical support and assistance to Health Information Parent Specialists, families
 of CSHCN, and service providers about eligibility for home and community services, and
 provide referrals to public long-term care programs and benefits.

Abstract

Because families are the primary caregivers of CSHCN, effective health care must support them in this role. Because they are also experts on their children's health care and support needs, the major strategy utilized by Parents Reaching Out is the provision of parent-to-parent support.

Over the past 20 years, Parents Reaching Out has developed a successful, statewide parent-to-parent network. This network is community-based, family-centered, and culturally competent. Parents of children and youth with special health care needs who have learned to navigate and access the health care system share their knowledge and experience with other families who have not yet learned to do so.

The grant's primary goal is to increase families' ability to understand, choose, and obtain health care services, including home and community services and supports, for their CSHCN. To achieve this goal, the grant will be used to fund educational and training activities and the development of family-to-family networks to provide mentors and resources for families of CSHCN who are entering or having difficulty navigating the health care system and obtaining information and services.

NEW YORK

Grant Information

Name of Grantee Parent to Parent of NYS, Inc.

Title of GrantFamily-to-Family Health Care Information and Education CenterType of GrantFamily-to-Family Health Care Information and Education CentersAmount of Grant\$150,000Year Original Funding Received2004

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Children with special health care needs (CSHCN).

- Increase understanding of appropriate health care resources for CSHCN.
- Improve access to quality services and supports for CSHCN.

- Develop a network of Health Care Resource Parents by training parents of CSHCN as volunteers to provide support to three other families.
- Design educational materials regarding waiver services in New York State (NYS), Communication Skills—Communicating with Service Providers, understanding insurance policies, handling denials and appeals, grievances, being a Health Care Resource Parent, understanding terms and acronyms, navigating multiple service systems, and understanding the philosophy of individual and family-centered supports. A series of fact sheets are available for download at http://www.parenttoparentnys.org.
- Develop a clearinghouse/library/database of relevant information about accessing health care information and services, and design strategies to disseminate this information.
- Train and provide technical assistance to families of CSHCN to secure health care coverage, ensure that medically necessary services are reimbursed by insurance, develop effective partnerships with health care and service providers, keep their children at home and in community settings by ensuring access to necessary support services, and provide parent-to-parent support to strengthen parenting and advocacy skills.

Abstract

In 1999, parents of CSHCN seeking to establish a parent support network founded Parent-to-Parent of NYS, Inc., a statewide network of parents helping parents to deal with issues related to parenting CSHCN.

The organization includes 11 regional offices and a business office with 21 part-time paid coordinators. The parent-to-parent matching program includes a network of over 1,200 volunteer support parents.

Parent-to-Parent of NYS works closely with the NYS Office of Mental Retardation and Developmental Disabilities, thereby giving parents a voice in the service planning and implementation processes as well as providing a means to share information and resources.

The primary goal of this project is to increase understanding of appropriate health care resources for CSHCN and improve access to these resources.

Activities include educational and training initiatives as well as the development of a network of Health Care Resource Parents, which will use volunteer parents to provide support and information to other parents of CSHCN.

NORTH CAROLINA

Grant Information

Name of Grantee The Exceptional Children's Assistance Center

Title of Grant Family-to-Family Health Information Center Planning and Training

Grant

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Children with special health care needs (CSHCN) and their families.

- Increase the amount of information, education, and training available to assist families of CSHCN to meet these needs.
- Enhance the capacity of existing organizations and agencies to serve CSHCN and their families.

- Determine the information and education opportunities currently available to families of children with special health care needs and identify information and education gaps.
- Identify and catalogue agencies and organizations providing education, information, or referrals to families of children with special health care needs, as well as the type of information and services they provide.
- Identify parent information and education needs, review available resources, and develop or revise existing information and education materials to address these needs.
- Review and catalogue available materials and education curricula and develop and distribute materials in Spanish.
- Provide the families of children with special health care needs information, education, and training on health care, home and community long-term services and supports, eligibility for public programs and benefits, and referrals to programs for which they may be eligible.
- Develop train-the-trainer education programs.
- Provide accurate, accessible, and usable information and educational materials to organizations and agencies serving families of children with special health care needs.

Abstract

North Carolina has many organizations and agencies providing information and education in an uncoordinated manner. For the first several months of this grant, project staff will conduct surveys with families of children with special health care needs, agencies, and other organizations to determine the level and type of information and education needed. The second step in project implementation will be to analyze the information and educational resources available, prioritize information needs of families, and identify needs and gaps in information.

The process of prioritizing information and educational needs and gaps will be accomplished using a variety of methods including surveys and focus groups with organizations and parents in different parts of the State representing urban/rural and diverse families.

After the information and education priorities and gaps are identified, grant staff and their grant partners will develop a basic information packet, and an information and referral guide will be produced that will include newly created materials from partner organizations and publications from existing national resources. Topics will be based on the needs assessment but could include subjects such as working with providers to create and maintain a "medical home" environment for delivery of health care services; using available health insurance resources to cover health care needs of children with chronic illness, disabling conditions, or other special health care needs; and accessing Medicaid wavers and the Children's Health Insurance Program (CHIP). Materials will be produced in multiple formats and translated into Spanish to reach as many people as possible and address the language and literacy barriers that exist within the State.

In addition, grant staff will conduct train-the-trainer sessions for members of the Special Needs Federation and Family Advisory Council and additional training sessions for statewide organizations targeting families from underserved areas or populations. At least one workshop will be conducted in Spanish for organizations and agencies serving native Spanish-speaking families.

The grant project will not replace existing information networks, but will provide information, training, and technical assistance to enhance the capacity of existing information networks and improve the quality of information and referral being provided.

NORTH DAKOTA

Grant Information

Name of Grantee Family Voices of North Dakota (FVND)

Title of Grant FVND Health Information and Education Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$150,000 Year Original Funding Received 2004

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Families of children and youth with special health care needs (CYSHCN).

- Increase opportunities for families to obtain the full range of services and supports needed by their children with special health care needs.
- Ensure that all families of CYSHCN have access to the information, resources, and training
 to be knowledgeable and effective navigators of their child's system of care and to make
 informed decisions about services and supports.
- Improve and increase education and training opportunities for families and professionals so
 that families of CYSHCN have the skills and knowledge necessary to advocate for programs
 and policies that are responsive to their needs.

- Develop and strengthen collaborative partnerships with agency programs and providers to increase family leadership and needed health care information, assess ongoing family needs, and foster collaborations with those concerned with the system of care for CYSHCN.
- Recruit culturally diverse and appropriate representation to the FVND Board of Directors to review materials and serve as liaisons to their respective communities, the FVND, and the Center. Provide easy-to-use, culturally relevant health care information and materials to families of CYSHCN.
- Develop and provide educational and training opportunities for families, youth with special health care needs, and professionals to increase active participation in the programs for CYSHCN.
- Increase awareness of programs for CYSHCN through outreach activities, presentations, displays and trainings. Provide outreach to underserved areas and recruit families who can assist and advise the Center and its professional partners and serve as peer mentors.
- Conduct a public awareness campaign.
- Identify existing materials and informational packets to include on the Family Voices of North Dakota Web site.
- Provide workshops for families and professionals on health care financing and systems of care.
- Identify existing transition models and explore the development of youth training and activities.
- Conduct an evaluation of the effectiveness and usefulness of the training opportunities.

Abstract

Families with CYSHCN need timely access to high quality services and supports in the health and long-term care systems within their community system of care. They often have difficulty obtaining services and supports due to the complexity of the systems, multiple programs with different eligibility requirements, and a lack of service coordination. Families who are knowledgeable about the relevant service systems and who have a support network are better equipped to ensure that their children receive needed services and supports.

The goal of this grant is to provide the information and support networks that families and their children need by establishing a Family-to-Family Health Information and Education Center within FVND. The Center will utilize the six core outcomes for CYSHCN in the President's New Freedom Initiative to identify gaps in the current community-based system. The Center will (1) assist consumers to become informed decision makers and obtain services and (2) provide coordination to help identify and address unmet needs.

Grant activities will build on existing efforts and increase coordination among families, communities, and other agencies and organizations that serve CYSHCN.

FVND, a statewide nonprofit organization, is a grassroots advocacy network of families and professionals dedicated to obtaining comprehensive, coordinated, family-centered, culturally competent care for all CYSHCN.

UTAH

Grant Information

Name of Grantee Utah Family Voices at the Utah Parent Center

Title of GrantUtah Family Voices Health Information and Education CenterType of GrantFamily-to-Family Health Care Information and Education CentersAmount of Grant\$150,000Year Original Funding Received2004

Contact Information

Gina Pola Money, Project Director Utah Family Voices	801-584-8236	utahfamilyvoices@juno.com
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Subcontractor(s)

None.

Target Population(s)

Families of children and youth with special health care needs (CYSHCN).

- Establish a statewide Family-to-Family Health Care Information and Education Center to serve all families of CYSHCN.
- Increase access to services by providing information about health care, home and community services, benefit programs, and other relevant community resources and programs.
- Create an infrastructure for collaboration and sustainability by (1) developing new family advocacy and interagency relationships and (2) strengthening existing ties with communitybased, local, state, and national organizations.

- Provide information and education on health care to families with children with special health care needs, parent groups, existing information and referral programs, and providers and other stakeholders.
- Provide training and education on home and community services and supports.
- Provide information and referrals to other programs and public benefits that can help children remain in the community.
- Help families assess their potential eligibility for public long-term care programs and benefits.
- Develop and implement strategies for training and supporting a network of family health partners to share experience and expertise with families in their own communities across the State.

Abstract

Families who have the information they need to support their child with a disability or special health care need are in the best position to ensure access to quality health and community supports for their child.

The grant will be used to establish a statewide Family-to-Family Health Care Information and Education Center that builds on the best practices from other Family-to-Family Centers, promotes the philosophy of individual and family-directed supports, encourages and supports the meaningful participation of individual family members, and utilizes available resources to better serve all families of CYSHCN.

The grant will be used to establish a statewide Family-to-Family Health Care Information and Education Center to serve all families of CYSHCN. The Center will increase services by providing information about health care, home and community services, benefit programs, and other relevant community resources and programs.

The grant will also be used to create an infrastructure for collaboration and sustainability by (1) developing new family advocacy and interagency relationships and (2) strengthening existing ties with community-based, local, state, and national organizations.

WEST VIRGINIA

Grant Information

Name of Grantee	People's Advocacy I	nformation and Resource Services (PA	IRS)
Title of Grant	Family-to-Family He	alth Care Information and Education Ce	enter
Type of Grant	Family-to-Family He	Family-to-Family Health Care Information and Education Centers	
Amount of Grant	\$150,000	Year Original Funding Received	2004

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Families of children with special health care needs (CSHCN).

- Establish new capacity to provide information and education to families who have CSHCN.
- Promote the philosophy of individual- and family-directed support and educate individuals and their families about effective health care options within the community.
- Maximize community-based options for health care for CSHCN.

- Develop and maintain a Web site for the PAIRS Center to serve as a source of health care information for families of children with disabilities.
- Establish a statewide toll-free information line staffed by parents of CSHCN.
- Develop a media campaign to promote the PAIRS Center.
- Establish peer-to-peer networks across the State to provide support and information about health care and other supports to families in need.
- Develop and disseminate materials on best practices in health and long-term health care.
- Develop a white paper on issues facing direct care staff and their ability to provide quality supports in the community.
- Collaborate with other statewide organizations that promote community health care options to develop full access to health care services in the community.

Abstract

Dedicated parents and professionals have worked hard to develop the capacity for programs to support families of young children (birth to 3 years). However, a majority of families in need of services encounter barriers in obtaining services because they have a limited knowledge of services and assistance available to them. The PAIRS project plans to empower and educate families and challenge the State to carry out a system of long-term health care that is centered on the individual and their family; provides support in the most integrated setting; treats people with dignity and respect; and provides real, informed choices for quality health care across the State.

PAIRS will collaborate with many organizations to establish an expanded capacity to provide information and education to families of CSHCN. The primary focus of PAIRS will be on promoting the philosophy of individual- and family-directed supports and developing full access to health care services in the community.

PAIRS will match families facing similar situations as a way to provide moral support and to inform individuals and family members of the benefits of person- and family-directed supports. This will implement real change in the delivery of services for people with special health care needs through a grassroots campaign to make individual- and family-directed supports a reality.

ARKANSAS

Grant Information

Name of GranteeDepartment of Human Services (DHS)Title of GrantArkansas Systems Transformation GrantType of GrantReal Choice Systems Transformation Grant

Amount of Grant \$2,856,575 Year Original Funding Received 2005

501-682-2441

Contact Information

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Subcontractor(s)

State University of New Jersey, Rutgers Center for State Health Policy Strategic Management Systems, Inc. (SMS)

Target Population(s)

Elders and people with disabilities of all ages.

- Improved access to life-term support services: development of one-stop system.
- Comprehensive quality management system.
- Transformation of information technology to support systems change.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.

- Develop and implement a statewide one-stop system for long-term services and options for individuals with disabilities and seniors including universal Web-based record for applicants to the one-stop and market campaign.
- Develop a screening assessment tool, a financial tool to predict eligibility, and a strategy to triage individuals referred to the one-stop.
- Combine three current Home and Community-Based Services (HCBS) waivers operated by DAAS into one waiver. Develop and implement an automated comprehensive quality management system.
- Add quality management staff to the DHS Waiver Quality Management Unit.
- Develop capacity within the automated comprehensive quality management system to routinely disseminate quality management reports to key entities and stakeholders.
- Add periodic evaluation of the quality management strategy to the evaluator's duties during the grant period. Determine best methods to continue periodic evaluation after the grant period.
- Develop and implement Web-based common applications, assessments, and individualcentered plans of care for waiver programs.
- Develop and implement a plan to transition from paper-based, program-specific processes to automated, common processes using information technology. Speed eligibility and enrollment through the use of online application.
- Develop and implement Web-based case records accessible to stakeholders.
- Use the comprehensive quality management system developed under Goal 2 to monitor quality of services.
- Develop and implement a system of primary care case management targeting dually eligible persons and others with chronic illnesses.

Abstract

The focus of the grant is establishing a one-stop service system that ensures access to community-based services by providing accurate, consumer-specific information to individuals about available services, whether public or private, and connecting them with those services. The grant will also build a comprehensive, automated quality management system that enables the State to measure and report on system performance and to ensure that discovery, remediation, and systems improvement become part of how the State normally does business day-to-day. Additionally, the grant will transform information technology to support systems change from the current paper-based application, assessment, plan of care, and case record processes into an online, Web-based process supported by the Medicaid Management Information System or its interfacing systems. Finally, the State will create a system that effectively manages funding for long-term supports for community living by developing a statewide primary care case management program for people who are dually eligible and others with chronic illnesses.

IOWA

Grant Information

Name of Grantee Department of Human Services, Iowa Medicaid Enterprise Title of Grant

IowaCare: Rebalancing for Increased Community Capacity,

Access, and Choice

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,286,469 Year Original Funding Received 2005

Contact Information

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Subcontractor(s)

The Center for Disabilities and Development (CDD), University of Iowa Iowa Department of Transportation Iowa Finance Authority Myers and Stauffer Iowa Foundation for Medical Care

Target Population(s)

All individuals with disabilities and the elderly.

- Improved access to life-term support services: development of one-stop system.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.
- Long-term supports coordinated with affordable and accessible housing.

- Augment Iowa's Aging and Disability Resource Center (ADRC) project to create a Webbased information and referral system for older Iowans and people with disabilities that customizes information for users.
- Develop an accessible housing registry and link it to the ADRC project's enhanced virtual information and referral system.
- Establish an eligibility/assessment work group of community providers, case managers, and lowa Medicaid Enterprise (IME) personnel to develop strategies to improve efficiencies in the eligibility/assessment process, and to identify areas of confusion about policies, staffing issues, and training needs.
- Ensure that hospital discharge planners and other health professionals in the "long-term care critical pathway" are trained and equipped to support community living options.
- Develop a statewide resource allocation plan that will expand home and community services for both the frail elderly and people with disabilities.
- Develop mechanisms to ensure the availability of technical assistance and support to institutional providers seeking to diversify.
- Develop a case-mix adjusted reimbursement methodology for intermediate care facilities for the mentally retarded and for home and community services.
- Develop and implement the framework for the use of electronic medical records to track
 Medicaid service utilization by individuals with complex health care needs.
- Implement assessments to monitor the health care quality of people with mental retardation and developmental disabilities to identify opportunities to improve health status and outcomes.
- Enhance coordination and expansion of transportation services as a critical support for community living by designing and implementing a regional service brokerage program.
- Develop counseling and assistance with housing-related supports for individuals at risk of institutionalization to help them stay in the community.
- Present a "Housing Summit III" in collaboration with the Executive Office to educate stakeholders on the continuing urgent need for affordable and accessible housing in lowa.

Abstract

The heart of IME's Systems Transformation efforts is the IowaCare Medicaid reform legislation, passed during the 2005 legislative session, that sets the direction for the redesign of Iowa's system of long-term supports for individuals with disabilities and older Iowans. The Systems Transformation grant will improve information and access, streamline the eligibility and assessment process, develop a case-mix adjusted reimbursement methodology for disability services and a plan for expansion for home and community services, and develop strategies to improve health care quality for people with mental retardation, developmental disabilities, and complex medical conditions.

LOUISIANA

Grant Information

Name of Grantee Department of Health and Hospitals

Title of GrantLouisiana Systems Transformation GrantType of GrantReal Choice Systems Transformation Grant

Amount of Grant \$3,022,545 Year Original Funding Received 2005

Contact Information

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Louisiana Systems Transformation Grant

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Subcontractor(s)

Roger Auerbach, consultant Human Services Research Institute (HSRI) The Muskie School of Public Service, University of Southern Maine NCB Development Corporation SocialServe.com

Tulane School of Public Health, evaluator

Target Population(s)

People who are aging or have a disability acquired during adulthood, people with a developmental disability, and people with mental illness who have long-term care (LTC) and/or housing needs.

- Comprehensive quality management (QM) system.
- Transformation of information technology (IT) to support systems change.
- Long-term supports coordinated with affordable and accessible housing.

- Establish and implement a plan for organizing, staffing, and supporting a QM system.
- Design business practices to support discovery, remediation, and improvement functions.
- Select core indicators to focus QM activity.
- Prepare QM reports and convene internal and external stakeholders to review, provide feedback, and recommend quality improvement priorities.
- Design, implement, and evaluate quality improvement projects at the system level.
- Develop a means of regularly communicating information about development and implementation of the QM strategy.
- Establish a formative evaluation to allow for ongoing revisions and updates to the QM system.
- Develop a Department of Health and Hospitals (DHH) generalized model for a single client record and standard applications that will be used as a foundation for all services provided to individuals in both the Office for Citizens with Developmental Disabilities (OCDD) and the new Aging/Adult LTC Unit and will be implemented through a secure, Web-enabled application.
- Expand LouisianaAnswers.com to provide access to information about quality of long-term supports and services and about affordable, accessible housing.
- Enable collection, extraction, and compilation of data that can be used in trend analysis and monitoring of both individual and systemwide outcomes.
- Conduct statewide physical survey of apartment complexes and units developed with Lowincome Housing Tax Credits, HOME Partnership Funds, and Community Development Block Grant (CDBG) funds.
- Expand and enhance Community Housing Advocacy Networks (CHANs).
- Provide training and consultation to housing developers.
- Develop policy, regulations, and pilot/implement Permanent Supportive Housing and Medicaid-funded assisted living.
- Implement a Web-based affordable, accessible Housing Locator Registry.

Abstract

A primary focus of the grant is on development of a comprehensive approach to QM and an IT infrastructure that supports both QM and functions of a single-entry-point system. Louisiana will ensure that the QM and IT infrastructure across OCDD and the Office for Aging/Adult Services are as integrated, uniform, and/or compatible as possible. Another focus of the grant is establishing the necessary, ongoing infrastructure to transform the availability of affordable, accessible housing and housing with supports. This will occur, in part, by replicating the CHANs developed under a previous Real Choice Systems Change grant to four additional regions in the State, thereby providing statewide coverage; and development of an accessible housing database and locator. In collaboration with its state housing finance agency, Louisiana is also launching a major Permanent Supportive Housing initiative for people with disabilities.

MAINE

Grant Information

Name of Grantee Department of Health and Human Services (DHHS)

Title of Grant Transforming Maine's Systems for Persons with Disabilities

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,564,610 Year Original Funding Received 2005

Contact Information

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Director of Systems Transformation Team Office of the Commissioner, DHHS 40 State House Station

Augusta, ME 0333-0040

Subcontractor(s)

Muskie School of Public Service, University of Maine Center for Health Policy & Research, University of Massachusetts Medical School

Target Population(s)

All persons of all ages with disabilities.

- Improved access to life-term support services: development of a one-stop system.
- Increased choice and control: development/enhancement of a self-directed service delivery system.
- Transformation of information technology to support systems change.
- Long-term supports coordinated with affordable and accessible housing.

- Develop customer service standards for the Department and its contracted providers.
- Develop a "first contact" protocol that articulates how people will get the information and assistance they need on first contact with the Department, regardless of how or where they make contact (Web, phone, regional office, program office).
- Develop a preliminary "sorting" assessment for identifying potential needs for persons accessing services through the Department or one of its contracted providers.
- Develop standards for linking people to needed services.
- Develop protocols and tools for streamlining the eligibility determination process.
- Articulate a range of supported decision-making approaches that can prevent guardianship.
- Develop an education and outreach plan to educate key audiences on alternatives to guardianship.
- Redesign Department's Web site to create a user-friendly Web site targeted to consumer and caregiver needs.
- Convene an Affordable Accessible Housing Work Group that will develop a plan to unify supportive-housing policy, practices, and resource development.
- Create an Inter-Agency Housing Database (IAHD).

Abstract

Maine will focus on four interrelated goal areas that have been identified as high priorities by the Commissioner and Deputy Commissioners of DHHS, based on the Governor's goal of transforming its two legacy departments into a unified department. Activities within each goal area will integrate previously independent policies and procedures across departments in the newly established DHHS and will provide a system of integrated access that screens people's needs accurately, and links people to appropriate services, regardless of where they enter.

MASSACHUSETTS

Grant Information

Name of Grantee University of Massachusetts Medical School

Title of Grant Massachusetts Community First Systems Transformation Grant

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,893,946 Year Original Funding Received 2005

Contact Information

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Subcontractor(s)

To be determined during the strategic planning process.

Target Population(s)

People of all ages living with disabilities.

- Comprehensive quality management system.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.
- Long-term supports coordinated with affordable and accessible housing.

- Develop uniform quality management approach for assessing quality of Home and Community-Based Services (HCBS) waivers and long-term support program service delivery, using the information to make improvements, and reporting the quality information to different audiences.
- Identify manageable number of quality goals, measures, and measurement approaches.
- Ensure quality reports for different audiences are accessible and provide useful and actionable information.
- Determine whether a quality management unit and integrated data collection processes are needed.
- Identify populations to target for transition and diversion.
- Identify possible financing approaches that enable use of institutional funds for community services.
- Assess best nursing facility diversion/transition practices employed here and elsewhere.
- Determine how to best coordinate, expand, and implement best diversion/transition practices, including new financing approaches.
- Place housing support functions in community agencies.
- Fully integrate assessment of housing needs into individual service planning.
- Enhance Mass Access Housing Registry.
- Conduct education and outreach about home modifications and retro fitting existing housing.

Abstract

The grant will address gaps within the current long-term support infrastructure to provide an array of effectively managed, long-term support choices and the opportunity for individuals within the Commonwealth of Massachusetts to exercise those choices. In particular, the grant will focus on the development of a comprehensive system of quality management that includes quality indicators and strategies for assessing long-term support programs or services; establishment of alternative financing mechanisms as tools to strengthen nursing facility diversion and transition efforts; and creation of accessible and affordable housing options that allow individuals to transition to or remain in their own communities.

MISSOURI

Grant Information

Name of Grantee Department of Mental Health, Division of Mental Retardation and

Developmental Disabilities (DMRDD)

Title of Grant MRDD Systems Transformation Initiative

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,971,944 Year Original Funding Received 2005

Contact Information

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Subcontractor(s)

Change and Innovation Agency (CIA)

University of Missouri Kansas City, Institute for Human Development (UMKC-IHD)
University of Missouri Columbia, Thompson Center for Autism and Neurodevelopmental
Disorders

Target Population(s)

Persons with mental retardation and developmental disabilities.

Goals

- Comprehensive quality management system.
- Transformation of information technology to support systems change.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.

Activities

- Develop a consumer/family/self-advocate board that provides feedback and guidance to DMRDD regarding the quality management system.
- Fully utilize the Missouri Quality Outcomes standards as measures for success.
- Ensure that key stakeholders participate in the development, implementation, and evaluation of the education/training process.
- Include the Division of MR/DD's Quality Integrated Functions as a component in the College of Direct Support training.

- Analyze the current quality management system and adapt, as required.
- Expand a system that will identify changes in the quality of life of individuals transitioning from habilitation centers to the community.
- Integrate current data systems to more efficiently meet information needs.
- Develop activities to ensure stakeholders can effectively utilize the information system.
- Leverage available funding from all sources.
- Broaden options for contracting with qualified providers to increase service capacity.
- Ensure a consistent process for transition planning and sharing important information (case histories, support preferences, relationships, etc.) for individuals who are transitioning.
- Strengthen mentoring opportunities as a means of helping consumers transition (peer-to-peer, family-to-family, etc.).
- Ensure that the person-centered planning process identifies and utilizes the system of informal supports (neighbors, friends, coworkers, churches, etc.).
- Further develop self-directed support options.
- Develop the MR/DD-specific content for the Network of Care Web page.
- Develop a variety of resources that support individuals in making informed choices.
- Develop a compendium of evidenced based and best practices, and provide technical assistance regarding them to stakeholders.
- Develop community crisis teams and behavioral supports to include all disciplines (social work, psychiatry, etc.) and other agencies (police departments, etc.).
- Develop community alternatives to hospitalization, and improve access to outpatient services.
- Develop an Interactive Autism Network.
- Develop and implement a training program that meets the needs of targeted stakeholders.
- Support the expansion of the College of Direct Support online training program statewide.

Abstract

The focus of the grant is on creating the infrastructure needed to develop an integrated comprehensive quality management system that includes (1) improved measures of outcomes for both consumers and providers and (2) an advanced information technology system that fully integrates quality management databases and provides ready access to information and resources. In addition, Missouri will rebalance the long-term community support system through facilitating the transitions of individuals in state-operated institutions to community services and supports. Through these initiatives, the State will develop a more coherent system of long-term care supports in Missouri.

NEW HAMPSHIRE

Grant Information

Name of Grantee NH Department of Health and Human Services (DHHS)

Title of Grant Transforming New Hampshire's System of Long-term Care:

Achieving the Promise of Self-Directed Community Services and

Supports

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,066,699 Year Original Funding Received 2005

Contact Information

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DHHS

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Real Choice Grants

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Subcontractor(s)

Randy Benthien, strategic planning consultant Technical assistance consultants Evaluation consultant

Target Population(s)

Elders and people living with disabilities and chronic conditions.

- Improved access to life-term support services: development of one-stop system.
- Increased choice and control: development/enhancement of self-directed service delivery system.
- Transformation of information technology to support systems change.

- Develop awareness of the ServiceLink Resource Centers (SLRCs) and stronger professional standards for the information and referral services they provide, including seamless access to Medicaid financial eligibility determination.
- Ensure that information is consumer friendly and is available and accessible in various formats by providing follow-up to ensure that people are referred to appropriate services, make the necessary connections with providers, and are satisfied with the outcome.
- Develop strategies to monitor and address racial and ethnic disparities in access to and utilization of services and supports in consumer-directed care.
- Leverage and replicate the work being done in the Littleton Model Community and Seniors Count in Manchester to transform 20 other communities.
- Establish referral protocols and strong working relationships between facility discharge
 personnel and community case managers and create new community-based service
 models, such as adult family care, to increase the availability of an array of flexible supports
 to meet individual needs.
- Develop and pilot a Rapid Response Team at the local level to address the needs of people at imminent risk for admission to an institution through the timely identification of individuals in need of long-term care, assessment, and approval of services.
- Provide training for staff, medical personnel, families, students, and consumers in personcentered planning using the Methods, Models, and Tools curriculum and make personcentered planning available through the SLRCs to all individuals who request services.
- Enhance implementation of the new clinical assessment process that ties amount of service to needs rather than available funding and develop a statewide system of fiscal intermediaries to advance individualized budgeting.
- Develop an Independence Plus waiver for older adults and adults with disabilities.
- Improve consumer access to services and supports, along with a greater coordination among services by developing Web portals that enable consumers to access their individual budgets or to select a service provider, or for providers to access service delivery data.
- Locate electronic information kiosks in areas where consumers are to be found.
- Catalog existing program goals, objectives, and performance indicators across programs
 and identify areas where these are lacking, inadequate, or inconsistent with the vision and
 goals of the ideal long-term support system and develop a formal, structured process to
 keep systems change efforts connected.
- Develop integrated reporting mechanisms and a process to integrate the data for those programs that are not already part of the Enterprise Data Warehouse.

Abstract

The grant will support New Hampshire's Medicaid reform efforts, which are aimed at substantially expanding access to community-based, consumer-directed services and supports; increasing the percentage of people referred to and enrolled in home and community-based as opposed to institutionally-based services; and developing nationally relevant and innovative community practices that can be replicated by other states.

NEW MEXICO

Grant Information

Name of Grantee Aging & Long-Term Services Department (ALTSD)

Title of GrantNew Mexico Systems Transformation GrantType of GrantReal Choice Systems Transformation Grant

Amount of Grant \$2,736,384 Year Original Funding Received 2005

Contact Information

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Subcontractor(s)

Mr. Michael Coop, evaluation consultant

Target Population(s)

Elderly and adults with disabilities.

- Improved access to long-term support services: development of one-stop system.
- Comprehensive quality management system.
- Transformation of information technology (IT) to support systems change.

- Expand Aging and Disability Resource Center services statewide and to new populations.
- Develop and implement a care coordination model.
- Develop and implement a 24-hour clinical intake system for abuse allegations.
- Create an individualized care planning tool and process for senior and adult disabled populations.
- Participate in the development of an online Social Service Resource Directory to provide access to Home and Community-Based Services (HCBS) information statewide.
- Participate in a cross-agency development of a single-point-of-entry eligibility determination system for HCBS.
- Develop and implement a comprehensive quality management strategy, consistent with the State's transformation of its long-term support system.
- Develop and routinely disseminate quality management reports to key entities and other stakeholders, including but not limited to state and local agencies, participants, families, other interested parties, and the public.
- Periodically evaluate the quality management strategy.
- Design IT applications that will support program practices and processes that are individual centered and enable persons to direct their own services.
- Improve client access to long-term care services through the use of integrated IT system(s).
- Use integrated systems to monitor the quality of services rendered.

Abstract

The focus of the grant is on increasing the State's capacity to meet the additional demands of new home and community-based populations, to develop new models of service delivery such as self-directed care, to create a quality management program for all HCBS, and to design and implement new IT platforms and systems to link all sources of information needed by consumers and providers to ensure the quality of individual plans of care. The grant will lead to successful implementation of a statewide, long-term care system that will significantly increase access to HCBS concurrently with the implementation of self-directed care for some of these services.

OREGON

Grant Information

Name of Grantee Department of Human Services, Seniors and People with

Disabilities (DHS/SPD)

Title of Grant ReBAR Project: Restructuring Budgets, Assessments and Rates

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,444,193 Year Original Funding Received 2005

Contact Information

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Subcontractor(s)

Human Services Research Institute

Target Population(s)

Persons with developmental disabilities/mental retardation (DD/MR) in the Developmental Disabilities Comprehensive Services System.

- Increased choice and control: enhancement of self-directed service delivery system.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.
- Quality Management System: support individual resource allocation and rate restructuring through effective quality management methods and tools associated with the first two goals.

Oregon views the accomplishment of all three goals as part of a single coherent project intended to create systems transformation in the Developmental Disabilities Comprehensive Services System. Individual resource allocation will help support choice, rate restructuring will help target resources, and quality management will focus on ensuring that these specific changes accomplish the desired objectives. As such, there are a number of activities that will be common to all the goals:

- Establish a Stakeholder Steering Committee including self-advocates, family members, advocacy organizations, providers, counties, and agency representatives.
- Engage in strategic planning to further define desired policy outcomes and steps to be taken to achieve them.
- Research alternative systems for individual resource allocation, rate restructuring, and associated quality management elements used in other states.
- Analyze potential impacts on individuals served, service delivery mechanisms, providers, and overall system resources.
- Determine which of these methodologies may best be implemented in Oregon.
- Communicate recommendations to key decision-makers.
- Implement decisions.
- Develop systems.
- Communicate broadly with stakeholders on a statewide basis.
- Test and pilot changes.
- Assess and modify as necessary.
- Integrate with Medicaid Management Information System (MMIS) and other data systems.
- Train key program staff, consumers, service providers, and other stakeholders statewide on the implementation of the tools, procedures, and processes.
- Implement across all desired elements.
- Implement quality management elements to ensure that objectives of individual resource allocation and rate restructuring are being met, that key stakeholders have good information about outcomes, and that regular review and improvement occurs.

Abstract

Oregon will improve community-integrated services by responding to critical issues identified by Oregon consumers, advocates, providers, and agencies. The Developmental Disabilities Comprehensive Services System will move from slot-based funding methods to an individual resource allocation system based on an assessment of the person's needs and available supports. Rate-setting methodologies will be restructured to support the exercise of choices determined through person-centered planning, and be based on valid, consistent analysis of allowable service costs within available funding. In addition, quality management activities will be developed to support the system transformation activities related to individual resource allocation and implementation of new cost and rate-setting methodologies.

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SOUTH CAROLINA

Grant Information

Name of Grantee Lieutenant Governor's Office on Aging (LGOA)

Title of Grant Links for Community Options

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,971,779 Year Original Funding Received 2005

803-734-9899

Contact Information

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Subcontractor(s)

South Carolina Department of Health and Human Services

Lower Savannah Council of Governments

Appalachia Council of Governments

Santee Lynches Council of Governments

Susan Reinhard, Ph.D., R.N., Rutgers Center for State Health Policy

University of South Carolina Center for Health Services and Policy Research (USC CHSPR)

University of South Carolina Institute for Public Policy Survey Research Laboratory (SRL)

Target Population(s)

Older adults and adults with physical and/or developmental disabilities.

- Improved access to long-term support services: development of one-stop system.
- Transformation of information technology (IT) to support systems change.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.

- Expand the Lower Savannah Aging and Disability Resource Center (ADRC) target group to serve adults with developmental disabilities/mental retardation and to include four additional counties.
- Establish ADRCs in two additional regions: Appalachia and Santee-Lynches.
- Link consumers with transportation needed to access other long-term supports in the community in Lower Savannah.
- Reduce duplicative intakes to decrease consumer burden and increase staff efficiency.
- Design and implement protocols in the Lower Savannah region for providing short-term interim assistance to seniors and adults with physical disabilities awaiting Community Long-Term Care (CLTC) services identified as being at high risk of institutionalization or rehospitalization.
- Engage key stakeholders in the strategic planning process to review strategies and set common priorities for IT development that are mutually valuable and feasible.
- Streamline and simplify access to transportation services by creating a process for assisting individual consumers with transportation needs, locating resources, tracking services rendered, and coordinating local resources through a Mobility, Information, Assistance, and Management Center.
- Develop software for SC Access to maintain accounts for consumers that include basic application information.
- Develop and implement a methodology for prioritizing seniors and adults with physical disabilities who are interested in receiving services from CLTC's Community Choices waiver.
- Develop a model one-stop/call Mobility, Information, Assistance, and Management Center in the Lower Savannah region to enhance consumers' access to community services and resources by better meeting their transportation needs.

Abstract

The grant will empower and support older adults and adults with disabilities living in the community through streamlined access to services and increased consumer choice. South Carolina will expand activities of the current ADRC to develop additional linkages to simplify the application processes and reduce duplicative intake; expand the ADRC target group to encompass adults with developmental disabilities and to include four additional counties; design a short-term interim assistance component for the current ADRC; integrate a transportation onestop/call Mobility; Information, Assistance, and Management Center into the Lower Savannah ADRC; and apply lessons learned from the implementation of the current ADRC to establish new ADRCs in two other regions. The grant will also develop the technology to support consumer-oriented transportation access, install mobile data terminals (MDT) and global positioning satellite units (GPS) in area vehicles participating in the project to allow for real-time vehicle scheduling and dispatching, and expand the SC Access Information Web site to incorporate information on transportation resources. Finally, South Carolina will develop a methodology for prioritizing the list of individuals who are interested in receiving the Medicaid Home and Community-Based Services (HCBS) waiver to promote more efficient utilization of funding.

CALIFORNIA

Grant Information

Name of Grantee California Health and Human Services Agency

Title of Grant California Community Choices

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$3,000,000 Year Original Funding Received 2006

Contact Information

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Subcontractor(s)

California Institute on Human Services at Sonoma State University (SSU/CIHS) Community-based organizations to operate two new one-stops Information technology contractor External evaluator

Target Population(s)

People with disabilities, chronic illnesses, or long-term health care needs, including older adults.

- Improved access to long-term support services: development of one-stop system.
- Transformation of information technology to support systems change.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.

- Build capacity of information and referral systems: Pilot CalCareNet Web site for use in CommunityLink Resource Centers (CLRCs) to provide consistently updated information and referral services to consumers.
- Improve communication and collaboration among long-term care (LTC) service providers: develop local-level collaborations between CLRCs and LTC providers, create community kiosks, and develop a collaborative learning center for the existing Aging and Disability Resource Centers (ADRCs) and CLRCs to share and develop best practices.
- Conduct brief screenings to establish/review general needs, determine current service needs, and analyze potential eligibility for home and community-based services (HCBS).
- Develop an intake process for CLRCs.
- Conduct formal assessment by gathering information relating to LTC needs, functional eligibility requirements, and supporting resources.
- Provide benefit counseling to ensure that individuals receive information about (and assistance in) applying for public and private benefits for which they are eligible, as well as LTC options counseling to develop consumer care plans.
- Focus on building relationships with hospitals, nursing homes, and other providers in the LTC critical pathway to ensure that consumers avoid unnecessary institutionalization in times of crisis.
- Develop a triage system to reach people who do not need the level of care to qualify for waiver programs, but who need information and support services to remain safely in a community setting.
- Transform the CalCareNet portal to provide comprehensive, easy-to-use, consistently updated information.
- Commission a study to analyze the elements necessary to develop an aging and LTC data storage system that collects, stores, analyzes, and reports trends and comparisons on the quality and outcomes of services rendered in noninstitutionalized settings.
- Conduct a comprehensive study and analysis of funding management reforms that will help increase use of HCBS and move the State toward a rebalanced system.

Abstract

The California Community Choices grant is critical to addressing existing barriers and making progress in systems transformation, in part because California does not currently have a coordinated mechanism for developing a statewide infrastructure for LTC. The California Health and Human Services Agency (CHHSA), the grantee agency, seeks to develop solutions that address barriers by (1) building, enhancing, and connecting infrastructures among multiple agencies and departments through information technology; (2) building on the one-stop system to connect consumers to services; and (3) developing and implementing more flexible payment methodologies for HCBS.

KANSAS

Grant Information

Name of Grantee Kansas Department of Social and Rehabilitation Services

Title of Grant Transforming the Kansas Long-Term Care System

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,198,629 Year Original Funding Received 2006

Contact Information

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Subcontractor(s)

The Self-Help Network of Kansas, Wichita State University, evaluator Melissa Ness, Connections Unlimited, facilitator

Target Population(s)

Individuals of all ages with long-term support needs.

Goals

- Increased choice and control: enhancement of self-directed service delivery system.
- Transformation of information technology (IT) to support systems change.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.

Activities

- Enhance person-centered planning across all disability fields and waiver services so they become consumer controlled, strength based, and outcomes focused.
- Develop and implement person-centered plans (PCPs) that will not require professional services to interpret.
- Identify state-of-the-art PCPs, train the appropriate stakeholders, and build the capacity for continued improvement in the PCP process so that it results in improved outcomes.
- Create training programs (face-to-face or online) and field-test them with policy leaders, practitioners, and consumers in each of the five stakeholder groups (developmental disability, physical disability, mental health, brain injury, and aging).
- Develop peer-to-peer networks statewide with self-advocacy/consumer-controlled organizations to provide orientation, support, and training to individuals and families.

- Consider amending statutes, regulations, and definitions to establish universal definitions for services across all waivers.
- Establish individual budgeting (based on the PCP) for identified services within the Physical Disabilities (PD), Traumatic Brain Injury (TBI), and Mental Retardation/Developmental Disabilities (MR/DD) waivers.
- Continue the work of the K-PASS (Kansas Personal Assistance Supports and Services) to support persons choosing to self-direct by providing ongoing education and resources.
- Ensure that stakeholders inform the state waiver operating agencies (SWOAs) on what is needed to empower persons with disabilities to develop individual budget control and develop peer-to-peer support networks to provide support for people controlling their individual budgets.
- Ensure that stakeholders work with SWOAs to establish policies and procedures for fiscal intermediaries to aid individuals who choose to direct their own services.
- Increase the success rates of persons who choose to self-direct through participantemployer arrangements.
- Create a single data-based quality management system across the Kansas Home and Community-Based Services (HCBS) waiver.
- Assess whether the IT application practices of Kansas are consistent with participantcentered principles.
- Expand and broaden routine processes, based on the IT assessment, to ensure a statewide virtual resource center that is available to all participants needing access to long-term care (LTC) information, services, and supports.
- Expand and broaden current IT applications to provide ongoing outcomes measures.
- Develop performance-incentive payment methodologies that weigh payment for MR/DD residential and day services based on the level of independent living.

Abstract

This project seeks to promote community living for Kansans of all ages with LTC support needs by continuing and building upon the achievements of previous New Freedom grants awarded to Kansas. The project's primary goal is to encourage community living options by enhancing consumer control and direction through a coordinated service delivery system.

MICHIGAN

Grant Information

Name of GranteeMichigan Department of Community HealthTitle of GrantMichigan's System Transformation GrantType of GrantReal Choice Systems Transformation Grant

Amount of Grant \$2,389,770 Year Original Funding Received 2006

517-335-0276

Contact Information

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Subcontractor(s)

Michigan Disability Rights Coalition Michigan Public Health Institute Rutgers Community Living Exchange DYNS, Inc.

Target Population(s)

Individuals in need of long-term care (LTC), including the elderly and adults with disabilities.

- Improved access to LTC support services: development of a one-stop system.
- Increased choice and control: development of self-directed service delivery system.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.

- Provide awareness, information, and assistance through marketing, outreach, and a resource database.
- Develop capability to provide short-term critical intervention to stabilize situations for individuals at imminent risk of nursing facility placement.
- Develop a targeting methodology and implement a diversion strategy for individuals pending hospital discharge by working closely with staff to explore a variety of care options.
- Develop a targeting methodology and implement a diversion strategy for high-needs populations that are at risk of institutionalization due to safety issues.
- Develop case-finding methodologies using available data to identify individuals in nursing facilities with high potential for transition.
- Develop a state-level policy and practice guideline and site review criteria for personcentered planning that includes guidance on backup plans and other risk management strategies that minimize threats to health and welfare.
- Develop and implement multiple layers of training on person-centered planning to accomplish the shift in attitudes and practices necessary for a person-centered approach throughout the LTC system.
- Develop state-level guidance to develop and implement individual budgets, including a methodology based on actual service utilization and cost data.
- Amend the MI Choice waiver to expand opportunities for participant direction.
- Establish policy support for a single state budget appropriation line for LTC.
- Develop state Medicaid policy requiring an independent level of care assessment and person-centered options counseling for individuals considering admission to a nursing facility.
- Implement a model that assigns risk-adjusted payment rates for all LTC options.
- Focus on Detroit and other urban areas to implement prepaid health plan models for LTC that can integrate Medicare and other health and social service benefits.

Abstract

Michigan's Systems Transformation Grant (STG) will contribute to building an integrated and highly responsive LTC system, characterized by easy access, consumer choice and control, high-quality services and outcomes, and flexible funding. The grant will build on the broad administrative, legislative, and stakeholder support for transformation of Michigan's LTC services. This support has been developed through the work of the Governor's Medicaid LTC Task Force, which issued a set of recommendations in 2005 that align fully with the STG goals. In response to the Task Force's recommendations, the Governor established the Office of LTC Supports and Services (the grantee agency) and the LTC Supports and Services Advisory Commission, and directed the development of single point of entry demonstration sites.

NEW JERSEY

Grant Information

Name of Grantee New Jersey Department of Health and Senior Services (DHSS)

Title of Grant New Jersey Partnership for Systems Transformation

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,281,514 Year Original Funding Received 2006

Contact Information

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Subcontractor(s)

Rutgers Center for State Health Policy (technical assistance subcontractor) Neighbours, Inc. (consumer support subcontractor) IT Engagement Manager consultant

Financial consultant

Target Population(s)

Older adults and persons with disabilities across all incomes.

- Improved access to long-term support services: development of one-stop system.
- Transformation of information technology (IT) to support systems change.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.

- Develop a public awareness strategy (which may include conducting focus groups to learn how consumers access information about services, or identifying key messages that might be important in developing effective outreach strategies to these populations).
- Integrate New Jersey's Division of Developmental Disabilities (DDD) Connection Centers into Aging and Disability Resource Centers (ADRC) and an NJ211 Partnership.
- Include cultural and linguistic competence curricula in program administration and service delivery to increase service access, consumer satisfaction, and improve client outcomes.
- Develop protocol establishing a standard set of links for all Web sites that promote services for people with disabilities and long-term illnesses.
- Create a Connections Center, which will be accessible by phone and Web site, for individuals who have established eligibility for DDD services.
- Standardize a core set of intake questions and protocols that will enable Connection Center staff and partners to track and share client data.
- Develop strategies to support individuals who may not meet the threshold for long-term care support services, but still require supportive services to maintain their independence.
- Identify and counsel individuals at-risk of being placed or remaining in a nursing home to understand the full range of home and community-based support services.
- Facilitate and coordinate a consumer-directed service planning process.
- Provide ongoing support and service coordination in the community.
- Create a "team" approach that strengthens collaboration between hospital and nursing home discharge planners, community choice counselors, and community care managers.
- Implement the hospital PAS Pilot statewide.
- Develop and integrate IT models across all units and populations that facilitate individual choice and control throughout enrollment, planning, service delivery, and quality assurance and quality improvement.
- Streamline the payment system to enable clients transitioning out of institutional settings to easily access funds, monitor budget expenditures, and pay service providers directly.

Abstract

New Jersey's Department of Health and Senior Services (DHSS) (the grantee agency) proposes to use the Systems Transformation Grant as a catalyst for continued infrastructure improvements for older adults and persons with disabilities across all incomes. The success of the project will depend on the State Management Team, comprising leadership from DHSS, the Division of Aging with DHS, the Division of Developmental Disabilities, Disability Services, and Medical Assistance and Health Services. To ensure that the voices of individuals who access services are a part of the planning, development, and implementation process, the state partners will establish Advocate Advisory Panels comprising consumers, self-advocates, and provider agencies from three networks (aging, developmental disabilities, and physical disabilities). Work teams for each of the three goals will guide planning efforts throughout the grant period. The outcome of this project will be a consumer-driven human services delivery system with a "no wrong door" pathway to services, a "money follows the person" funding structure, and IT systems that facilitate service delivery to consumers.

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NEW YORK

Grant Information

Name of Grantee New York State Office of Mental Retardation and Developmental

Disabilities (OMRDD)

Title of Grant Real Choice Through Options for People Through Services

(OPTS)

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,864,487 Year Original Funding Received 2006

518-486-1152

Contact Information

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Subcontractor(s)

The Public Consulting Group (PCG), Boston, MA

The Evaluation Consortium, Rockefeller College, State University of New York at Albany

Target Population(s)

Individuals with developmental disabilities and their families.

- Increased choice and control: development/enhancement of self-directed service delivery system.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.
- Long-term supports coordinated with affordable and accessible housing.

- Increase systemwide understanding of person-directed service opportunities by holding comprehensive public information/outreach sessions throughout the State.
- Create curricula and materials related to person-centered planning, and develop regional resource teams that offer training, plan facilitation, and technical assistance to selfadvocates, families, and nonprofit agencies.
- Ensure that each project measures consumer satisfaction with Options for People Through Services (OPTS) (Systems Transformation grant) services, and participates in general statewide OPTS customer satisfaction assessments.
- Work with Parent-to-Parent of NYS and the Self-Advocacy Association of New York State (SANYS) to develop tools that families and self-advocates can use to become better informed about self-directed options.
- Support students to transition seamlessly from school to work by collaborating with educational system, families, and staff from supported work agencies.
- Develop standardized protocols and processes to address the needs of individuals with developmental disabilities.
- Strengthen and formalize partnerships between the Office of Mental Retardation and Developmental Disabilities (OMRDD) (grantee agency) and state agencies that develop or support affordable housing, including the Division of Housing and Community Renewal (DHCR), State of New York Mortgage Agency (SONYMA), the Office of Temporary and Disability Assistance (OTDA), and the Housing Finance Agency (HFA).
- Retrofit existing housing to enable better service provision and accessibility.
- Build on OMRDD's existing Quality Assurance system and the NYS-CARES satisfaction survey to enhance data collection that extends the definition of quality to encompass satisfaction with an individual's overall package of housing and long-term supports.
- Identify mechanisms to enable individuals with developmental disabilities who are dependent on government benefit programs to "shelter" savings for purposes related to obtaining and maintaining person-controlled housing.

Abstract

New York State's OPTS is an organized health care advocacy group that was created in 2004 to promote increased choice, inclusion, and individualization, as well as to serve as a vehicle for expanding service opportunities through a unique and flexible funding methodology. To ensure that OPTS continues to reflect the input of all constituents and to assist OMRDD in its Systems Transformation Grant implementation, a Steering Committee supported by three subcommittees (Choice, Funding, and Housing) was appointed to guide the initiative's creation, development, implementation, and monitoring activities. Funding will be used to conduct OPTS outreach, public information, and education series; increase the availability of person-centered services; make available comprehensive support brokerage throughout NYS; target high-cost individuals, services, or geographic areas with high unmet needs; and establish one-stop shopping through regional resource centers to improve access to housing.

NORTH CAROLINA

Grant Information

North Carolina Department of Health and Human Services

(DHHS)

Title of Grant Systems Transformation Grant

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,343,141 Year Original Funding Received 2006

Contact Information

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Assistant Secretary for Long Term Care

and Family Services

Subcontractor(s)

Susan Reinhard, evaluation and technical assistance consultant UNC Center for Aging Research & Education Services, evaluation

Additional subcontractors forthcoming

Target Population(s)

Individuals in need of long-term services and supports, including older adults, individuals with physical or sensory disabilities, and individuals with mental illness, developmental disabilities, or substance abuse diagnoses.

- Improved access to long-term support services: development of "one-stop" system.
- Increased choice and control: development/enhancement of self-directed service delivery system.
- Transformation of information technology to support systems change.

- Expand Aging and Disability Resource Centers (ADRC) in local communities to become one-stops where consumers can get information, assistance, and access to long-term care (LTC) services (including access to person-centered planning and tools for illness selfmanagement).
- Fully implement a new information and assistance Web portal (NC Care Link).
- Integrate the ADRC model with new case management models.
- Retool the Medicaid eligibility process, with particular emphasis on uniform screening and functional/medical eligibility processes.
- Expand chronic-care case management model for high-risk and high-cost children and adult Medicaid beneficiaries to the chronic care Medicaid population in need of long-term services and supports.
- Create changes in the current CAP-DA waiver criteria to enhance the "high end" of home care and provide Medicaid recipients with more options to remain at home.
- Develop and implement a case mix methodology to allow the design of new service packages that can go up to 100 percent of the nursing home reimbursement level, instead of the 80 percent limit now in place.
- Review planning processes, formats, and qualitative consumer data to determine the extent to which plans are person centered and facilitate illness self-management.
- Obtain technical assistance regarding appropriate person-centered planning models to use within aging and other disability fields.
- Incorporate assessments of consumer support needs for self-direction and selfmanagement into person-centered planning processes, policies, and instruments.
- Develop/modify a "train the trainer" orientation on person-centeredness for direct care staff of LTC services programs; develop a train the trainer curriculum for facilitators of personcentered planning.
- Adapt a Web-based application, provisionally called NC Self-Care, designed to provide consumer self-management tools and self-direction supports.
- Create a consumer-centric outcomes framework, including measures of self-management capacities and self-efficacy, and consumer satisfaction goals.

Abstract

With broad-based input, North Carolina developed two primary "blueprint" documents to guide reform of long-term services and supports. The State has taken significant steps to implement recommendations from these documents, with progress reviewed annually by the North Carolina Department of Health and Human Services (DHHS) (the grantee agency), stakeholders, and policy makers. DHHS continues to pursue numerous recommendations within these two blueprints, with the goal of achieving an easily accessible, more efficient long-term services and supports system that is conducive to consumers having more independence and flexibility. Next steps include achieving streamlined, integrated, and easy access for all persons needing information and long-term services and supports; integrating key health and social services and supports to address multiple needs; expanding self-direction and self-management; and enhancing technological systems to enable information sharing.

RHODE ISLAND

Grant Information

Name of GranteeRhode Island Executive Office of Health and Human ServicesTitle of GrantRhode Island Real Choice Systems Transformation Project

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,177,665 Year Original Funding Received 2006

Contact Information

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Subcontractor(s)

Project manager

Beth Pinkham, project assistant

New England States Consortium Systems Organization (NESCSO)

Susan Allen, PhD, Brown University

Jane Griffin, MCH Evaluation, Inc.

Chuck Milligan, Center for Health Program Development and Management, University of Maryland Baltimore County (UMBC)

Target Population(s)

Adults with disabilities, elders on Medicaid, and individuals who receive non-Medicaid long-term supports.

- Improved access to long-term support services: development of one-stop system.
- Comprehensive quality management system.
- Creation of a system that more effectively manages the funding for long-term supports that promote community living options.

- Compile discharge packets for hospital and institutional providers to be discussed with and distributed to patients beginning at the time of admission.
- Distribute informational materials to physicians' offices and emergency rooms for improved awareness of community-based alternatives to institutional care.
- Provide the capacity for application and initial screen information to be transmitted electronically for more timely eligibility determinations.
- Integrate initial application and screening process with ADRC Information and Referral entity, The Point, and the Web-based resource, "Ask Rhody."
- Examine the feasibility of setting presumptive eligibility for home and community services in hospitals or other settings.
- Create and charge a Long-Term Support Services (LTSS) Quality Management Systems Workgroup to be made up of relevant government staff and consumer, advocate, and provider representatives.
- Develop a quality strategy that includes the identification and design of program and participant outcome indicators (e.g., waiting lists, time between eligibility application and approval, rate of participant self-direction, unmet needs, quality of life, and health).
- Create a documentation and dissemination plan for quality management activities that addresses multiple audiences.
- Develop payment strategies that ease the ability of money to follow the person. Payment strategies include the establishment of reimbursement methodologies that are driven by individual assessments of need and consumer-driven strategies.
- Incorporate incentives and develop programs to better use private funding sources for longterm support services.
- Develop the financing mechanisms to assist with the institutional transitions of individuals to community-based options.

Abstract

The overarching vision of Rhode Island's Systems Transformation Grant is to create an infrastructure that focuses on prevention of avoidable institutionalization by integrating health care and support services to promote independence in the community for elders and people with disabilities and long-term illness. The Systems Transformation grant will further assist the Rhode Island's Executive Office of Health and Human Services in the infrastructure development and system integration to improve access, financing, and quality information across Rhode Island's public and community-based services and programs that serve individuals of all ages and disabilities. Activities under this grant will be conducted in partnership with consumers, state agencies under the Executive Office of Health and Human Services, providers, and advocates, and will build upon the progress made to date.

VIRGINIA

Grant Information

Name of Grantee Virginia Department of Medical Assistance Services

Title of Grant Virginia's Long-Term Support System Transformation Grant

Type of Grant Real Choice Systems Transformation Grant

Amount of Grant \$2,245,000 Year Original Funding Received 2006

Contact Information

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Subcontractor(s)

Jean Tuller of Tuller Consulting, Inc., strategic planning facilitator
The Medstat Group, Inc., evaluation contractor
The Partnership for People with Disabilities of Virginia Commonwealth University
Senior Navigator

Target Population(s)

Individuals who are elderly or have disabilities, and their families.

- Improved access to long-term support services: expansion of a one-stop system.
- Increased choice and control: enhancement of self-directed service delivery system.
- Transformation of information technology (IT) to support systems change.

- Recruit a No Wrong Door manager at the Department for the Aging to lead statewide and demographic expansion of the Community-based Coordinated Services System (CCSS).
- Develop a memorandum of understanding with Virginia 2-1-1 to leverage existing toll-free line and regional call centers to connect individuals without Internet access to CCSS.
- Train community support networks on the purpose and services of the one-stop system and consumer-directed online tool.
- Design a virtual roadmap for one-stop entry to long-term care information and services.
- Expand the CCSS to focus on including those individuals with disabilities who are at risk for institutionalization.
- Use person-centered planning approaches to facilitate change in service delivery practice (from programs to an individual approach) in communities across Virginia.
- Develop a protocol for follow-along to evaluate the flexibility of the plans, how they interface
 with other procedures and plans, the implementation of the person-centered plans,
 outcomes related to the plans, and changes in quality of life.
- Develop recommendations on the methodology needed to calculate individual budgets.
- Determine the roles and responsibilities of involved parties in the development of individual budgets (including consumer-directed [CD] employers, case managers, pre-authorization staff, CD services facilitators, and direct service workers).
- Develop a process to adjust individual budgets if they no longer meet individual needs.
- Develop an action plan for implementation of individual budgets that includes timelines, processes to determine budget amounts, person-centered planning, and mechanisms for feedback and evaluation (including outcome indicators).
- Pilot and implement the individual budgeting process in Virginia.
- Provide training and technical assistance to individuals and professionals for individual budgeting and other self-directed support mechanisms.
- Develop a business process action plan with outcome indicators for the development of the Individual Budget (IB) IT system, and pilot and implement the IB IT system statewide.
- Develop a Web-based application for the Office of Mental Retardation Information
 Technology to improve and streamline MR waiver services for individuals and families.

Abstract

Virginia's Systems Transformation (ST) Project is an important opportunity for stakeholders to continue to advance the agenda of reform and move closer to the Commonwealth's vision of "One Community" for all citizens. At the conclusion of the ST Project, Virginia will have (among other things) expanded Aging and Disability Resource Centers by increasing the number of sites and broadening the target population, created individual budgeting and explored other consumer-directed options, ensured a statewide fusion of the person-centered planning and self-direction practices, established a Web-based case management IT application in MR Home and Community-Based waivers, and produced a critical incident and management reporting system as a part of the Commonwealth's Quality Management System.

CONNECTICUT

Grant Information

Name of Grantee FAVOR, Inc.

Title of Grant Connecticut Family-to-Family Health Information Network

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$165,000 Year Original Funding Received 2005

Contact Information

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FAVOR, Inc.

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Rocky Hill, CT 06067

Subcontractor(s)

None.

Target Population(s)

Children with special health care needs (CSHCN), including those with mental health needs and their families, as well as providers, state agencies, and policy makers.

- Develop the Connecticut Family-to-Family Health Information Network and promote the Network across the State.
- Provide training, advocacy, and support to Connecticut families of CSHCN.
- Provide information and resources to providers.
- Develop policy responses to issues identified by families of CSHCN in Connecticut and implement a policy agenda.

- Provide outreach through printed, electronic, telephone, and face-to-face contact.
- Engage families through provision of direct support to meet their immediate needs.
- Provide health information specialist training annually.
- Convene quarterly meetings of the Family-to-Family Grant collaborators, regional medical homes, and others to discuss system issues related to the delivery of health care to Connecticut's CSHCN.
- Disseminate fact sheets and toolkits to parents and providers.
- Train Family-to-Family health information specialists.
- Provide supervision and ongoing training to the health information specialists.
- Provide direct individual Family-to-Family support, information, and training using a toolkit developed by the project.
- Document contacts, strategies, and issues through data collection using the Family Voices Solutions Database and anecdotal data.
- Conduct face-to-face meetings with the project staff and management team and include staff from the Regional Medical Home Support Centers and other medical home providers in the State.
- Disseminate printed material, including outreach material, toolkits, and fact sheets.
- Use the data collected to formulate policy agendas.
- Promote Family-to-Family policy issues with state legislators at the agency's annual legislative breakfast at the Capitol.
- Convene an annual legislative breakfast at the Capitol to promote the legislative agenda to policymakers.
- Track bills, legislation, and policy changes that are implemented as a result of project recommendations and action.

Abstract

FAVOR, a statewide family-directed advocacy organization for children's mental health, will administer the Connecticut Family-to-Family Health Information Network. The project will be operated in collaboration with the Connecticut Family Support Council, Easter Seals, Yale Center for Children With Special Health Care Needs, the Connecticut Department of Public Health, and Bridgeport Child FIRST Program.

The project will provide support, information, and advocacy to families in Connecticut who have CSHCN, including children with mental health needs. The primary outcome of this project will be to assist families and providers in navigating the public and private health care financing service delivery systems and to develop appropriate strategies and policies to improve these systems. The project will establish a statewide network of specialists who will be directly supporting families. These specialists will provide technical assistance, information, and direct advocacy to 360 families and will develop training materials and a toolkit that can be broadly disseminated to parents in the State. All information will be utilized to formulate recommendations for policy change, and families will be mobilized to promote those policy change recommendations.

IDAHO

Grant Information

Name of Grantee Idaho Parents Unlimited, Inc. (IPUL)

Title of Grant Idaho Family-to-Family Health Care Information and Education

Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$165,000 Year Original Funding Received 2005

Contact Information

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Subcontractor(s)

Idaho Hispanic Resource Center Consultant for graphics design and editorial/content writing for newsletter Evaluation consultant Database consultant/contractor

Target Population(s)

Children and youth who have special health care needs (CYSHCN) and their families, especially underinsured families throughout the State.

- Establish a sustainable, centralized statewide Family-to-Family Health Information Center based on identified needs.
- Provide outreach, dissemination of information, education, and training to families of CYSHCN.
- Create an infrastructure for collaboration and sustainability by developing new family and interagency relationships and strengthening the existing ties with community-based local, state, and national partners.

- Identify and recruit families of CYSHCN who want to be a part of the Family-to-Family Advisory Council, as well as key stakeholders/professionals who serve CYSHCN and want to be a part of the Advisory Council. Identify long-term strategies for sustainability by working closely with the Advisory Council.
- Identify and utilize the experiences of other funded Family-to-Family Health Information Centers across the State to help ensure that Idaho's plan stays on track and learns from prior experience.
- Establish a toll-free telephone line for CYSHCN and their families.
- Develop and disseminate information statewide about the Family-to-Family Health Information Center in Idaho via various marketing methods.
- Review and enhance the Medical Home of Idaho information to include a Family Module that is easily accessible on the Web.
- Develop specific health care information fact sheets based on the needs of families.
- Collaborate with existing Family-to-Family Health Information Centers and other resources on best practices and lessons learned in providing services to CYSHCN.
- Partner with other national, state, and local family organizations working with CYSHCN to identify ways to facilitate effective systems change and look for additional partnerships (i.e., immigration agency, foster care, adoption agencies that provide placement for CYSHCN).
- Serve as a clearinghouse for state-level organizations that are seeking family involvement for program and policy development and conferences. Work with families to mentor them into these roles through various family leadership skills development workshops or trainings.

Abstract

Idaho Parents Unlimited (IPUL) plans to expand the agency's existing services under the Family-to-Family grant to include new staff training on the health care system. This will enable IPUL to deliver current information on best practices in Medical Home models and on how to navigate and utilize home and community-based health care services. The new efforts will revise both IPUL's data collection methods and its internal data system so that it can provide a greater level of information and referral on health care—related services in Idaho. These new efforts will build on the services currently provided by the established IPUL statewide network of over 8,500 parents, parent groups, and disability-related professionals.

The Family-to-Family Project will provide services statewide. The statewide activities will develop training and information materials; present workshops; publish *The Idaho Parent Network*, a quarterly newsletter; create and maintain Internet and Web-based instruction; and offer other technologies (i.e., video conferencing). IPUL staff will conduct conferences and statewide meetings and will provide professional development for the parent education coordinators on health care issues.

MICHIGAN

Grant Information

Name of Grantee Michigan Parent Participation Program (PPP)

Title of Grant PPP Family-to-Family Health Care Information and Education

Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$165,000 Year Original Funding Received 2005

Contact Information

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Subcontractor(s)

Association for Children's Mental Health Issues Citizens to Uphold Special Education (CAUSE) New Center Community Mental Health Henry Ford Hospital Devoss Hospital

Target Population(s)

Children with special health care needs (CSHCN) and their families, especially underserved families (including the uninsured and underinsured).

- Provide information to increase access to and utilization of coordinated, ongoing care in a Medical Home, and health care and public health insurance for families of CSHCN.
- Increase outreach, training, and parent-to-parent support to underserved populations receiving special education and early intervention services.
- Increase and coordinate the dissemination of information on resources and services to families of children with genetic conditions, birth defects, and mental illness. Provide information on transitioning to adult health care, work, and independent living for CSHCN and their families.
- Ensure that families of CSHCN develop effective partnerships with service and health care providers, and that they are satisfied with the information, supports, and services that they received.

- Develop, print, and distribute a Medical Home brochure, a Medical Home workbook, a Watch Me Grow calendar page on health care resources and public health insurance options, a Physicians Health Care Resources and Public Health Insurance Options card, and a Family-to-Family Health Information and Education Center brochure.
- Develop and incorporate six training modules in the CSHCS On-Line Training Course and FSN Training Curricula: Health Care Access, Transition, Medical Home, Health Care Resources and Public Health Coverage Options.
- Conduct joint training and public outreach activities with the Citizens Alliance to Uphold Special Education (CAUSE)—the State Parent Training Institute, Early On—the State Early Intervention System, Michigan's 211 System, New Center Community Mental Health, the Association for Children's Mental Health (ACMH), and the Michigan Developmental Disabilities (DD) Council.
- Provide skill development; health and basic education rights, medical home, guardianship, social security, and other topics as determined by a family-to-family collaborative work group training; and technical assistance to families onsite and online.
- Expand the Family Support Network (FSN)—make the Parent Participation Program's (PPP's) toll-free Family Phone Line available to all parents of children with special needs; offer Family Support Training to Health Resource Parents; collect, store, and disseminate information on issues relative to home and community services and supports through the Lending Library; and establish and implement an information referral and tracking database.
- Provide in-service training to local health department staff persons who will identify and refer potential parents to FSN.
- Develop a Family-to-Family Web site and provide linkages to other sites (i.e., Emergency Preparedness, Early On, Bridges 4 Kids, CAUSE, DD Council, ACMH, Social Security, 211, AAP Medical Home, Michigan Protection and Advocacy, Genetics, and others as determined by the family-to-family collaborative work group).

Abstract

The purpose of the Michigan Parent Participation Program (PPP) Family-to-Family Health Information and Education Center is to expand and improve the information, education, parent-to-parent support, and decision-making opportunities available to all families of CSHCN in Michigan. To reach these objectives, PPP will work with a host of family, community, state, and national partners to enhance its existing network resources and expand its collaborative efforts for outreach, training, and parent-to-parent support. Partners will assist PPP in designing effective health, health care coverage, Medical Home and transition information, and education and training materials to supplement existing curricula. These materials will be designed to help families (a) obtain information so they can access the services necessary to keep their children at home in their communities, (b) know what health care coverage options are available to pay for medically-necessary services for their children, (c) identify a Medical Home, (d) develop effective partnerships with service providers and health care providers, (e) receive emotional parent-to-parent support, and/or (f) help prepare their youth for adulthood. PPP's Lending Library will be enhanced with relevant information and dissemination strategies, and new materials will be developed and integrated with existing resources.

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NEW HAMPSHIRE

Grant Information

Name of Grantee New Hampshire Coalition for Citizens with Disabilities

Title of Grant New Hampshire Family-to-Family Health Care Information and

Education Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$165,000 Year Original Funding Received 2005

Contact Information

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Coalition for Citizens with Disabilities

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Subcontractor(s)

Curriculum development, outreach, and translation consultants from Minority Health Coalition, National Family Voices Staff

Target Population(s)

Children and youth with special health care needs (CYSHCN) and their families and service providers.

- Create a sustainable infrastructure to increase state and local capacity to offer timely, appropriate training, technical assistance, and support to families of CYSHCN throughout the State.
- Increase access to and participation in family-selected community programs and activities for at least 2,700 families (100 per county/year) of CYSHCN via education, training, technical assistance (TA), support, and information dissemination to families and providers.
- Provide outreach, information, TA, and support to specific populations (i.e., grandparents raising CYSHCN, families of diverse cultural and ethnic backgrounds having CYSHCN, and families accessing SSI benefits for their CYSHCN) to enhance their access to community services and information.

- Review relevant literature and existing materials related to Individual Healthcare Plans (IHPs), Emergency Healthcare Plans, and other pertinent topics.
- Survey community service providers, along with a random sample of the 2,000 families from the New Hampshire Family Voices (NHFV) database, and families identified through liaisons with Minority Health Coalition, AARP, and other venues to identify priority content for the curriculum.
- Finalize curriculum and related materials based on survey results. Work with the Minority Health Coalition to ensure that all materials address the needs of diverse families.
- Work with Partners in Health (PIH) to determine the feasibility of PIH coordinators serving in the capacity of family leaders on a long-term basis, or at a minimum, assisting the project in identifying potential family leaders in their areas and providing ongoing support.
- Train at least nine family leaders, one from each of New Hampshire's nine counties, who will then provide training and offer support to families in their areas.
- Utilize NHFV's advisory committees and state partnerships to identify and implement strategies at both the state and regional/community levels.
- Provide individualized TA and support.
- Work with family leaders and partner organizations to identify and implement strategies to sustain these efforts at the state and regional/local levels.
- Identify community organizations, agencies, programs, and representative providers working with grandparents raising CYSHCN.
- Identify community organizations, agencies, programs, and representative providers working with families of diverse cultural or ethnic backgrounds who have CYSHCN.
- Collaborate with Title V, CYSHCN program, and SSI Outreach Coordinator to develop outreach to families receiving SSI benefits to enhance access to information and education.
- Work with project partners and the Family Resource Connection to generate and implement strategies to sustain dissemination and outreach efforts.

Abstract

New Hampshire Family Voices (NHFV) will create a Family-to-Family Center to implement and evaluate state and regional training, TA, and support infrastructures to ensure that all families of CYSHCN in New Hampshire have timely access to services and information in their communities. The Family-to-Family Center will focus on:

- Planning—NHFV will develop and implement a training curriculum to help families develop IHPs for children and adolescents to support their full inclusion in community activities and services. NHFV will also support informed decision-making about the Home and Community-Based waiver supports available through New Hampshire Medicaid.
- Learning—Parents will learn concepts and skills to support their partnerships with professionals serving CYSHCN.
- Networking—NHFV will establish a network of trained, supportive parents to assist families
 in their region of the State with the development of health care plans for CYSHCN.

OREGON

Grant Information

Name of Grantee Family Action Coalition Team

Title of Grant Oregon Family-to-Family Health Care Information and Education

Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$165,000 Year Original Funding Received 2005

Contact Information

Becky Adelmann
Project Manager/Coordinator
Family Voices of Oregon
Family Action Coalition Team
7830 SE Foster Road

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Subcontractor(s)

Family Voices of Oregon Disability Navigators, Inc.

Portland, OR 97206-5140

Target Population(s)

Children or youth with disabilities and/or chronic health needs (including mental and emotional health needs) and their families.

- Develop infrastructure for a Family-to-Family Center, emphasizing family leadership and partnerships.
- Expand the network of families, youth, and providers who are knowledgeable and willing to share their expertise.
- Identify resources, materials, and strategies to adapt for diverse families and youths.
- Develop a dissemination plan to include multiple approaches for sharing information, educating, and mentoring families.
- Identify tracking system(s) for data, including the number of participating families, evaluative information on information/services received, issues, and gaps/challenges in services.
- Evaluate experiences and share data/lessons learned with policymakers to promote systems change and quality improvement.

- Establish contracts.
- Arrange for Steering Committee to plan and guide meetings.
- Acquire portable equipment and Internet access to support project activities.
- Identify family and youth to serve as educators and mentors.
- Provide training and education for Community Guides.
- Identify resource materials.
- Develop and adapt materials for diverse families.
- Convene regular meetings of Dissemination Workgroup.
- Track family-to-family encounters.
- Compile feedback and evaluation forms and surveys.
- Convene regular meetings of Evaluation Workgroup.
- Identify promising practices and publish or present to providers and families/groups.
- Compile evaluation results and data for policymakers.

Abstract

Oregon's Family-to-Family Health Information and Education Center will be spearheaded and coordinated by Family Voices in Oregon (FVO), which exists under the umbrella of the Family Action Coalition Team (FACT). Rather than creating a new physical location, Oregon's Family-to-Family Center will use the facilities of FACT member organizations. FACT comprises an extensive network of families and family organizations, which together bring collective capacity and meaningful collaboration to launch a successful family-driven center. The overarching goal of the project is to develop a coordinated statewide education and dissemination system for families who have children or youths with disabilities and/or chronic health needs, including mental and emotional health. Unlike many traditional information and referral centers, this effort will be managed through family-to-family contacts. Veteran families will share experiences and effective strategies with families seeking information and supports. Specific attention will be focused on People First language and multiple formats to honor culture, learning styles, and literacy levels of families in Oregon.

Secondary goals for developing a center include (1) developing an infrastructure to carry out activities; (2) expanding the network of families and youths who are knowledgeable and willing to share their expertise; (3) identifying resources, materials, and strategies, and adapting them for diverse families and youths; (4) developing a dissemination/training/mentoring plan that will include multiple approaches to information-sharing; (5) tracking data that identifies useful information, successful strategies, and gaps and challenges in service; and (6) sharing information and lessons learned with policy/decision-makers to promote systems change and quality improvement.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

RHODE ISLAND

Grant Information

Name of Grantee Rhode Island Parent Information Network (RIPIN)

Title of Grant Rhode Island Family-to-Family Health Care Information and

Education Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$165,000 Year Original Funding Received 2005

Contact Information

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Rhode Island Parent Information Network 175 Main Street

Pawtucket, RI 02860

Subcontractor(s)

Evaluation consultant

Target Population(s)

Children and youth with special health care needs (CYSHCN) and their families, as well as the professionals, policymakers, community agencies, and organizations that care for them.

- Increase leadership capacity to promote effective and enduring improvements in community long-term support systems.
- Contribute to the understanding of effective and efficient methods of accessing quality and appropriate services and supports.
- Promote knowledge about and opportunities for family and professional partnerships in policies and practices related to individual and family-directed supports within integrated community settings.

- Review Rhode Island Parent Information Network (RIPIN) workshop materials specific to CYSHCN and promote through outreach to Family Voices audience.
- Promote RIPIN and other workshops to audiences of the Family-to-Family Health Information and Education Center.
- Develop training materials to address health care financing, medical homes, leadership, and advocacy.
- Provide ongoing technical support.
- Provide information about health, health insurance, family support, diagnosis specifics, public and private programs, policy and legislative updates, medical homes, early screening and intervention, and access to services and supports.
- Enhance and expand the ongoing development of the statewide peer-to-peer network,
 Family-to-Family Network of Rhode Island.
- Increase attendance/participation at conferences and fairs by providing program brochures, newsletters, and other timely information.
- Increase contact with physicians' offices, hospital clinics, community health centers, special education advisory committees, specialized daycare centers, and professional organizations.
- Organize an outreach plan utilizing RIPIN-staffed regional teams, Parent Consultants working in Early Intervention sites, and pediatric medical practices through the Pediatric Practice Enhancement Project (PPEP).
- Promote the use of the Family-to-Family Network of Rhode Island through multiple methods designed to connect families with other families, obtain information about upcoming events, and exchange other information useful to families of CYSHCN.

Abstract

RIPIN is a statewide, nonprofit organization with a reach that extends to every Rhode Island community, the State's major family-serving systems, health care providers, schools, associations, and agencies. Its mission is to inform, educate, support, and empower all families to be equal partners in advocacy for the education, health, and socioeconomic well-being of their children. In addition, RIPIN works to achieve family-centered systems changes that are culturally competent and community-based by partnering and collaborating with key stakeholders at community, state, and national levels.

Through its Family Voices program, RIPIN will establish itself as Rhode Island's Family-to-Family Health Information and Education Center by focusing on three areas: leadership capacity to promote effective and enduring improvements in community long-term support systems; effective and efficient methods of accessing quality, appropriate services, and supports; and family/professional partnerships in policies and practices related to individual and family-directed supports within integrated community settings.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

andypope@familyconnectionSC.org

SOUTH CAROLINA

Grant Information

Name of Grantee Family Connection of South Carolina, Inc. (FCSC)

Title of Grant Family-to-Family Health Care Information and Education Center

for South Carolina

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$165,000 Year Original Funding Received 2005

Contact Information

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Executive Director

Family Connection of South Carolina, Inc. 2712 Middleburg Drive, Suite 103-B

Columbia, SC 29204

Subcontractor(s)

Web site developer consultant Evaluation consultant

Target Population(s)

Children with special health care needs (CSHCN) and their families, providers, and other stakeholders.

- Develop the capacity of the statewide Family-to-Family Health Care Center.
- Provide technical assistance (TA) and facilitate peer-to-peer TA of varying intensity and duration, including information, referrals, and short-term assistance.
- Collect, store, and disseminate information on issues relevant to home and community services and supports, local providers, philosophy of consumer and family-directed care, medical home, and health insurance.
- Develop and disseminate original materials to assist CSHCN and their families, providers, and other stakeholders with the goal of meeting identified needs or gaps in available materials.
- Provide input and feedback to CMS, state agencies, and existing Family-to-Family Centers on Family Connection of South Carolina, Inc.'s (FCSC's) ongoing operations and training activities. Identify barriers that will impact future policy decisions and update CMS with reports.

- Establish project management.
- Train at least 120 parents as volunteer Health Care Resource parents.
- Provide peer-to-peer telephone or e-mail TA.
- Provide in-person TA.
- Present at Hopes and Dreams Conference.
- Collect relevant information and resources.
- Disseminate information and materials.
- Identify gaps in available materials, particularly for underserved populations.
- Develop additional materials.
- Disseminate developed materials.
- Provide reports on project activities to CMS and project partners.
- Provide information on barriers and recommendations for change to CMS and relevant state agencies.
- Participate in opportunities for exchanges between Centers.

Abstract

Family Connection of South Carolina, Inc. (FCSC), a nonprofit statewide organization consisting of over 15,000 families of CSHCN, will establish a statewide Family-to-Family Health Care Information and Education Center that builds on the best practices from other Family-to-Family Centers. FCSC will promote the philosophy of individual and family-directed supports; provide education, training, and information dissemination to families with CSHCN, parent groups, providers, and other stakeholders; provide training and education on home and community services; help families access their potential eligibility for public programs and benefits; and provide a forum for peer group discussions and interaction. The Family-to-Family Center will draw upon many resources, especially its member families' years of knowledge and experience with the long-term care system. Through parent-to-parent connections and parent/professional collaborations, information for families of CSHCN will be available in a readily accessible manner. Grant-funded staff will collaborate with state agencies and other projects and organizations to develop family friendly materials for dissemination and training. Materials from partner organizations and publications from existing national resources will also be used.

FCSC will maintain a directory of access to new and existing home and community-based resources, which will aid in creating informed and involved consumers in their local communities. FCSC will build on its existing network and develop enhanced relationships with SC ACCESS, a database of comprehensive information and assistance for children and adults of all ages with disabilities, long-term illnesses, or other needs.

TEXAS

Grant Information

Name of Grantee Texas Parent to Parent (TxP2P)

Title of Grant Texas Parent to Parent Health Care Information and Education

Program

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$165,000 Year Original Funding Received 2005

Contact Information

Laura J. Warren, Executive Director Texas Parent-to-Parent

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Subcontractor(s)

None.

Target Population(s)

Children with special health care needs (CSHCN) and their families, as well as the service providers and other professionals who work with them.

- Provide health care information, resources, programs, and other necessary information to parents of CSHCN, parent groups, and service providers/professionals who work with CSHCN on health care services.
- Provide training opportunities to parents of CSHCN and other stakeholders.
- Promote and educate parents, parent groups, and providers/professionals about the philosophy of home and community-based supports.
- Train and provide continuing support to Supporting Parent Volunteers.
- Provide opportunities for peer support and discussions between parents.
- Collaborate with existing Family-to-Family Health Care Information and Education Centers and the Texas Department of State Health Services (TX DSHS).
- Provide opportunities for parents of CSHCN to become parent leaders in health care policymaking and advocacy.

- Provide general information about and referrals to programs, services, and benefits that can help children stay in their community and progress in their development. Provide individualized information on services for children based on families' personal information (i.e., where they live in Texas, their income information, the age of the child, and the child's type of health care needs and/or disabilities).
- Provide outreach, education, and training opportunities for parents of CSHCN, parent groups, service providers, and other professionals who work with CSHCN on health care services and resources for CSHCN.
- Provide a one-on-one match with a Supporting Parent Volunteer who will supply information, referrals, health care information, and emotional support to new parents or parents new to the special health care need.
- Develop and promote a Transition Program for parents of teens and young adults through written information, articles in the newsletter and on TxP2P's Web site, one-on-one support from a Transition Coordinator, and trainings to be provided in conjunction with other monthly trainings.
- Provide opportunities for peer support, discussion, and interaction through the expansion of Internet listservs, the annual statewide parent conference, and matches with Supporting Parent Volunteers. Provide technical assistance and advertising for local parent groups while continuing to identify and provide additional avenues of interaction for parents.
- Maintain current and accurate information on resource lists, Web site resource directory, and newsletter.
- Collaborate with existing Family-to-Family Health Care Information and Education Centers in other states to benefit CSHCN. Continue existing collaborations and pursue additional ones with TX DSHS on best practices and findings from resource dissemination.
- Provide opportunities for parents of CSHCN to become parent leaders in health care policymaking and advocacy.

Abstract

Texas Parent to Parent (TxP2P) will operate a Family-to-Family Health Care Information and Education Center in Texas to assist families of children with disabilities and special health care needs. Through the Center, TxP2P will provide families with the necessary information and resources to make informed choices about the care that their children receive, especially regarding services and service providers. The Family-to-Family Center will also assist in long-term planning, with the goal of ensuring that children can continue to live at home or in an integrated community setting whenever possible. TxP2P will ensure that families are aware of the philosophy of home and community-based supports. Information will also be provided to parent groups, service providers, and other professionals who work with CSHCN.

VIRGINIA

Grant Information

Name of Grantee Medical Home Plus, Inc.

Title of Grant The Virginia Integrated Network of Family Support Organizations

Center (VA INFO Center)

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$165,000 Year Original Funding Received 2005

Contact Information

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Co-Director, Virginia Family to Family Resource Center

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Dana Yarbrough, Co-Director 804-795-1481 PTPofVA@aol.com

Virginia Family to Family Resource Center Executive Director of Parent to Parent of Virginia

Subcontractor(s)

Graphics design consultant

Evaluation and strategic planning consultants

Target Population(s)

Families with children and youth with special health care needs (CYSHCN), as well as grassroots organizations and other stakeholders.

- Create a statewide Family-to-Family Health Care Information and Education Center (called the Virginia Family to Family Resource Center) designed to strengthen and expand the capacity to connect CSHCN and their families with services and resources that promote health and well-being.
- Provide leadership (through expansion of the newly forming Integrated Network of Family Support Organizations coalition—called VA INFO) to the Center by linking collaborators and grassroots organizations, and promoting awareness, support, and participation of families.
- Develop a statewide and national presence that supports systems change, providing feedback to Virginia's stakeholders, CMS, and existing Family-to-Family Health Care Information and Education Centers to improve health care for children.

- Gather, create, and disseminate information on resources, services, and training opportunities for families with CYSHCN.
- Promote training and education on home and community services and support for CYSHCN, parent groups, providers, and other stakeholders.
- Create a timely and cost-effective process for sharing information and making referrals that support children and their families in their communities across the Commonwealth (e.g., Medicaid waiver, respite, home health, transportation, etc.) through partnerships.
- Maintain updated information on the Center Web page and share point portal (electronic workspace).
- Coordinate matches between families for emotional support.
- Partner with family support groups and/or agencies to create new resources for families.
- Provide forums for families in different parts of the State; facilitate peer group discussion.
- Create a process that enables providers and family support organizations to work together
 to identify needs, develop proposals, and secure funding to address unmet needs of
 children with disabilities and special health care needs in Virginia.
- Participate in state and local councils, committees, and task forces to help facilitate systems improvements.
- Provide input and feedback to Virginia's stakeholders, CMS, existing Family-to-Family Health Care Information and Education Centers; and status updates to legislators.

Abstract

Today in Virginia, family members of over 270,000 CYSHCN (approximately 15 percent of Virginia's total child population) struggle to find resources and services. The percentage of Virginia's children with disabilities (ages birth to 17 years) is higher than the national average, as is the percentage of these children living in poverty (*National Survey of Children with Special Health Care Needs*). Family Voices of Virginia (a program of Medical Home Plus, Inc.) and Parent to Parent of Virginia, in collaboration with VA INFO (the Virginia Integrated Network of Family Support Organizations), are committed to addressing this critical need.

The Virginia Family to Family Resource Center will build capacity in the Commonwealth to assist CYSHCN and their families by gathering and disseminating information, providing training and technical assistance, developing resources, creating partnerships across agencies and family support organizations, promoting individual- and family-directed supports, and collaborating with other Family-to-Family Health Care Information and Education Centers nationally. The work of the Center will be assisted by the family support coalition (VA INFO), whose members are committed to supporting the development and operation of the Center, and working toward a "seamless" system of care for CYSHCN and their families.

WASHINGTON

Grant Information

Name of Grantee Washington PAVE

Title of Grant Family Voices Health Information and Education Center

Type of Grant Family-to-Family Health Care Information and Education Centers

Amount of Grant \$165,000 Year Original Funding Received 2005

Contact Information

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Washington Family Voices Washington PAVE 6316 S. 12th Street. Suite E

6316 S. 12th Street, Suite B Tacoma, WA 98465-1900

Subcontractor(s)

None.

Target Population(s)

Children with special health care needs (CSHCN) and their families, as well as the advocacy groups, stakeholders, and constituency groups that work with them.

- Establish a statewide family-directed Family-to-Family Health Information Center in partnership with the Washington Family-to-Family Network (WFFN).
- Survey family needs to identify the information and training to be developed and coordinated through existing Washington State Parent-to-Parent Support Programs Regional Coordinators.
- Expand and improve information, referrals, and linkages to existing community, state, and national programs and agencies providing information on health care and home and community-based services (HCBS).
- Collect data on issues, barriers, and gaps that families identify in accessing public and private health care systems.
- Promote and participate in a collaborative leadership forum with parents, youth, advocacy
 groups, stakeholders, and constituency groups to develop strategies to promote effective,
 quality, and integrated systems of long-term care for children and youth with special health
 care needs.

- Establish the Family Advisory Committee, which will meet four times each year in conjunction with the WFFN Partnership Committee.
- Develop a brochure for the Center and disseminate it through a wide variety of current family support and stakeholder groups.
- Develop a self-assessment tool to evaluate the leadership and decision-making skills of the Family Advisory Committee.
- Develop a tool to evaluate the WFFN Partnership with the Center and Family Advisory Committee.
- Survey families in Washington to learn about the training and information they need in order to improve their children's access to health care and HCBS.
- Develop and set up guidelines for the listserv. Develop a Web page on the Washington PAVE Web site for the program.
- Use the Family Voices Solutions Data System to collect information on issues, barriers, and gaps. Obtain technical assistance from Family Voices on how to expand the system to collect the data needed for Washington State.
- Meet with the ARC and the Developmental Disabilities Council to sponsor and support meetings to develop strategies based on the information gathered by the Family Voices Solutions Data System.

Abstract

The Washington Family Voices Health Information and Education Center will operate as a program within Washington PAVE. PAVE, a parent-directed organization, exists to increase independence, empowerment, and future opportunities and choices for consumers with special needs, their families, and communities, through training, information, referral, and support. Families have consistently identified the need for timely, high-quality services, supports, and information in the health care and community service systems. The complexities of the current systems, multiple funding streams, and lack of coordination make it difficult for families to obtain the services their child needs.

To address these needs, the Center will promote the core goals of the CMS Family-to-Family Health Care Information and Education Center and create a clearinghouse of information that will be supported through an existing partnership with WFFN. The Center will build on existing community-based supports and leadership to identify and support families with the information they need in making decisions for their children and youth with special health care needs. The Center will work to promote quality, effective, integrated systems of care to align with the goals and performance measures of the Washington State Children with Special Health Care Needs Program.

The Center will collect data with the Family Voices Solutions Data System to move the goals of the Center forward.

Note: This Compendium form was not reviewed by the Grantee prior to publication.

Appendix: List of Completes

Community-Integrated Personal Assistance Services and Supports Grants (C-PASS) 2001

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

Community-Integrated Personal Assistance Services and Supports Grants (C-PASS) 2002

COLORADO
DISTRICT OF COLUMBIA
HAWAII
INDIANA
KANSAS
NORTH CAROLINA
TENNESSEE
WEST VIRGINIA

Nursing Facility Transitions Grants (NFT) 2001

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

(continued)

Nursing Facility Transitions Grants (NFT) 2002

ALABAMA

ARKANSAS

CALIFORNIA (ILP)

DELAWARE (ILP)

DELAWARE

LOUISIANA

MINNESOTA (ILP)

NEBRASKA

NEW JERSEY (ILP)

NEW JERSEY

NORTH CAROLINA

OHIO

RHODE ISLAND

SOUTH CAROLINA

UTAH (ILP)

WYOMING

Real Choice for Systems Change Grants (RC) 2001

ALABAMA

ARKANSAS

DELAWARE

FLORIDA

GUAM

HAWAII

IDAHO

ILLINOIS

IOWA

KENTUCKY

MAINE

MARYLAND

MASSACHUSETTS

MICHIGAN

MINNESOTA

MISSOURI

NEBRASKA

NEW HAMPSHIRE

NEW JERSEY

NORTH CAROLINA

OREGON

SOUTH CAROLINA

TENNESSEE

VERMONT

VIRGINIA

Real Choice for Systems Change Grants (RC) 2002

ALASKA

CALIFORNIA

COLORADO

COMMONWEALTH OF NORTHERN MARIANA ISLANDS

CONNECTICUT

DISTRICT OF COLUMBIA

GEORGIA

INDIANA

KANSAS

LOUISIANA

MISSISSIPPI

MONTANA

NEVADA

NEW MEXICO

NEW YORK

NORTH DAKOTA

OHIO

OKLAHOMA

PENNSYLVANIA

RHODE ISLAND

TEXAS

UTAH

WASHINGTON

WEST VIRGINIA

WISCONSIN

Alphabetical Listing

ALABAMA (NFT-ILP)

ALABAMA (NFT-SP)

ALABAMA (RC)

ALASKA (C-PASS)

ALASKA (NFT-SP)

ALASKA (RC)

ARKANSAS (C-PASS)

ARKANSAS (NFT-SP)

ARKANSAS (RC)

CALIFORNIA (NFT-ILP)

CALIFORNIA (RC)

COLORADO (C-PASS)

COLORADO (NFT-SP)

COLORADO (RC)

COMMONWEALTH OF NORTHERN MARIANA ISLANDS (RC)

(continued)

Alphabetical Listing (continued)

CONNECTICUT (NFT-SP)

CONNECTICUT (RC)

DELAWARE (NFT-ILP)

DELAWARE (NFT-SP)

DELAWARE (RC)

DISTRICT OF COLUMBIA (C-PASS)

DISTRICT OF COLUMBIA (RC)

FLORIDA (RC)

GEORGIA (NFT-ILP)

GEORGIA (NFT-SP)

GEORGIA (RC)

GUAM (C-PASS)

GUAM (RC)

HAWAII (C-PASS)

HAWAII (RC)

IDAHO (RC)

ILLINOIS (RC)

INDIANA (C-PASS)

INDIANA (NFT-SP)

INDIANA (RC)

IOWA (RC)

KANSAS (C-PASS)

KANSAS (RC)

KENTUCKY (RC)

LOUISIANA (NFT-SP)

LOUISIANA (RC)

MAINE (RC)

MARYLAND (NFT-ILP)

MARYLAND (NFT-SP)

MARYLAND (RC)

MASSACHUSETTS (NFT-SP)

MASSACHUSETTS (RC)

MICHIGAN (C-PASS)

MICHIGAN (NFT-SP)

MICHIGAN (RC)

MINNESOTA (C-PASS)

MINNESOTA (NFT-ILP)

MINNESOTA (RC)

MISSISSIPPI (RC)

MISSOURI (RC)

MONTANA (C-PASS)

MONTANA (RC)

NEBRASKA (NFT-SP)

NEBRASKA (RC)

NEVADA (C-PASS)

NEVADA (RC)

Alphabetical Listing (continued)

NEW HAMPSHIRE (C-PASS)

NEW HAMPSHIRE (NFT-SP)

NEW HAMPSHIRE (RC)

NEW JERSEY (NFT-ILP)

NEW JERSEY (NFT-SP)

NEW JERSEY (RC)

NEW MEXICO (RC)

NEW YORK (RC)

NORTH CAROLINA (C-PASS)

NORTH CAROLINA (NFT-SP)

NORTH CAROLINA (RC)

NORTH DAKOTA (RC)

OHIO (NFT-SP)

OHIO (RC)

OKLAHOMA (C-PASS)

OKLAHOMA (RC)

OREGON (RC)

PENNSYLVANIA (RC)

RHODE ISLAND (C-PASS)

RHODE ISLAND (NFT-SP)

RHODE ISLAND (RC)

SOUTH CAROLINA (NFT-SP)

SOUTH CAROLINA (RC)

TENNESSEE (C-PASS)

TENNESSEE (RC)

TEXAS (NFT-ILP)

TEXAS (RC)

UTAH (NFT-ILP)

UTAH (RC)

VERMONT (RC)

VIRGINIA (RC)

WASHINGTON (NFT-SP)

WASHINGTON (RC)

WEST VIRGINIA (C-PASS)

WEST VIRGINIA (NFT-SP)

WEST VIRGINIA (RC)

WISCONSIN (NFT-ILP)

WISCONSIN (NFT-SP)

WISCONSIN (RC)

WYOMING (NFT-SP)