Real Choice Systems Change Grants

Compendium
Third Edition

U.S. Department of Health and Human Services
Centers for Medicare & Medicaid Services
March 2004

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 awarded approximately $158 million in Systems Change Grants for Community Living to 49 States and 2 Territories and the District of Columbia. We have prepared this Third 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 identify other Grantees with similar goals and activities. A web-based edition of the Compendium will be made available on the CMS website at http://cms.hhs.gov/newfreedom/accomplish.asp as well as on the Home and Community Based Resource Network (HCBRN) website at http://www.hcbs.org.

The Compendium contains basic information about each of the Real Choice Systems Change Grantees. It is divided into sections corresponding to the different types of grants: Community-Integrated Personal Assistance Services and Supports grants, Nursing Facility Transitions—State Program grants and Nursing Facility Transitions Independent Living Partnership grants, Real Choice Systems Change grants, and for the grants awarded in FY 2003—Feasibility Studies and Development grants and Research and Demonstration grants. Each section is alphabetical 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.

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

Sincerely,

Glenn A. Stanton
Acting Director, Disabled and Elderly Health Programs Group

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ALASKA

Grant Information

Name of Grantee	Department of Administration, Division of Senior Services
Title of Grant	Alaska's Personal Assistance Services and Supports Project
Type of Grant	Community-Integrated Personal Assistance Services and Supports
Amount of Grant	$900,000
Year Original Funding Received	2001

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Subcontractor(s)

Center for Human Development, University of Alaska, RSA

Governor's Council on Disabilities and Special Education, RSA

Target Population(s)

Individuals with disabilities or long-term illnesses, provider agencies, and other key stakeholders.

Goals

- Improve personal assistance services that are consumer-directed or controlled.
- Develop statewide training standards and competency testing for personal assistants working in agency-based programs.
- Increase training opportunities for personal assistants.
- Provide technical assistance to provider agencies, which advances the concept of individual dignity, choice, and consumer input and control.
- Provide opportunities for consumer feedback to provider agencies and the Division of Senior Services.

Activities

- Determine standards, develop competency test and testing process, and develop curricula for statewide training and testing.
- Identify technical assistance needs and a plan for providing technical assistance either directly or through a contractor.
- Develop RFP for regional training contracts.
- Assist consumer-directed PCA agencies in developing training manuals.
- Develop standardized consumer feedback form for all provider agencies.
- Conduct statewide consumer satisfaction survey.

Abstract

Alaska's Personal Assistance Services and Supports (PASS) project will be used to improve personal assistance services that are consumer-directed or controlled. The project will build upon existing and planned changes to Alaska's personal assistance programs, administered by the Division of Senior Services (DSS). The consumer-directed program (CDPAS), which provides consumers with the option to hire, train, and supervise their personal assistants, with the support of a fiscal intermediary agency, was implemented in October of 2001. Changes are also being proposed to the agency-based program, which will result in greater consumer choice and availability of services. These changes are scheduled for implementation in 2002.

Project funds will be used to develop training programs and provide technical assistance to provider agencies to improve consumer control and input for those individuals receiving agency-based services. Training will also be made available to individuals with disabilities or long-term illnesses and other key stakeholders to advance the concepts of individual choice and consumer control. Funds will also be used to implement strategies to increase the recruitment and retention of personal assistants.

ARKANSAS

Grant Information

Name of Grantee	Department of Human Services Division of Developmental Disabilities (DDS)		
Title of Grant	DDS Pass Grant		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$900,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

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Oregon Technical Assistance Corporation	Jean Tuller	503-364-9943
Independent Living Services	Jackie Fliss	501-327-5234
Ouachita Industries, Inc.	Sandra Kennedy	870-836-3056
Rainbow of Challenges, Inc.	Patti Manus	870-777-4501
Bost Inc.	Kent C. Jones	479-478-5551
Board of Trustees, University of Arkansas/ People First	Kim Worlow	870-488-9000

Target Population(s)

Individuals who meet the definition of developmental disabilities as defined by Arkansas state statute.

Goals

- Enhance consumer self-advocacy.
- Improve quality of life for individuals receiving services through the developmental disabilities system, in area of direct care staff.
- Explore new options for service delivery that embrace the concepts of self-determination and consumer choice and control.

Activities

- Develop a DDS advisory council composed of consumers and families to provide guidance as Arkansas seeks to incorporate best practices into the service delivery system.
- Enhance the self-advocacy network by empowering consumers and advocates with information from a website and handbook.
- Develop an advertising campaign and materials for recruiting direct support professionals to provide community-based services.
- Commission a study and develop new service delivery options to include a one-stop shopping model inclusive of fiscal intermediaries and community boards.

Abstract

The Division of Developmental Disabilities Services through the PASS grant seeks to promote a change in the way services are provided to individuals with developmental disabilities. Our current model of cursory input as "consumer control" is no longer acceptable to many individuals who request and/or receive services through DDS. Concepts of independence, self-determination, and consumer control will be included as we move to design a more flexible and responsive system.

Through the PASS grant, DDS will develop an advisory council, train and support self-advocacy networks, and create an interactive website and handbook. These accomplishments will create an environment that will empower individuals and families to advocate for changes to the system, from initial design to implementation. The development of new service delivery system options that expand consumer choice and control and enhance quality is also a goal of this grant.

GUAM

Grant Information

Name of Grantee	Department of Integrated Services for Individuals with Disabilities
Title of Grant	Inadanñá para Tinilaika—Partners for Change
Type of Grant	Community-Integrated Personal Assistance Services and Supports
Amount of Grant	$300,000
Year Original Funding Received	2001

Contact Information

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Subcontractor(s)

Catholic Social Services	Cerila Rapadas	671-635-1410
Guam Center for Excellence in Developmental Disabilities Education, Research and Services	Heidi San Nicolas	671-735-2480/81

Service Coordinator to be decided.
Off-island consultant specializing in individualized budgeting to be decided.
Resource Developer to develop a Creative Funding Task Force to be decided.

Target Population(s)

Ten individuals with developmental disabilities in need of personal assistance services who will participate in a 6-month pilot project. These individuals may include individuals who currently reside in group home settings, individuals who are inappropriately placed in institutions, and individuals who have minimal support systems.

Goals

- Develop and implement an individualized budgeting program that incorporates the development of an infrastructure representative of the needs and choices of persons with disabilities and their families.
- Develop a database infrastructure to create a system to track individual budgets and expenses under consumer-directed systems, and to conduct ongoing needs assessments of the number of persons with disabilities in need of personal assistance services.
- Promote and facilitate strong cross-program/natural support partnerships to optimize funding sources, and identify other creative funding mechanisms for the individualized budgeting program.

Activities

- Pilot and implement the individualized budgeting program.
- Develop an emergency response system for the individualized budgeting program.
- Develop consumer-directed quality assurance/personal outcomes measures that promote consumer and family involvement.
- Develop a Creative Funding Task Force to identify and research various funding alternatives and a mechanism for developing a comprehensive consumer-directed service delivery system.

Abstract

Guam's citizens with significant disabilities are in compelling need of personal assistance services. Although personal assistance is the most frequently used long-term care service throughout the United States, there are no personal assistance services available on Guam to enable persons with disabilities to live integrated and meaningful lives in the community. Due to the lack of personal assistance services, persons with disabilities are inappropriately placed in treatment facilities, continue to remain in congregate settings, and experience prolonged waiting periods for housing and supportive services. This problem is also aggravated because Guam is ineligible for funding under SSI and there is a cap on federal expenditures for Guam's Medicaid program.

Established in 1997, the Department of Integrated Services for Individuals with Disabilities (DISID) has experienced a rapid influx of persons with disabilities in need of supportive services. With a shortage of funding levels coupled with program overloads, there has been little or no hope for assistance or funding to develop an infrastructure to expand much-needed services.

DISID in partnership with two housing support providers, Guma' Mami and Catholic Social Services, proposes to create a model demonstration individualized budgeting program entitled: *Inadanñá para Tinilaika—Partners for Change* for individuals with disabilities who require supports to live in the most integrated community setting to meet their needs and preferences. This pilot project will develop Guam's individualized budgeting infrastructure for persons with significant disabilities; implement an individualized budgeting pilot program; enhance interagency and natural support partnerships by sustaining a network of valuable supports, and develop consumer-directed quality assurance/personal outcomes measures that promote consumer/family involvement, to name a few activities.

MICHIGAN

Grant Information

Name of Grantee	Department of Community Health, Long Term Care Initiative		
Title of Grant	Community-Integrated PASS Grant		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$755,972	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Developmental Disabilities Institute Wayne State University	Sharon Milberger, Sc.D. smilberg@math.wayne.edu	313-577-2654

Target Population(s)

All Michigan residents who receive Medicaid funded personal assistance services.

Goals

Optimize community integration and quality of life for children and adults by offering maximum consumer control of personal assistance and supports in all programs.

Activities

- Complete a service delivery system analysis.
- Forecast utilization possibilities and conduct cost analysis to support budget neutrality.
- Establish comparable assessment tools and care planning protocols across programs.
- Provide training and technical support for consumers and providers.
- Develop coordinated information systems.
- Integrate changes into ongoing programs for sustainability.

Abstract

Although in recent years Michigan has improved the quality of and expanded publicly funded personal assistance services and supports (PASS), the service system for people with functional limitations will have to undergo infrastructure reform if it is to meet future challenges. Presently in Michigan, five discrete programs offer PASS and serve over 73,000 children and adults. Each program was developed at different points in time in response to different needs and has its own eligibility criteria, care planning protocols, assessment tools, information system, and varying degrees of consumer control.

This 3-year project builds on existing system strengths to achieve radical systems change that will optimize community integration and quality of life for children and adults by offering maximum consumer control of PASS in all programs. Project activities include a service delivery system analysis to clearly identify system-level needs that involve all stakeholders, including consumers and families; a cost analysis to identify possible changes while maintaining cost neutrality; training and technical assistance to consumers, personal assistants, caregivers, and agency staff; developing comparable care planning protocols and assessment tools; coordinating information systems; supporting a sustainable long-term care workforce; and establishing feedback mechanisms for quality assurance for PASS in all programs.

A consumer task force will ensure consumer involvement in the implementation of all project activities. In addition to the integration of systems changes into ongoing program development, sustainability summits involving all stakeholders will convene in Years 2 and 3 to develop a plan to ensure that each project activity is sustained beyond the grant period. Evaluation strategies using an empowerment evaluation model will be implemented throughout the project to ensure that formative and summative data results will inform ongoing project activities.

MINNESOTA

Grant Information

Name of Grantee	Department of Human Services Continuing Care for Persons with Disabilities
Title of Grant	Pathways to Choice: Minnesota's Consumer-directed Personal Assistance Program
Type of Grant	Community-Integrated Personal Assistance Services and Supports
Amount of Grant	$900,000 ***Year Original Funding Received*** 2001

Contact Information

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Subcontractor(s)

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Target Population(s)

Consumers of all ages with all types of disabilities, especially communities of color.

Goals

- Increase the use of consumer-directed options for PCA services.
- Increase the availability of personal care workers.

Activities

- Develop consumer-initiated partnership and support networks to increase options for consumer-directed services.
- Develop programs to teach consumers fiscal skills to achieve savings that can be used to pay higher salaries for personal assistance workers.
- Develop consumer-tested training materials that can be shared on the Internet.

Abstract

For people of all ages with disabilities or long-term illnesses, Minnesota has developed a community-based system of comprehensive services with an array of options to move or keep people out of institutions. In its Medicaid plan and waiver services, the state offers personal assistance services or personal care assistance (PCA) services, with options giving consumers greater control over their service. However, very few consumers currently use these consumer-directed PCA options. In addition, as consumers note, service availability means little if there are no PCA workers available to get them out of bed in the morning. With one of the nation's tightest labor markets, Minnesota has a chronic worker shortage, keeping consumers from receiving needed services.

Minnesota seeks to both increase consumer direction and control of PCA services and address the worker shortage problem through the development of a consumer-initiated partnership and support networks (CIPS) model. Through CIPS, consumers will access each other's natural supports, such as family and neighbors, to provide PCA services, as well as to create backup options. Networks will offer members opportunities for cooperative training, support, respite, service management, and group insurance policies.

CIPS members will be trained on how to increase control over the PCA process, including training in consumer-direction practices that can reduce administrative costs by teaching consumers how to be fiscal agents. The savings achieved will be used to offer higher salaries for PCAs, which will attract more workers. By using CIPS members as an interactive test group, the state will develop training materials that more effectively promote consumer-directed options among all service consumers.

The state will recruit organizations to sponsor networks. Inclusion of people of color, of tribes, and with severe disabilities will be a consideration in sponsor selection. Networks will become self-sustaining by serving as consumer-run fiscal agents, with funding by consumers who direct their case management dollars to the networks.

MONTANA

Grant Information

Name of Grantee	Department of Public and Human Services Senior & Long Term Care Division		
Title of Grant	Montana CHOICE		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$850,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

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Summit Independent Living Center	Mike Mayer	406-728-1630

Target Population(s)

Consumers of all ages and disabilities.

Goals

- Alleviate competition for attendant-level personnel and ensure a consistent training process.
- Tap into previously underutilized resources such as older workers.
- Better community education and understanding of the need for quality personal care assistance.

Activities

- Develop a central mechanism for recruiting, screening, and training attendants to work across the home care continuum.
- Recruit, train, and place older workers as personal care attendants.
- Develop a statewide website with training modules for individuals wishing to perfect attendant management skills through distance learning and on a consistent basis.
- Develop a public relations campaign to better educate the community to service needs and attendant abilities and challenges in providing this service.
- Develop caregiver support groups.

Abstract

Montana CHOICE is based upon and stands for Consumers Having Options in Community Environments. The grant project comprises a series of activities that will lead Montana's consumers and providers to understand, emulate, and promote integrated community living through the use of personal assistance services. We focus on three key areas: education, workforce, and services. Each area has specific projects that are interrelated to one another.

The grant's purpose is to change the average person's view of home-based long-term care and to provide participants (consumers, providers, or family members) with the knowledge base to participate fully in personal assistance services. Montana will manage a public relations campaign and a training program to meet this goal.

Montana CHOICE proposes two specific projects to address workforce issues. First, in collaboration with two Area Agencies on Aging, we seek to develop a program to attract older workers to the direct care pool. Second, our largest project is to create and blueprint ACCESS (Attendant Center for Communication, Education and Support Services). This central point for recruitment, training, education, and support will enable collaboration in addressing the workforce issue. Instead of competing for attendants, service organizations will participate in focused efforts to improve the system as a whole.

During our planning process, focus groups indicated the need to evaluate, enhance, and potentially modify the program. Evaluation will be through a consumer RESPOND group who will look at ALL issues relating to personal assistance service and make the tough administrative recommendations normally reserved for state personnel. Enhancement will come through caregiver support groups, continuation of focus groups, and a web-based attendant management program. Together these groups will create or suggest modifications to the program to help make it work for all parties involved.

Consumers, advocates, family members, and providers of long-term care services will all participate in Montana CHOICE. Summit Independent Living Center will be the technical advisor on all projects to ensure we work towards community integration. The continuation of consumer focus groups will allow the state to receive honest input regarding grant activities, evaluations, and quality throughout the grant period. An integrated oversight committee will monitor overall grant activities.

NEVADA

Grant Information

Name of Grantee	Department of Employment, Training & Rehabilitation Office of Community Based Services		
Title of Grant	Community-Integrated Personal Assistance Services and Supports		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$655,988	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Southern Nevada CIL	Mary Evilsizer	702-889-4216
Northern Nevada CIL	Paul Gowins	Home: 775-329-3008 Office: 775-353-3599

Target Population(s)

People with disabilities in need of or at risk of needing personal assistance services (PAS).

Goals

- Create a statewide network of cross-population PAS that will ensure access to PAS regardless of age, ethnicity, income, disability, or geographic location.
- Design, implement, and evaluate facilitating practices that ensure consumers are fully informed and able to select and direct their own services and care from a variety of models including a budget and service responsibility model.
- Demonstrate and document the efficacy of PAS services in providing access to available assistive technology and other independent living services as an integral part of service planning.
- Demonstrate and document the efficacy of training and employing adults with mental retardation as personal assistants through a supported employment prototype.

Activities

- Assess proposed interdisciplinary strategies from the consumer perspective and provide a consumer-directed basis for such strategies; develop strategies and structures for ensuring consistent consumer involvement in systems and policy development and in developing and evaluating PAS delivery options, training, and services; and ensure continuing feedback to consumers regarding all activities undertaken through this grant.
- Recommend and coordinate interdisciplinary action to remove and/or ameliorate barriers to consumer-preferred PAS models caused by policy, regulation, operational procedure, impeding practices, and deficiencies in the training provided to agency and/or provider personnel.
- Design, develop, and coordinate implementation of preferred service modes.
- Establish a consumer-directed State Governor's Council on Assistance Services to assess quality assurance issues and recommend legislation, policy development, and systemic change related to the provision of PAS in Nevada.
- Create a PAS website for consumers of services that offer tips on service management, resource and service access information, announcements of meetings/events/opportunities for participation, "Topics of the Month," links to benefits counseling, and disability-related information.
- Train and provide supported employment opportunities for the high-functioning developmental disabilities population in provision of PAS services.
- Provide, through the Centers for Independent Living, peer evaluation of the perceptions, satisfaction, and issues of consumers of PAS services in all the state's programs.

Abstract

Through the efforts of Nevadans with disabilities, the 2001 Legislature mandated that all Nevadans requiring assistance with bathing, toileting, and eating must be identified and that planning for their needs must begin. The law also established a consumer-directed Personal Assistance Council to guide the state's efforts in providing access, consumer choice and control, training, and systems change related to all PAS.

The project is a collaboration of the PAS Council, State Aging Services, Medicaid, Family Health Services and Community-Based Services Agencies, Nevada Universities, the Nevada Community Enrichment Center, the Council and Centers for Independent Living, and the Associations for Retarded Citizens.

NEW HAMPSHIRE

Grant Information

Name of Grantee	Granite State Independent Living		
Title of Grant	ACCESS Consumer Controlled and Empowered Support		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$900,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Franklin Pierce Law Center Institute for Health, Law & Ethics	Michele Winchester	603-228-1541
EP&P Consulting, Inc.	Susan Flanagan	202-628-1134

Target Population(s)

Consumers on the state's Elderly and Chronically Ill Medicaid Waiver, and children with special health care needs and their families.

Goals

- Create comprehensive cross-disability and cross-age-group access to consumer-directed personal care.
- Increase the availability of personal care workers.
- Increase retention of personal care workers.
- Identify and address gaps in community services.

Activities

- Develop a model consumer-directed personal care service provider program (PCSP) that expands consumer-directed personal care to individuals who have not had access to such services.
- Implement a model consumer-directed PCSP program, which includes outreach and training to populations who have been previously denied access to such a program.
- Expand the availability of consumer-directed PSCP by providing education, outreach, and technical assistance to community-based entities that support a variety of different constituencies of individuals with disabilities throughout the state.
- Develop and implement backup personal care coverage models.
- Make available mechanisms to better support the consumer-directed personal care workforce and thereby increase retention of personal care workers.
- Conduct a community Services Gap Analysis, identifying deficiencies, and work to expand the opportunities for individuals to live in the community and to have real choices regarding the services they want and need.

Abstract

The central goal of this project is to create comprehensive cross-disability and cross-age-group access to consumer-directed personal care. The project will expand consumer-directed personal care to large groups of people with disabilities in New Hampshire who have historically been denied access to such services.

New categories of eligible consumers will include people on the state's Elderly and Chronically Ill Medicaid Waiver, and children with special health care needs and their families. Additionally, the project will expand the availability of direct care workers and backup coverage for all consumer-directed personal care programs.

The project will also work with consumers to identify and implement improvements to the entire community support system to provide more choices and control over service options.

OKLAHOMA

Grant Information

Name of Grantee	Oklahoma Department of Human Services Aging Services Division		
Title of Grant	Oklahoma's CD-PASS Project		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$850,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Long Term Care Authority of Tulsa	Michael Lester	918-879-5223
Ability Resources	Carla Lawson	918-592-1235
Progressive Independence	Jeff Hughes	405-321-3203

Target Population(s)

Aged, blind, and disabled persons with developmental disabilities.

Goals

- Create infrastructure that supports the availability of personal assistance services in a manner that affords consumers maximum control over the selection of individuals working on their behalf and the manner in which services are provided.
- Develop ILC-based Intermediary Services Organizations (ISOs) to serve as consumers' business agent and consultant for employer responsibilities.

Activities

- Guide the creation of CD-PASS infrastructure and develop an ISO implementation plan.
- Produce recommendations for Continuous Quality Improvement (CQI) contracting requirements as conditions of Provider Participation for CD-PASS ISOs.
- Develop CD-PASS infrastructure, implement CQI CD-PASS ISO contracting Conditions of Provider Participation and CD-PASS ISO startup operations providing consumers CD-PASS.
- Launch a second CD-PASS ISO.
- Evaluate and recommend modifications to the Nurse Practice Act provisions for delegation of nursing tasks to nonlicensed persons.
- Produce a comprehensive evaluation of all grant infrastructure development activities.

Abstract

DHS/ASD and DHS/DDSD are the Oklahoma state agencies responsible for administering Oklahoma's 1915(c) waiver programs. The LTCA of Tulsa is a local public trust authority that is the Administrative Agent for the ADvantage Program, the statewide waiver that serves 10,000 frail elderly and adults with physical disabilities. Ability Resources is an Independent Living Center (ILC) that has been a case management provider in the ADvantage Program since 1995. These entities are partnering to provide leadership to achieve the goals and objectives of this Project, which will focus on four major areas.

Consumer/community valued service delivery system. The Project will promote accountability of the service delivery system to consumers, providers, and policy makers through development of infrastructure modifications that afford consumer/community control in the design, implementation, and quality monitoring of PAS and CD-PASS service delivery.

Consumer-directed personal assistance services. The Project will create an infrastructure that supports the availability of personal assistance services in a manner that affords consumers maximum control over the selection of individuals working on their behalf and the manner in which services are provided. Infrastructure includes development of the ILC-based ISOs to serve as consumers' business agent and consultant for employer responsibilities.

Available, reliable, appropriate, and quality CD-PASS. The Project will produce a service delivery infrastructure that supports a CQI system that accords premium value for ISO provider and program evaluation and improvement of CD-PASS service delivery.

Flexible, accountable delegation of nursing tasks. The Project will recommend Nurse Practice Act language that supports appropriate delegation of nursing tasks to unlicensed staff or to family or friends who have received training from, and demonstrated skill attainment to, a registered nurse.

RHODE ISLAND

Grant Information

Name of Grantee	Department of Human Services		
Title of Grant	Rhode Island's Community-Integrated Personal Assistance Services and Supports		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$539,730	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Affiliated Consumer Systems/Birch and Davis

Rick Jacobsen, Ph.D.	401-462-6357	rjacobse@gw.dhs.state.ri.us

RFP issued for PASS Grant activities (7/1/02–9/30/04).

Target Population(s)

Medicaid-eligible children with special health care needs.

Goals

- Design and implement a consumer-directed Personal Assistance Services and Support (PASS) program that will maximize control and choice for children with special health care needs and their families, potentially substitute for other therapeutic services in high demand, expand the pool of current service providers, and improve the continuum of services for children.
- Provide PASS support to children with special health care needs to enhance their independence and ability to live and participate in the community.

Activities

- Collaborate with consumers, advocates, and providers to guide the key design components of PASS.
- Develop certification and performance standards for PASS providers.
- Integrate PASS services into the existing Rhode Island Medicaid infrastructure CEDARR (Comprehensive Evaluation, Diagnosis, Referral, and Reevaluation services and supports) for children with special health care needs.
- Develop and implement specialized training modules targeted to key parties in the PASS program (consumers, broker agencies/fiscal intermediaries, PASS direct workers, CEDARR Family Centers).
- Implement a quality assurance and PASS program evaluation system that is data driven.

Abstract

The Rhode Island Department of Human Services (DHS) will establish two new services to expand consumer choice and maximize consumer control. These will be consumer-directed PASS for children and families using the Service Responsibility model and the Service Choice model. Services will be available to children and families with all types of disabilities. Presently the state plan does not include PASS for children outside residential facilities, and waiver-based PASS are overwhelmingly geared to adults. Currently, within the children's system, children and families often endure long waiting lists and inconsistent service provision.

These PASS services will fill a large void in Rhode Island. By the end of the grant period approximately 350 to 400 families will access Community PASS services. Funded as service benefits under EPSDT rules, the services developed through this grant will continue to be supported beyond the period of this grant.

This grant is particularly timely. Over the past 3 years DHS has partnered with consumers, providers, and other state agencies to redesign the ways in which services are available to children with special health care needs (CSHCNs) and their families. The resulting CEDARR initiative provides the supporting infrastructure and method for implementing Community PASS services to maximize informed choice, consumer control, continuing support for families, and continuous quality improvement. CEDARR includes two delivery system components developed in phases. Phase 1 was the development of CEDARR Family Centers (CFCs), which provide family-directed coordinated services to help families understand and navigate the system of services for CSHCNs. The first statewide CFC opened in April 2001, the second in September 2001, and a third is due in the spring of 2002.

Phase 2 is the development of CEDARR-certified direct services to fill gaps in the existing system. Community PASS services will be developed as CEDARR direct services. In partnership with consumer-focused workgroups, specific service requirements and responsibilities will be delineated and certification standards will be written. Any entity that can demonstrate compliance with the standards will be certified as an eligible provider. DHS brings both an experienced team and a tested approach to the tasks of service design, implementation and startup, targeted training and technical assistance (for families, service worker brokers, direct service workers, and CEDARR Family Center staff), and quality assurance oversight and monitoring.

The CEDARR Policy Advisory Committee, an 11-member body that includes six family representatives (one as co-chair) and one member each from five state agencies, will ensure direct consumer involvement through all phases of this project.

COLORADO

Grant Information

Name of Grantee	Department of Health Care Policy and Financing		
Title of Grant	Colorado Community Personal Assistance Services and Supports (COmPASS)		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$725,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Consumer trainers
In-home support services agencies (one urban, one rural)
Research design consultant
Project evaluator

Target Population(s)

Adults, adolescents, and parents of children with disabilities.

Goals

- Increase the independence and self-sufficiency of Coloradans with disabilities through community integration.
- Improve the quality of attendant support received by Coloradans with disabilities through enhanced consumer control.

Activities

- Design and implement a personal assistance services and supports (PASS) option in which consumers exercise control over selection or assignment of attendants, scheduling decisions, location and service delivery decisions, care planning, and training.
- Develop consumer-oriented materials, curricula, and training programs that would build skills in self-advocacy, problem solving, and negotiating PASS programs and benefits.
- Establish a train-the-trainer program that would enable trainers to become community-based training resources for the state, provider agencies, advocacy groups, and individuals.
- Design and conduct provider training for staff in home health agencies, personal care/homemaker agencies, independent living centers, and case managers in nursing certification and consumer-direction philosophy.
- Implement a Home Health Agency Consumer-Direction Pilot that would test a model that is an alternative to both the Consumer-directed Attendant Support (CDAS) model and to traditional home health services.
- Conduct formal evaluations to analyze client outcomes and to study effectiveness, satisfaction, and quality among various PASS programs and services.

Abstract

Colorado is recognized as a national leader and innovator in long-term care services, including PASS. However, Colorado faces a number of PASS-related challenges that come from uneven geographic population distribution, jobs, economic prosperity, services, and resources. These statewide challenges include chronic provider and worker shortages, measurement issues related to assessing and monitoring the quality of PASS, and the various training needs of PASS clients, providers, workers, and case managers.

Colorado seeks to help connect clients to PASS options that enable them to live in the most integrated community settings appropriate to their individual support requirements and preferences. The project will engage in a strategy to provide extensive training at all levels to ensure that the philosophy of consumer direction is incorporated across all COmPASS options. The project will also identify and seek to remedy any regulatory, statutory, or program obstacles.

COmPASS will focus primarily on training and materials development; however, other systems changes are necessary to ensure the improvement of PASS quality and the promotion of client independence.

The COmPASS Project will result in enduring systems change in the areas of access, availability and adequacy of services, quality of services, and value. The CDAS waiver will address provider shortages and access issues by broadening the potential PASS labor pool. In addition to client training, interested providers and workers may also seek training. Provider training will be open to certified and noncertified attendants and may increase the pool of attendants available to the CDAS waiver project.

A project evaluation will formally analyze “client-directedness,” health concerns, independence outcomes, and satisfaction. Hopefully, when quality increases for the same price, value is also enhanced.

DISTRICT OF COLUMBIA

Grant Information

Name of Grantee	Department of Health, Medical Assistance Administration		
Title of Grant	Consumer-Directed Attendant Care Services		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$725,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

To be determined by the RFP process.

Target Population(s)

Elderly persons and individuals with physical disabilities 18 to 64 years of age.

Goals

- Build the infrastructure for a cost-effective personal assistance services system.
- Create mechanisms to ensure full community participation and to coordinate policy decision-making across District government agencies.
- Improve the flow of HCBS information to consumers and streamline the eligibility determination process.
- Create a consumer-centered personal assistance service system.

Activities

- Convene an Advisory Committee composed primarily of consumers, but also including representatives from District agencies and provider organizations.
- Coordinate services referral, eligibility determination, options counseling of consumers, the selection of providers and services, and timeframes for initiation of services with the Resource Center.
- Assist consumers in expediting eligibility determinations and payment methods.
- Develop a fiscal intermediary for management of funds and payment of workers and other tasks related to human resources, including personnel actions, employment benefits, and federal and state employment-related taxes.
- Determine appropriate rates for the consumer-directed PASS program.
- Develop a database to track individual PASS budgets and expenses.
- Train consumers in areas of hiring, firing, training, directing, supervising, retaining personal assistants, risk management procedures, contingency planning and urgent response system, administration of services, and improving the quality of services.
- Recruit, train, and support personal assistants and mentors to improve service quality.
- Develop a QA/QI plan for internal, routine evaluation of services received by consumers.

Abstract

As more elderly and individuals with physical disabilities choose to live in home and community based settings, consumer choice and preferences have become increasingly critical public policy issues. Consequently, the District has developed a PASS program to provide community supports to the elderly and individuals with physical disabilities.

The project will focus on improving access to home and community based services by creating a Personal Assistance Services and Supports (PASS) program that is consumer-directed. To accomplish this, an Advisory Committee that is composed of consumers, providers, and representatives across District agencies will be established. The PASS project is designed to: (1) build the infrastructure for the delivery of cost-effective personal assistance services that will provide self-determination in the selection and delivery of services, (2) streamline the eligibility determination process, (3) disseminate information to consumers regarding HCBS, and (4) recruit, train and support personal assistants and mentors.

The outcome of the project will be to increase the availability of home and community based services with subsequent reduction in institutionalized services. A quality assurance and continuous quality improvement mechanism will be created for monitoring of the services. Significant and sustainable outcomes will include a system that fosters greater consumer control and choice in the selection of services and the recruitment, hiring, training, and management of the providers of those services.

HAWAII

Grant Information

Name of Grantee	State of Hawaii, Department of Health		
Title of Grant	Hawaii Systems Change for Community Living: Community Personal Assistance Services and Supports		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$725,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

The Center on Disability Studies at the University of Hawaii is contracted to administer the CPASS grant.

Target Population(s)

The elderly and persons with developmental disabilities, mental illness, and neurotrauma.

Goals

- Involve all stakeholder groups and maximize individual participation in a collaborative community and systems change process through an individual-majority Advisory Council.
- Promote individualized planning to increase the involvement and control of individuals in planning and evaluating personal supports, relationships, and community connections.
- Support brokering and coordination activities of individuals to help them make informed choices about how the personal assistance services and supports specified in their individualized plans will be delivered and managed.
- Provide training, technical assistance, and information to stakeholders on the attitudes, skills, and knowledge they need to effectively participate in the development and implementation of project innovations.
- Develop a Qualities of Life tool to enhance the ability of individuals to communicate their visions of a high quality of life, promote effective individualized person-centered planning, and improve quality assurance at the consumer and community levels.

Activities

- Build community connections and improve quality of life measures for persons in the four targeted populations through alternatives to paid support services, increased utilization of community resources, and the building of relationships and natural support services through community development activities.
- Connect resources of the service delivery system with existing targeted community resources to support marginalized persons in achieving quality lives.
- Develop a Community-Based Resource Center that will provide a central location for the provision of training, community assessment and education, networking, and building of relationships for participants.
- Provide community outreach to ensure that all staff and volunteers involved with the Community Pass Grant understand the tenets of self-determination.
- Develop and organize leadership by individual service recipients and their families to collaboratively guide project implementation and to institute similar innovations in policies, procedures, and practices within each of four Department of Health (DOH) systems.
- Develop a survey to measure quality of life improvements.

Abstract

The Hawaii Personal Assistance Services and Supports Grant (PASS) will pilot and demonstrate person-directed personal assistance by linking individuals with disabilities to Volunteer Personal Assistants in one targeted community on the island of Oahu, Hawaii. The project will combine best practice methodologies for developing community connections, person-directed planning, community awareness, and the development of social equality. The interventions and methodologies will facilitate and build community connections, make available community resources, and develop a system of natural supports for 20 to 40 individuals participating in the project. Just as significantly, this project will develop a survey instrument that is normed to the general community population in the target area and stratified across two age groups (22 to 59 and 60+). Individual participants will take part in pre and post surveys that compare their qualities of life against the general population in the targeted community, both before and after participation in the demonstration project. The project will test the relationship between interventions in building community connections and the overall improvement in quality of life measures for persons in the four target populations.

INDIANA

Grant Information

Name of Grantee	Family and Social Services Administration		
Title of Grant	Indiana Community Personal Assistance Services and Supports		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$725,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Malone Consulting

Capitol Health Strategies

Target Population(s)

All consumers, regardless of funding source, if they are interested and an appropriate candidate (as determined by a physician).

Goals

- Creation of an enduring infrastructure to support consumer-directed personal assistance services.
- Educate older adults and persons with disabilities and their families or caregivers about these options.
- Assist consumers in recruiting and training providers.
- Expand services available through consumer-direction.
- Ensure that consumers are not abandoned in their privacy and independence, but welcomed and integrated into their communities.

Activities

- Provide outreach and information to increase awareness of consumer-directed personal attendant care services.
- Develop a consumer-directed personal assistance services model and the infrastructure needed to support it.
- Establish a fiscal agent process to ensure accurate and timely claims payment and/or system changes to the Medicaid contractor system.
- Provide enhanced training for state staff and local providers. Case managers will receive additional training on the newly designed consumer-directed attendant care model.

Abstract

This project is designed to maximize consumer choice and self-determination. The Family and Social Services Administration (FSSA) will serve as the lead agency. FSSA will implement the following changes:

- **Focus on systems change.** Staff will create an enduring infrastructure to support consumer-directed personal assistance services.
- **Direct services.** No more than 20 percent of the total grant dollars will be used to directly fund consumer-directed attendant care.
- **Collaborators and partnerships.** FSSA, as the lead agency, will work closely with other state agencies, the CHOICE Board, the Arc of Indiana, the Indiana Area Agencies on Aging, Independent Living Centers, local advocates and other organizations to provide information, outreach, and establish statewide policies.
- **Enhanced training.** State staff and local providers will participate in enhanced training to promote consumer-directed care, person-centered planning, quality assurance, and fiscal agent coordination.
- **Outcome-Based Reporting.** Evaluations will be conducted on the timeliness, adequacy, and quality of the services provided, as well as the impact of care provided by self-directed personal attendants on quality of life measures.

KANSAS

Grant Information

Name of Grantee	The University of Kansas Center for Research, Inc.		
Title of Grant	Community-Integrated Personal Assistance Services and Supports		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$725,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Kansas Association of Centers on Independent Living (KACIL)

Three Developmental Disability Organizations TBA.

Target Population(s)

Kansans with mental retardation or developmental disabilities who are served on the MR/DD waiver and who use personal attendant services.

Goals

- Increase the use of consumer-directed options for Personal Care Assistant (PCA) services in all regions of the state.
- Increase the availability of personal care workers at home, at work, and when away from home.
- Ensure consumer safety while supporting informed consumer choice/risk.
- Measure consumer and PCA satisfaction and adjust services based on this information.

Activities

- Share consistent information across all regions of the state so that persons with developmental disabilities can make informed choices and personally manage their attendant care services.
- Work with three pilot developmental disabilities organizations (one urban, one rural, one low unemployment region) to increase self-directed services, identify barriers, and model changes identified by pilot group.
- Identify barriers and develop a plan to address barriers to increase self-directed services.
- Develop a plan to increase labor pool, job satisfaction, and retention among PCAs.
- Develop and disseminate training materials that assist consumers in advertising for, interviewing, selecting, resolving conflict with, and supervising PCAs.
- Analyze the range of services being utilized in self-directed services.
- Collect and evaluate data regarding consumer satisfaction and safety.

Abstract

This effort focuses on increasing personal care attendant options for persons who have mental retardation or developmental disabilities and who are eligible for the Kansas Medicaid waiver program. This program will support individuals served on the MR/DD waiver in personally managing their attendant care services. In order to live and participate fully in their communities, PCAs must be available in an individual's home, at work, and when away from home. Objectives include (1) sharing consistent information regarding the range of activities that an individual might self-direct in regard to their personal attendant services and (2) increasing the availability of PCA services across the state. Currently, agreement on self-directed services is lacking and contributes to the impression that agencies or personal care attendants are driving plans of care for persons with mental retardation or developmental disabilities.

This goal will also work towards giving consumers maximum control in exercising choice over all aspects of personal assistant services and to have sufficient training to direct these services. A pilot program with service providers and consumers served by three Community Developmental Disability Organizations (CDDOs) will be conducted. Project staff will work with the pilot programs to develop a model that encourages reimbursement of self-directed plans of care for persons with developmental disabilities based on the consumer's needs, including evaluation of rates paid.

This program will develop an infrastructure to support individuals with developmental disabilities or their families/guardians to develop and exercise management skills, obtain and evaluate customer feedback, use customer feedback to identify and correct problems, and create a plan for dealing with recurring issues. Data will be collected regarding the range of activities persons are currently self-directing and their satisfaction with these services. Data from the consumers, the pilot agencies, and a control group will be collected annually. The stakeholder group will consider changes that could be made in reporting systems to annually collect information regarding quality indicators. An additional review of a random sample of plans of care from persons served on the MR/DD waiver will be conducted to review the range of services utilized, the range of entities providing these services, and customer satisfaction with the self-directed care process.

NORTH CAROLINA

Grant Information

Name of Grantee	Department of Health and Human Services		
Title of Grant	Community PASS		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$725,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Subcontractors will conduct some components of the project. Oregon Technical Assistance Corporation is conducting public education, training and technical assistance to increase consumer-directed options. The Center for Urban Affairs at NC State University is conducting evaluation of the effects of the three systems change grants on North Carolina's ability to provide consumer-directed supports. Another subcontractor will conduct the legislative and rule analysis for regulatory reform but negotiations have not been finalized. The community demonstrations will go through an RFA process.

Target Population(s)

Consumers of all ages and types of disabilities.

Goals

- Facilitate consumer direction of services and supports through regulatory reform.
- Increase consumer-directed options for personal assistance services and supports.
- Increase consumer leadership and community resources to support people remaining in and/or returning to communities from segregated facilities.

Activities

- Conduct an assessment of state fiscal and regulatory policies and initiate statutory and rule reform.
- Identify provider practices that interfere with consumer direction.
- Develop and conduct training and technical assistance with agency based and independent providers to encourage consumer-directed practices.
- Develop technical assistance team(s) to create and sustain statewide capacity to promote and facilitate consumer-directed options.
- Create community demonstration models of consumer leadership in community resource development to support consumer direction.

Abstract

North Carolina has few options for persons who seek to direct their own supports and services. Our fiscal regulations and programmatic policies promote facility-based, professionally directed care. The state relies on the private sector to provide most of the personal assistant-type services and supports and providers establish business practices consistent with that regulatory framework. This grant will address both of these issues, and, in combination with North Carolina's Real Choice grant, will dramatically change the infrastructure of the human services system to enable our citizens with disabilities and long-term illnesses to live where and with whom they choose.

North Carolina's human service delivery system is undergoing a variety of reforms in both scale and scope. This project will connect many of these initiatives designed to increase options for consumer choice, service, support, and self-direction. We will conduct a policy analysis and initiate statutory and rule changes that will focus system-wide. The Department of Health and Human Services has adopted a united vision, mission, and principles, and the regulatory framework must be adjusted to support that vision. This effort will likely go on long beyond the 3-year grant period.

We will undertake a major training and technical assistance effort to change business practices across our state and encourage new and nontraditional provider development. We will obtain the training and technical assistance capacity within the public system to continue building consumer-directed options. Many people will continue to seek more traditional providers, and these agencies must be knowledgeable and available to provide more person-centered services and offer more consumer-directed options. In addition, as self-direction becomes a more feasible option, many new independent personal assistants will come from the ranks of family and friends of individuals with disabilities. The system infrastructure must support these new workers, both to enhance consumer choice and self-determination and to protect health and safety.

The final component to this proposal is the establishment of demonstration models in three communities that will increase consumer leadership in local reform efforts. It is our belief that only people with disabilities and long-term illnesses can lead the movement to make communities places that welcome and embrace diversity and sustain options in services and supports. Individuals who remain in or return to the community need natural supports and many community resources in addition to personal assistants if they are to lead successful and productive lives. Consumers and their chosen partners will create consortia and develop a community agenda to address local obstacles to reform.

TENNESSEE

Grant Information

Name of Grantee	Department of Finance and Administration		
Title of Grant	Tennessee PASS		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$725,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

ARC of Tennessee Walter Rogers, Director 44 Vantage Way, Suite 550 Nashville, TN 37228	615-248-5878

Target Population(s)

People of all ages whose disabilities of any type result in a need for personal assistance services.

Goals

- Establish an integrated, accessible, and enduring system of personal support services in Tennessee.
- Increase the use of consumer-directed options for personal assistance services.

Activities

- Develop a consumer controlled Project Oversight Committee to direct and lead the project.
- Develop and provide practice-based training and resource tools for consumer-directed personal assistance.
- Develop and implement a program of consumer-led mentoring and technical assistance for individuals who use personal assistance and agencies and staff who provide personal assistance.
- Develop and pilot a system of consumer-directed personal assistance.

Abstract

A Consumer Task Force in Tennessee worked with the TennCare Bureau and other state agencies to develop this project. This project represents Tennessee's first effort to establish a system of consumer-directed Personal Assistance Services and Supports. Tennessee has traditionally relied heavily on institutional care as its primary model of publicly funded long-term care. Tennessee ranks 50th among states in its provision of home and community based long-term care services. Limited Medicaid waivers for elderly and disabled adults provide some access to personal assistance in a few geographic areas. Program design limits the flexibility of the services, as well as the number of people affected, and the amount of service that is available. Consumer-directed services are not available through these waivers.

Tennessee seeks to develop an enduring system of accessible, quality responsive, consumer-designed and directed personal assistance. The effort is designed to develop consumer and provider confidence and competence. Because virtually nothing exists now, this project will begin, build, modify, and sustain these services through the leadership of consumers in partnership with individual, community, and systems stakeholders who are capitalizing on a variety of available technologies.

The project is focused on developing tools and resources for people who want to direct their own services and supports in community settings, including deciding what services are needed; writing a plan for services and supports; directing payment of service providers; and hiring, training, and supervising staff. The project will also include a "pilot" program so people with disabilities can test and use the tools and resources developed to help them manage their own services. The pilot will also allow the state to build and test policies, procedures, and infrastructure needed to establish a new and workable long-term care system for the state.

A consumer-based Project Oversight Committee is primarily responsible for implementing, managing, and evaluating the project. The committee works with a state multi-agency Coordinating Council and the TennCare Project Coordinator.

WEST VIRGINIA

Grant Information

Name of Grantee	West Virginia University Research Corporation		
Title of Grant	C-PASS—Community Integrated Personal Assistant Services and Supports Grant		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$725,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

A fiscal intermediary agent will be determined later in the grant period.

Target Population(s)

Persons of all ages with disabilities or those with long-term care needs who require and are eligible for personal assistance services (PAS) in the home or in the community.

Goals

- Create a Consumer/Agency/Services (CAS) Oversight Board that participates in and ensures improvement and infrastructure changes that support community-integrated PAS and promotes consumer-directed services in West Virginia.
- Research, promote, and develop community-based PAS available to all eligible persons with disabilities and those with long-term care needs.
- Research, promote, and develop consumer-directed services for West Virginians.

Activities

- Create a CAS Oversight Board that participates in project direction, activities, and outcomes.
- Create a consumer-directed services curriculum.
- Develop and implement consumer awareness and information materials on PAS.
- Provide group and individual training on consumer-directed services and management.
- Apply for a waiver on consumer-directed services for PAS or develop a consumer direction demonstration project.
- Establish a Participatory Action Research Board for the demonstration project.
- Design a fiscal management and data collection system.
- Expand and modify Medicaid State Plan and waivers to make PAS consumer-directed and portable.
- Improve recruitment, training, and retention of direct care providers of PAS.
- Develop backup and crisis support plans for persons receiving PAS.

Abstract

The Center for Excellence in Disabilities at West Virginia University in partnership with state agencies, consumers, and provider groups will collaborate to establish opportunities for individuals to fully participate in the community through the expansion of PAS and increase their knowledge and options for consumer control and direction of their services and supports. Through the partnership and collaboration with existing initiatives in West Virginia, this project intends on creating a proactive, consumer-directed system of services and supports for persons needing PAS in the home or in the community.

West Virginia provides PAS for persons with disabilities or those needing long-term care through the Medicaid state plan, waiver programs, and state-funded programs in the Division of Rehabilitation. None of these services are provided in a manner that fully reflects informed consumer choice, control, and direction. Based on consumer, agency, and provider input and direction, Project C-PASS intends to collaboratively design, develop, implement, and evaluate a model for offering consumer choice in the recruitment and provision of services by personal assistants. The project's outcome objectives are initiated by the creation of a CAS Oversight Board that assists with project direction, activities, and outcomes. The CAS Oversight Board will participate in all activities and ensure that goals, objectives, and outcomes promote enduring improvement in the infrastructure to support consumer-directed, community-integrated PAS and promote the maximum ability of individuals to direct their services.

Action steps in accomplishing these goals include the development and delivery of a training curriculum to guide service providers in shifting their value system to maximize consumer direction; the design and delivery of a complete training package to prepare consumers for vision-driven, consumer-directed services; the construction of a sustainable model for maximum consumer control within a demonstration project that offers a range of choice in consumer control and direction; the development of a data collection system that provides tracking information, data analysis to assist with recommendations for project or statewide systems change and sustainability; and the development of strategies for recruitment and retention of personal assistants. Evaluation data from these project activities will be compiled into publications that will be used to promote public and consumer awareness and legislative initiatives for systems change that will ultimately impact the quality of life for persons with disabilities and those needing long-term care services and supports.

ALABAMA

Grant Information

Name of Grantee	Mid-Alabama Chapter of the Alabama Coalition of Citizens with Disabilities, *DBA* Birmingham Independent Living Center
Title of Grant	Partnerships to Independence
Type of Grant	Nursing Facility Transitions, Independent Living Partnership
Amount of Grant	$450,000 ***Year Original Funding Received*** 2001

Contact Information

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www.birminghamilc.org

Subcontractor(s)

No subcontractors planned.

Target Population(s)

People with disabilities who wish to transition from nursing homes to the community. The population includes residents of Jefferson, Shelby, St. Clair, Walker, and Blount Counties in Alabama.

Goals

- Increase nursing home residents' awareness of independent living options.
- Assist nursing home residents' transition to the community.
- Recruit, hire, and train qualified personnel who are committed to the philosophy of independent living and person-centered planning.
- Promote the development of resource networks through local and statewide implementation teams.

Activities

- Peer Outreach Advocates will be recruited, trained, and supervised to conduct outreach to nursing homes in the catchment areas.
- Develop a consumer-directed person-centered assessment model.
- Assist at least 25 individuals to transition from a nursing home to the community.
- Produce a manual that can be replicated by sites around the state, region, and country.
- To conduct local implementation team meetings monthly during the first year and quarterly during Years 2 and 3.

Abstract

Birmingham Independent Living Center (BILC), in collaboration with its partners, proposes to expand services to persons with disabilities in Alabama with an Independent Living Partnership Nursing Facility Transitions program entitled **Partnerships to Independence**. The cost of nursing home care in the State of Alabama is spiraling out of control. By the end of 2001, nursing home costs will exceed $600 million. At the same time, nursing home residents who desire to live in the community are given little opportunity to weigh community options. This project will develop the infrastructure, partnerships, and community services that will be required to offer the choice of community living to nursing home residents across the state.
The target population will include nursing home residents in the Birmingham service areas who express a desire to return to the community, regardless of age or disability. Contact with participants will be made at nursing homes. All potential participants will benefit from peer support, which means people with disabilities, older people, and family members who are familiar with the community will conduct outreach. A full-time Community Transitional Advocate will assist nursing home residents to plan their moves and obtain required supports. Plans will be developed according to independent living and person-centered principles. Community supports that will be put in place include personal assistance, housing, home modification, advocacy, peer support, transitional subsidies, and other resources. It is anticipated that 25 people will transition to the community during the 3-year project period.

Partnerships at the local and state level are a key to the success of this program. The Director of Alabama Medicaid's Long-Term Care Program will convene a group of statewide partners to advise on project direction and assist in the development of policy and sustainable resources for implementation. A local implementation team will be developed to enhance service planning and the development of local resources.

ALASKA

Grant Information

Name of Grantee	Department of Administration, Division of Senior Services		
Title of Grant	Alaska's Nursing Facility Transitions Project		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$800,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Kenai Peninsula Independent Living Center
Alzheimers Resource Agency
Center for Human Development

Target Population(s)

Medicaid eligible individuals or those determined to be within 6 months of Medicaid eligibility who want to make the transition from a nursing facility to the community.

Goals

- Provide services to enable people to transition from nursing facilities to the community.
- Develop an enduring system to transition and divert people from nursing facilities to the community to the extent they desire.
- Evaluate project activities and outcomes and develop recommendations to further improve the transition/diversion program.

Activities

- Identify and develop partnerships to facilitate the nursing facility transition grant.
- Work with nursing facility staff to identify targeted individuals.
- Assess each individual's transition/community needs and, once placed in the community, monitor the individual's situation to determine if his or her needs are met, and arrange resources and supports as needed.
- Work in conjunction with existing housing initiatives, AHFC, and other housing resources to develop a variety of strategies to increase the availability of accessible, affordable housing stock.
- Work in conjunction with other initiatives and activities to increase the availability of services and supports that will support transitions and diversion (e.g., accessible and affordable transportation and front line workers).

Abstract

The NFT project staff will help identify individuals who want to make the transition from nursing facilities to the community, and to ensure there is a system in place to provide supports and services needed for the transitions or diversion.

The State Independent Living Council (SILC), under supervision of the Division of Senior Services, will manage the project and employ a project coordinator responsible for education, information dissemination, outreach, and coordination of the transition process. The project coordinator will also work with nursing facility staff to identify targeted individuals. Once individuals are identified, the project coordinator will assess each individual's transition/ community needs, provide care counseling, and arrange for peer counseling if desired by the individual. The project coordinator will then convene a planning team to assist the consumer to determine needed services and resources.

In order to develop the infrastructure and programs to support the transition and ongoing support needs of participants, activities will be coordinated with Division of Senior Services staff. We are fortunate that the Rural Long Term Care Development staff members are located within the Division. These two staff persons are knowledgeable about housing efforts going on statewide and are a resource to staff.

Rural Long Term Care Development staff are part of a number of statewide committees looking at housing options. Feedback to the other organizations listed in the grant to partner and coordinate efforts will be a priority. The Division of Senior Services (DSS), as well as the other participating stakeholder organizations, such as the Governors' Council on Disabilities and Special Education, will be able to make policy recommendations to DSS, who in turn will work with the Department of Health and Social Services and, specifically, the Division of Medical Assistance (Medicaid single state agency), to develop a strategy for policy change, including how to fund and how to implement new policies and/or benefits.

COLORADO

Grant Information

Name of Grantee	Department of Health Care Policy and Financing Office of Medical Assistance		
Title of Grant	Colorado Transitions Project		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$800,000	***Year Original Funding Received***	2001

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Subcontractor(s)

Center for People With Disabilities	David Bolin	303-442-8662
	Jane Schiele	303-442-8662

Target Population(s)

Individuals of any age with disabilities in nursing facilities, particularly individuals with cognitive disabilities or mental illness.

Goals

- Build capacity across the state to reach out and support the transition of individuals in nursing facilities to a community-integrated living arrangement.
- Assure that individuals who wish to make the transition have developmentally appropriate information to make the decision and the supports necessary to sustain long-term residence and participation in the community.

Activities

- Create a State Transitions Resource Team to oversee and evaluate the project.
- Identify barriers to transitions and strategies to address them.
- Document a comprehensive model for transitions.
- Establish 10 support networks through Independent Living Centers to coordinate services, referrals, and follow-up.
- Inform over 1,200 individuals of their rights to live in the community.
- Transition at least 130 individuals in nursing facilities to community settings.

Abstract

The Colorado Transitions Project will create a state infrastructure for transition efforts and provide choice information to over 1,200 individuals in nursing facilities resulting in 130 transitions to the community. The approach will create a structure at the state level and in 10 communities to link resources, address barriers, and expand communication among providers to maximize the supports for community transitions.

The existing Olmstead Planning Group collaborated to design this proposal and will continue, with added members, as the State Resource Team. More partners will be added as the project expands and identifies additional key players.

A new product to be created through this project is a developmentally appropriate approach to informed consent for individuals with developmental disabilities, cognitive disabilities, brain injuries, language/literacy barriers, or mental illness, or who are affected by strokes. A video, a word board, and a picture book will be developed. These will reach individuals in a respectful manner and can be replicated in other states.

A Colorado Department of Health Care Policy and Financing State Transition Coordinator (0.5 full-time equivalent [FTE]) will coordinate the state infrastructure development, and the Center for People with Disabilities will hire a Project Coordinator (1.0 FTE) to implement the Colorado Transitions Project through the network of 10 Independent Living Centers across the state. The project will complement existing state programs and identify and transition a variety of consumers from nursing facilities to the community.

CONNECTICUT

Grant Information

Name of Grantee	Department of Social Services, Health Care Financing		
Title of Grant	Nursing Facility Transitions to Independent Living		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$800,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Connecticut Association of Centers for Independent Living, Inc. (CACIL)	Dawn Lambert	203-729-0153

Target Population(s)

Nursing facility residents who want to return to independent community living.

Goals

- Identify and transition 150 nursing facility residents who want to return to independent community living.
- Develop an effective and sustainable community-based system of transition for individuals residing in nursing facilities who desire to live in the community and can be appropriately served in the community.
- Establish a strong partnership with Connecticut's Centers for Independent Living (CILs).

Activities

- Research, evaluate, and implement best practices in nursing facility transition.
- Design and implement an effective outreach campaign with materials that inform nursing facility residents and their families about long-term care alternatives.
- Design professional development and value-based training for targeted audiences that includes information about the needs of persons with disabilities, the principles of independent living, self-determination and social role valorization, and cultural diversity.
- Create a flexible financial resource that will facilitate the transition of nursing facility residents back to the community and give them increased self-direction and control.
- Develop and implement a volunteer peer support network that will provide technical assistance to persons transitioning to the community and their families, and provide the critical link to the informal community system.
- Develop an effective system to access affordable, accessible housing resources.
- Implement a demonstration project to transition 150 people out of nursing facilities.

Abstract

The Connecticut Association of Centers for Independent Living (CACIL) will be responsible for the overall management and administration of grant activities including the provision of financial support for project staff in the five Centers for Independent Living that will implement the project's activities.

This grant grew out of an awareness that there is a lack of training and education about the needs of persons with disabilities living in the community and that this has led to a long-term care system that is not responsive to the needs of consumers or their families. Connecticut does not have a system in place to identify nursing facility residents who are appropriate for transition to the community. Connecticut nursing facility residents do not have information about the choices available to them or a way to identify themselves as possible transition candidates. Systems fragmentation and the eligibility requirements of community-based programs leave many people unable to find adequate community support.

To address these issues, the grant will be used to develop a variety of products to better inform state agency staff, professionals in the community, and nursing facility residents about the concepts of independent living and self-direction. Best practices and policies will be identified and made available. A self-assessment tool and a “step-by-step" guide to community transition will be developed so that nursing facility residents and their families can assess their readiness for a successful transition. A professional assessment tool along with a procedures and marketing plan for distributing information to nursing facility residents will be developed. A Common Sense Fund will be established to help pay for items that are usually not covered by government programs, such as rental deposits, utility deposits, and household goods. All of these products will form the foundation of the system being designed to transition nursing home residents back to community living.

GEORGIA

Grant Information

Name of Grantee	disABILITY LINK		
Title of Grant	TRANSITIONS: Introducing Institutionalized People with Disabilities to Community Living Alternatives		
Type of Grant	Nursing Facility Transitions, Independent Living Partnership		
Amount of Grant	$400,000	***Year Original Funding Received***	2001

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Subcontractor(s)

Access Center for Independent Living	Robert McGarry	770-534-6656
Bainbridge Advocacy Individual Network	Virginia Harris	229-246-0150
Disability Connections	Jerilyn Leverett	478-743-9805
Living Independence for Everyone	Nicolas Steenhout	912-920-2414
Walton Options for Independent Living	Tiffany Johnston	706-724-6262

Target Population(s)

Persons of all ages with disabilities who are currently residing in nursing homes.

Goals

- Develop a transition infrastructure within the Independent Living Network that will introduce people with disabilities to peer supporters and role models; expose interested persons to home and community based services; offer information, training, and skill development; develop community connections or circles of support; and develop comprehensive transition plans to assist those who choose to resettle in the community.
- Develop a partnership with two nursing home chains to identify people with disabilities who want and need alternatives; and develop a collaborative process for both diverting people from nursing facility placement and transitioning those who want a community alternative.
- Work with the Department of Community Health to address current problems—from the consumer perspective—with the HCBS waivers.

Activities

- Subcontract with Centers for Independent Living (CILs) across the state to hire and train transition team leaders. These individuals, with the assistance of volunteer peer supporters, will go into nursing home facilities to identify individuals wishing to transition to the community.
- Work with the Department of Community Health and two nursing home chains to identify and transition people with disabilities to their communities.
- Expand existing community-based services to serve all those who wish to live in their communities.
- Expand and strengthen the Consumer Systems Change Network.
- Develop resource committees statewide.

Abstract

Georgia will use this grant to build state capacity to reach out and support the transition of individuals to a community-integrated living arrangement consistent with their needs and preferences, and assure that these individuals have the supports necessary to sustain long-term residence and participation in the community. A considerable amount of matching resources will also be allocated to this project.

disABILITY LINK in Atlanta will serve as the fiscal agent for the grant, house the project director and contract with five other consumer-controlled nonprofit CILs to accomplish the goals, objectives, and deliverables of this grant. The Statewide Independent Living Council (SILC) will serve on the project's steering committee, meet quarterly, provide guidance and support to the project director, and assist with the development of the grant process. The SILC is a statewide organization that is consumer-controlled and includes disability groups that are most at risk for institutionalization—people with cognitive disabilities, mental disabilities, and severe physical disabilities.

The project's goals will be accomplished by securing a project director, securing transition team leaders in seven regions of the state through the CILs, supporting the participation of consumers in transition planning, providing information and training to all consumers and staff, developing resource materials, and evaluating the project.

GEORGIA

Grant Information

Name of Grantee	Georgia Department of Community Health Division of Medical Assistance, Aging & Community Services		
Title of Grant	Nursing Facility Transitions Grant		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$627,211	***Year Original Funding Received***	2001

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Subcontractor(s)

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disABILITY LINK	Rebecca Ramage-Tuttle	404-687-8890
Three Rivers Area Health Education Centers*	Jan Pittman	706-660-2499
Foothills Area Health Education Centers	Sheila Griffin	770-533-6866

Target Population(s)

Twenty-four Medicaid-eligible individuals residing in 18 rural and underserved counties in the state.

Goals

- Identify and implement policy changes needed to bring about improvements in the long-term care system.
- Build the capacity of providers of nursing home services in Georgia to offer community support services.
- Increase the number of individuals who transition from long-term care nursing facilities to appropriate community-integrated living arrangements.
- Increase the number of trained, reliable, and quality community service workers.

Activities

- Establish a Consumer/Provider Task Force to identify, prioritize, and develop strategies to overcome institutional bias in state policy.
- Conduct a comprehensive community resource mapping project and workforce development project in 18 county pilot areas to identify barriers and opportunities for increased community services and direct care workers.
- Identify individuals who express an interest in community placement through a statewide survey.
- Work in partnership with Centers for Independent Living to relocate 24 nursing home residents to the community.

Abstract

The purpose of this project is to build state capacity to provide outreach and support the transition of people residing in nursing homes to a community-integrated living arrangement consistent with their needs and preferences and to assure that these individuals have the support necessary to sustain long-term residence and participation in the community. This will be accomplished through careful study and recommended changes to state policy, development of community services and the direct care workforce, and relocation of 24 individuals presently residing in nursing homes to the community. Grant activities will focus on a service area of 18 rural and primarily underserved counties.

We will accomplish the goals of this project through collaboration with a diverse workgroup consisting of consumers, advocates, state agencies, and providers, including two of the three largest providers of nursing home services in the state of Georgia. By demonstrating that providers of nursing home services can encourage community placement, this project will establish a lasting legacy and true systems change. In essence, the project seeks to demonstrate that effective systems change can be a “win-win” situation for both consumers and providers.

Grant staff will work in close partnership with disABILITY LINK, a Georgia Center for Independent Living, which was also awarded a nursing facility transitions grant. Working together will enable the two grant projects to have greater impact on building state capacity and support for community living.

INDIANA

Grant Information

Name of Grantee	Family and Social Services Administration		
Title of Grant	Comprehensive Plan for Community Integration and Support of Persons with Disabilities		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$770,000	***Year Original Funding Received***	2001

Contact Information

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Division of Disability, Aging and Rehabilitative Services
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Subcontractor(s)

The Lewin Group has been selected as the vendor for consulting services. They will be helping design and implement the system for diverting individuals from nursing facilities and transitioning other individuals from nursing facilities. A second grant for a local coalition is in the final stages of being awarded.

Target Population(s)

Individuals currently residing in nursing facilities and individuals who are at risk of entering a nursing facility.

Goals

- Develop and implement changes needed to the preadmission screening process to determine individuals who could be successful in a community placement.
- Develop local coalitions for diversion and deinstitutionalization activities.
- Develop appropriate housing options.
- Develop a specialized case management system to aid in transition.
- Simplify eligibility for community services.

Activities

- Establish at least one local coalition.
- Make necessary changes to eligibility and preadmission screening laws and regulations.
- Establish partnerships with hospital discharge planners.
- Make necessary amendments to Medicaid waivers.

Abstract

The grant focuses on transitioning nursing facility residents for reintegration into their communities. The project also targets individuals who are at risk of entering a nursing facility. The funds will be used to implement the following changes. Using the preadmission screening process, Minimum Data Set assessment data, and outreach, we will identify appropriate candidates for participation. The grant will help develop a system to identify individuals for the long term. By bringing the Family and Social Services Administration, Long-Term Care Ombudsman, Area Agencies on Aging, Independent Living Centers, consumers, advocates, assisted living facilities, and the nursing home industry together, we will address barriers to success at the local level.

The intent is to make changes that are needed, which vary from place to place, and to bring about the most noticeable changes in each area. Case management functions will be extended to include more immediate and frequent communication, as well as onsite monitoring and contacts with service providers. An evaluation will be completed on the efficacy of the coalitions and enhanced quality activities.

MARYLAND

Grant Information

Name of Grantee	Making Choices for Independent Living, Inc.		
Title of Grant	Independent Living Partnership		
Type of Grant	Nursing Facility Transitions, Independent Living Partnership		
Amount of Grant	$450,000	***Year Original Funding Received***	2001

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Subcontractor(s)

Resources for Independence	Lori Magruder	301-784-1774
Center for L.I.F.E.	Gene Potts	301-884-4498
Eastern Shore CIL	Price Baum	410-221-7701
Independence Now, Inc.	Cathy Raggio	301-277-2839
The Freedom Center	Jamey George	301-846-7811

Target Population(s)

Persons with disabilities who live in nursing homes throughout the state who wish to explore the option to live independently in the community.

Goals

- Conduct outreach to nursing home residents who want to better understand their service options and who may want to relocate to the community.
- Educate and assist these individuals and their support systems to understand, identify, and procure local community resources.
- Compile and distribute resource materials from the local community using a first-person perspective.
- Empower individuals with disabilities to advocate for themselves.

Activities

- Provide outreach to nursing home residents, family members, support systems, significant others, and staff.
- Provide face-to-face peer counseling sessions with individuals who are interested in learning about community options.
- Provide accurate and useful information about community resources, including education about independent living centers and their philosophy of self-determination.
- Develop a peer counseling relationship for those who wish to discuss concerns and fears about transitioning.
- Work with existing state programs to ensure that the transitioning process is successful and consumer controlled.
- Develop a curriculum to empower individuals with disabilities to advocate for themselves.

Abstract

Making Choices for Independent Living, Inc. (MCIL), Maryland's oldest and largest center for independent living, proposes to work in partnership with Maryland's network of Centers for Independent Living (CILs) to conduct outreach and assistance to over 2,800 Medicaid beneficiaries currently residing in 231 nursing facilities across the state. Originally established in 1978, MCIL has an extensive and impressive history of assisting interested people to come out of nursing homes and return to the community. In 2000, MCIL was nationally recognized for its efforts.

This project, entitled the Independent Living Partnership (ILP), will be a unique and collaborative effort. It will partner with the other statewide CILs and State Medicaid Home and Community Based Services programs to supplement and improve existing services for the duration of the project and beyond. The results of the project could be replicated nationwide and will serve as a model for CILs in other states to use. In Maryland, the project will enable the rest of the CILs to gain valuable experience and expertise which can be used to expand on the grants' successes.

MARYLAND

Grant Information

Name of Grantee	Department of Human Resources (DHR) Office of Personal Assistance Services		
Title of Grant	Nursing Facility Transitions Grant		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$800,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Maryland Centers for Independent Living (6):

1. Making Choices For Independent Living
2. Center for L.I.F.E.
3. Eastern Shore CIL
4. Independence Now, Inc.
5. Resource for Independence
6. The Freedom Center

Target Population(s)

Individuals with physical disabilities, 65 years and younger, who are currently residing in nursing facilities and want to move into the community.

Goals

- Meet a minimum of 150 individuals' preferences and housing needs in a manner that allows for flexibility, choice, and self-direction.
- Provide better coordination of community housing and support services.
- Improve quality of transition services.
- Expand community housing alternatives.
- Develop policy, program, and regulatory changes to sustain the positive system changes.
- Develop measurable performance outcomes for monitoring, evaluation, and utilization review to promote effectiveness and efficiency.

Activities

- Educate and assist individuals and their support systems to understand, identify, and procure local community resources.
- Develop and sustain working relationships with public housing authorities and other housing resources in all Maryland jurisdictions.
- Systemically address the expansion and development of new housing resources.
- Compile and distribute listings of affordable, accessible housing resources and community support services.
- Provide grant funds not otherwise available for transitional costs associated with moving to the community.

Abstract

The Maryland Nursing Facility Transitions Grant is a statewide program designed to identify and expand affordable, appropriate, and safe housing for persons desiring to move from nursing facilities to the community, and assist with transition-related activities and costs including security deposits, utility hook-ups, furnishings, environmental modifications, procuring community based support services, etc. Federal funding will be used to develop a team, the ***Home Team***, for coordination/collaboration with local housing authorities and housing providers, outreach workers, and case managers to assist in obtaining housing for a minimum of 150 Medicaid beneficiaries currently residing in 231 Maryland nursing facilities.

The following agencies will collaborate in this project: the Maryland Department of Housing and Community Development (DHCD), the Department of Health and Mental Hygiene (DHMH), the Department of Human Resources (DHR), the six Maryland Centers for Independent Living (CILs), the Coordinating Center, the Public Housing Authorities, and other housing providers. This interagency collaborative program will be administered through the Department of Human Resources, Office of Personal Assistance Services, which will also provide program coordination. The Department of Housing and Community Development will house and recruit a "Housing Coordinator" position; and the state will award contracts to the six CILs who will provide Housing Transition Services.

The Nursing Facility Transitions State Program Grant will be closely linked with Maryland's Independent Living Partnership Grant through coordinated outreach and peer counselors to target individuals with physical disabilities, 65 years and younger, who are living in nursing facilities and want to move into the community. To maximize collaboration and resources, the two programs will have one advisory committee, comprising individuals with disabilities and agency representatives. Through implementation of these programs, Maryland expects to develop an extensive peer outreach program, reach well over 2,000 people, and build community-housing capacity. Major gaps related to affordable accessible housing, lack of education pertaining to community resources, and funding needed to assure successful transitioning will be addressed and resolved.

MASSACHUSETTS

Grant Information

Name of Grantee	Department of Mental Retardation Division of Systems Integration		
Title of Grant	The Massachusetts Bridges to Community Project		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$770,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

University of Massachusetts Medical School/Shriver Center	Margot Moomaw	781-643-0328
Seven Hills Foundation	Celia Brown	508-755-2340
Center for Living and Working in Worcester	Patricia Royea	508-363-1226
Massachusetts Advocates Standing Strong	Ed Bielecki	781-585-2422

Target Population(s)

Individuals with a significant disability residing in nursing facilities in the greater Worcester area who fall within the “H, J, K” case mix (individuals representing the least severe medical/nursing acuity levels as rated on the MMQ, which is the system by which Massachusetts establishes payment to nursing facility providers).

Goals

- Transition individuals with a significant disability living in nursing facilities into community homes by increasing access and the availability of long-term community services and supports, and improving stability and success in the community by using a dedicated interdisciplinary, cross-disability team approach.
- Increase access to, and availability of, affordable, accessible, and safe community housing options.
- Develop family and community connections for individuals in nursing facilities to increase their awareness of community services and supports, increase motivation and desire to leave the nursing facility, and afford the greatest opportunity for involvement and the exercise of choice.
- Develop a blueprint for interagency collaboration for identifying, developing, and coordinating housing for individuals transitioning out of nursing facilities.

Activities

- Establish interagency, interdisciplinary case management team to assist individuals transitioning to the community.
- Develop a coordinated housing strategy on a statewide basis and local strategies to secure accessible, affordable housing for individuals transitioning out of nursing facilities.
- Link person-centered advocacy and self-determination groups with individuals transitioning from or considering transitions from nursing facilities to community living to provide direct support through peer mentors and community connections facilitators.
- Educate the greater Worcester community to build community capacities to engage individuals transitioning from nursing facilities.
- Establish a local citizen advisory committee composed of at least 51 percent of individuals with disabilities and families that will promote the independence of individuals to transition out of nursing facilities, and provide direct advice to the project.

Abstract

The Massachusetts Department of Mental Retardation, with the cooperation and support of the Division of Medical Assistance, the Massachusetts Rehabilitation Commission, the Department of Public Health, the Executive Office of Health and Human Services, the Executive Office of Administration and Finance, and the Executive Office of Elder Affairs will use the grant to transition individuals with a significant disability from nursing facilities in the greater Worcester area to community living.

The 3-year project, known as the Massachusetts Bridges to Community Project, will examine the impact that three specific variables might have on the success of transitioning individuals out of nursing facilities and having them successfully remain in community settings. The three variables are: a dedicated interdisciplinary case management team approach; focused housing search along with expansion of housing options; and participation of individuals in the project management structure along with inclusion of peer mentoring, self advocacy organizations, and community education.

Year 1 of the project will include the following activities: establishing the project team; hiring the peer mentoring and self advocacy organizations; establishing the local citizen advisory committee and the interagency steering committee that will oversee policy direction; reviewing the Minimum Data Set in the state and other information to identify the individuals who will be targeted for this project; developing a working and collaborative relationship with the nursing home industry as well as local town and city officials, community service agencies, housing agencies, providers and developers, and faith-based organizations; and creating the methodology to evaluate the implementation of the project.

Years 2 and 3 will be focused on transitioning individuals out of nursing facilities, securing adequate and appropriate supports to assure success in the community, identifying community service gaps (including housing), and compiling data to evaluate project process and outcomes.

MICHIGAN

Grant Information

Name of Grantee	Department of Community Health, Long Term Care Initiative		
Title of Grant	Nursing Facilities Transition Initiative		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$770,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

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University of Michigan Turner Geriatric Clinic	Katherine Supiano	734-764-2556

Target Population(s)

Persons who reside in nursing facilities who either no longer require nursing facility care or no longer wish to remain in a nursing facility; persons leaving hospitals who do not wish to enter a nursing facility or who require only a short-term nursing facility stay.

Goals

- Assure that the needs of persons who have traditionally resided in nursing facilities are included in the planning and development of housing projects.
- Develop a working model for preventing precipitous admissions to nursing facilities.
- Inform housing providers regarding supportive services that are available to help persons avoid premature nursing facility admission.
- Identify a model of access to services that are available outside of nursing facilities.
- Assure that persons who require only a short-term nursing facility stay are offered the opportunity to return to the community.
- Identify obstacles to funding services and to develop a uniform funding protocol across affected systems.

Activities

- Educate local community housing consortia regarding the needs of the nursing facility population to assure that those persons will be included in the consortia's planning.
- Use HUD's Project Access Section 8 housing subsidies to transition nursing facility residents to the community.
- Develop and provide education, training, and technical assistance on housing and services to persons and entities identified through the various components.
- Create a cross-systems policy framework that identifies obstacles and facilitates the transition from nursing facility care to community living.
- Link nursing facility diversion staff to transition component activities and to local resources to assist, thereby diverting nursing facility admissions or extended nursing facility stays.

Abstract

There are four basic components to the grant activity: transition, diversion, education, and evaluation. In addition, grant activities will be linked with activities of a state-funded housing initiative designed to promote the development of affordable, accessible housing. *Transition*. Activities under the housing initiative are designed to educate housing consortia in communities regarding the needs of special populations and to assist in the development of strategies to meet the needs of individuals requiring complex care in community housing. Communities already engaged in creating supportive housing for persons with special needs will be the primary targets. This will allow for coordination with existing programs, which is viewed as the most effective way to provide linkage to those services needed and to identify those persons wishing/requiring alternative housing, with the ability to match them to housing units. The Department is aware of approximately 150 persons identified through the PASARR process who are in need of alternative living arrangements and who could form an initial referral pool of nursing home residents to benefit from this effort. We will develop strategies not only to provide housing for this population, but also to access the supports needed to enable persons to live independently. The state housing initiative expects at least 150 units of newly available housing after 3 years of effort. It is expected with the linkage to the Nursing Facility Transitions grant activities that additional units will be identified and specifically targeted to the nursing facility population. A last-resort transition fund, provided for in the grant, will help defray moving costs for extremely indigent individuals where other sources of public or private funds are not available. *Diversion*. Two efforts will be piloted. First, the University of Michigan's Turner Geriatric Program will work to link hospital personnel with transition activities and local resources, and to assist individuals being discharged to return to, or to find an alternative home in, the community. The second effort will be funded by the state housing authority to assist residents of state-financed housing to "age in place," and, in coordination with the transition component and with Turner Clinic, work to fill vacancies in existing state-financed housing. *Education*. This component will provide education, training, and technical assistance on specific aspects of the initiative to persons and entities identified through the other components. *Evaluation*. We will develop a prototype for evaluating the effort, focused on cost/ benefit analysis, changes in quality of life, and "lessons learned."

NEW HAMPSHIRE

Grant Information

Name of Grantee	DHHS, Elders Division		
Title of Grant	Community Wrap: Older Adult Wrap Around Services		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$770,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Dartmouth Psychiatric Research Center	Keith Miles	603-271-5747
Riverbend Community Mental Health, Inc.	Carrie Hughes	603-228-2101
Consumer Peer Support Outreach – to be decided.		
University of New Hampshire- Institute on Disability	Susan Fox	603-228-2084
New Hampshire State Hospital	Paula Mattis	603-271-5386
Glencliff Home for the Elderly	Todd Bickford	603-989-3111

Target Population(s)

Individuals in the Concord region with mental illness who are currently in a nursing home, or in the state psychiatric facility receiving a nursing home level of care but are no longer in an acute phase of their psychiatric illness.

Goals

- Ensure stable community residence for older adults with complex, multiple problems who are currently residing in nursing homes or receiving nursing home level of care in the state psychiatric facility.
- Expand housing opportunities for people with mental illness and other disabilities in the Concord community and statewide.
- Develop a system for providing the services needed to transition people from institutions to a community residence.

Activities

- Identify service gaps for individuals seeking community-based residency.
- Develop and implement a "Wrap Around Services" program to assist individuals transitioning to the community.
- Develop funding options for housing, social, adult daily living, medical and mental health needs including the development of a 1915(c) Mental Health/Home and Community Based Waiver application.
- Enhance older adult outreach capacity through intense case management, community outreach, and strengthened advocacy.
- Hire a housing specialist to pursue available and affordable housing through state and federal housing benefits.

Abstract

The Department of Health and Human Services' Division of Behavioral Health, in collaboration with the Dartmouth Psychiatric Research Center, Institute on Disability, Riverbend Community Mental Health Center, the New Hampshire Housing Finance Authority and Pathways to Recovery Peer Support Program, will work together to transition older adults with mental illness from nursing facilities to the community.

This 3-year program contains two interrelated initiatives targeted at "Wrap Around Services," for transitioning older adults with mental illness from nursing facility settings to community-based settings and expanding housing opportunities for people with mental illness and other disabilities in the Concord community and statewide. The wraparound approach has proven to be very effective in coordinating and delivering care when used with children diverted from, or transitioned out of, institutional placements, and has recently been shown to be similarly effective with older adults.

The goal of the project is to ensure that adequate and appropriate services and housing are delivered to ensure stable community residence for older adults with complex, multiple problems who are currently residing in nursing homes or are receiving a nursing home level of care in the state psychiatric facility.

Year 1 of the project will include a review and analysis of the Minimum Data Set in the state, a review and analysis of service gaps for individuals seeking community-based residency, and preparation of a waiver to support these specialized services. In Year 2 we will submit the waiver application and plan the Wrap Around Services demonstration. In Year 3 we will implement and evaluate the Wrap Around Team that includes a local Mental Health Peer Support Group with ten individuals from the Concord region.

Throughout the 3 years, a regional and statewide strategy to improve the availability of affordable and accessible housing will be implemented. Also over the 3-year period, the project process and outcomes will be documented in an evaluation provided by the New Hampshire Dartmouth Psychiatric Research Center.

TEXAS

Grant Information

Name of Grantee	ARCIL		
Title of Grant	Texas Independent Living Partnership		
Type of Grant	Nursing Facility Transitions, Independent Living Partnership		
Amount of Grant	$308,178	***Year Original Funding Received***	2001

Contact Information

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www.arcil.com/tilp.html

Subcontractor(s)

None.

Target Population(s)

People with all types of disabilities, of all ages, in nursing facilities and those at risk of nursing facility placement.

Goals

- Expand upon successful outreach activities to identify people with disabilities of all ages in nursing facilities who are seeking to transition to the community with appropriate services and supports.
- Develop and implement components of training targeted to state agency staff, consumers, volunteers, advocates, and private service providers to address barriers to community transition.
- Develop lasting partnerships and implement systemic changes that supplement the state's infrastructure.

Activities

- Coordinate annual conferences of CIL staff, state agency staff, and partners.
- Develop and disseminate materials to replicate "best practices" for identifying consumers for community transition.
- Participate in ongoing training activities in each of the 11 state regions.
- Present specific recommendations for local, state, and national policy changes.

Abstract

The Texas Independent Living Partnership is a cooperative effort of the Texas Association of Centers for Independent Living (TACIL), the Texas Health & Human Services Commission (HHSC), and the Texas Department of Human Services (TDHS). Centers for Independent Living (CILs) in Texas and state agencies assist people with disabilities who want to move from nursing facilities to their own homes in the community. The project will work with state agencies, community organizations, and advocacy groups who serve children and adults of all ages with all types of disabilities.

TACIL represents 11 organizations operating CILs in 18 communities. HHSC is the state Medicaid Agency and leads the state's “Promoting Independence” initiative. TDHS is the state agency that funds nursing facilities and many of the state's community-based long-term care programs. Organizations serving children with disabilities, individuals with specific disabilities, and elderly individuals have agreed to help with outreach materials, training activities, and recommendations for changes to the long-term care system.

WASHINGTON

Grant Information

Name of Grantee	Department of Social and Health Services		
Title of Grant	Supported Transitions		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$770,000	***Year Original Funding Received***	2001

Contact Information

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Aging and Disability Services Administration
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Olympia, WA 98504-5600

Subcontractor(s)

None.

Target Population(s)

Individuals under the age of 65 living in nursing facilities throughout the state.

Goals

- Strengthen the capacity of independent living providers, centers, and contractors to provide support and technical assistance regarding independent living and consumer-directed services.
- Expand access to accessible, affordable housing for people transitioning out of nursing facilities.
- Improve the provision of assistive technology services necessary to live in the community.
- Develop a system for planning comprehensive individualized services to support the transition from nursing home to community residences.

Activities

- Organize and partner with independent living consultants to provide peer support, skills training, and advocacy.
- Collaborate with housing authorities and other entities to increase the options for affordable and accessible housing.
- Conduct a study of the state's durable medical equipment program.
- Enhance the resources for assistive technology.

Abstract

Washington State Department of Social and Health Services—Aging and Adult Services Administration will use grant funds to further its efforts in moving clients from nursing homes to less restrictive settings in the community. We expect to support up to 300 people under the age of 65, who have a variety of disabling conditions or chronic illnesses. Funds will be used to develop a system of supports aimed at removing the barriers that keep these people in nursing homes.

We will develop relationships with housing authorities and related entities throughout the state to share information and collaborate in developing systems for referral and support. Three housing authorities in the state share the Access 2000 Section 8 vouchers that are dedicated to people leaving nursing facilities. Processes and practices developed in those communities will provide a foundation for improving access to housing throughout the state.

A second thrust of the grant is to cultivate and support the capacity of independent living consultants to provide individualized support focused on living in the community. This will be accomplished through contracted services on a fee-for-service basis. Nursing facility social workers will develop a plan with the resident to achieve desired outcomes in moving to the community and connect individuals with consultants best suited for particular needs. The consultants will provide peer mentoring, skills training, advocacy, and technical assistance on an array of topics such as managing personal assistants, budgeting, paying bills, etc.

Third, we will augment the provision of durable medical equipment so that people are able to obtain an appropriate type and quality of assistive and adaptive equipment before leaving the nursing facility. This effort also includes a study of the durable medical equipment program to determine utilization rates, regional differences, and systems issues.

WEST VIRGINIA

Grant Information

Name of Grantee	Department of Health and Human Resources		
Title of Grant	Transitioning to Inclusive Communities (TIC)		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$551,678	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Center for Excellence in Disabilities
West Virginia University

Sally Burchfiel

304-293-4692

Target Population(s)

Individuals of all ages with disabilities or long-term illness who reside in nursing facilities and/or segregated settings or are at risk of segregated placements.

Goals

- Increase information on community resources, supports, and services to enhance informed choices for community living for persons with disabilities or those with long-term care needs.
- Identify persons who wish to transition from nursing facilities into communities and identify necessary services and supports.
- Develop systems of peer supports and services to improve the transition process to inclusive communities.
- Identify barriers in Medicaid/Medicare service plans and waiver programs and recommend changes to support community living.
- Implement transitional support models and evaluate cost effectiveness and consumer satisfaction.

Activities

- Identify persons wanting to transition by developing informational and educational programs that provide guidance and build advocacy and self-determination skills for consumers, family members, and service providers.
- Develop a Consumer Oversight Commission that participates in grant activities, as well as a process to increase community supports in areas such as housing, education, attendant services, and in-home health care.
- Utilize, evaluate, and modify the Life Choices Assessment tool by conducting over 100 assessments and Person-Centered Planning for those interested in transitioning to the community or avoiding placement in nursing facilities.
- Develop and coordinate training for the development of Transition Support Teams statewide.
- Create a person-centered planning discharge and referral instrument that provides community options and resources and develops a data base that can be used to determine community service and support needs.

Abstract

The Transitioning to Inclusive Communities (TIC) Project will enable individuals who reside in nursing facilities or other segregated environments, or who are at risk of moving to such facilities, to transition to community residences. This goal will be accomplished through a number of activities. We will provide information resources for people with disabilities or long-term illnesses and their families, including a toll-free phone line, a website, training, and a public awareness multimedia campaign. This information will assist the individuals considering transition to make informed choices regarding community living options.

We will identify individuals interested in transition through responses to disseminated information and training, as well as through a person-centered Life Choices Assessment Tool, used for both transitioning from and avoiding nursing or congregate facilities. Self-determination and self-advocacy skills will be enhanced through collaborations with advocacy organizations and statewide training. Community transition options will be increased through contracts with advocacy and consumer support groups to provide model peer supports and “trial” community transition choice options.

Discharge planning and intake will be augmented with a person-centered system of supports. A Transition Support Team will be modeled at nursing and congregate settings as well as with rehabilitation hospital discharge and nursing home intake personnel. This interdisciplinary support team is made up of the individual transitioning, professionals, family and friends, community members, and volunteers. Technical assistance will be provided so that a selected number of individuals can develop their own consumer-directed Transition Support Team.

Finally, the TIC Project will build additional community supports through funding nonprofit advocacy, consumer or community groups to demonstrate the use of peer supports and services in the transitioning and diversion processes. Small amounts of additional funds will demonstrate the importance of assistive technology or home start-up funds as people transition.

Consumer direction and evaluation for the TIC Project is provided through a 25-member Consumer Oversight Commission, through ongoing follow-up, and through a consumer satisfaction survey in the last year of the grant.

WISCONSIN

Grant Information

Name of Grantee	Great Rivers Independent Living Center		
Title of Grant	Nursing Facility Transitions Project		
Type of Grant	Nursing Facility Transitions, Independent Living Partnership		
Amount of Grant	$450,000	***Year Original Funding Received***	2001

Contact Information

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www.ilresources.org

Subcontractor(s)

Access to Independence	Tracy Miller	608-242-8484
Center for Independent Living of Western Wisconsin	Kay Sommerfeld	715-233-1070
IndependenceFirst	Deb Langham	414-291-7520 ext. 204
Midstate Independent Living Consultants	Jennifer Fasula	715-344-4210 ext. 17
North Country Independent Living Center	Dee Truhn	715-392-9118 ext. 19
Options for Independent Living	Kathryn Barry	920-490-8270 ext. 183
Society's Assets	Karen Olufs	262-637-9128

Target Population(s)

Any person with a disability or long-term illness residing in a nursing facility, ICF-MR, or state center for 90 days or more, who would like to receive services in the community.

Goals

- Identify and address methods to eliminate barriers that limit or prevent persons with disabilities or long-term illnesses from living independently in the community of their choice.
- Facilitate successful community placement for 210 persons with various disabilities and ages statewide who are currently living in nursing facilities.
- Enhance existing Independent Living Center peer support programs to provide information and assistance to consumers, families, and guardians regarding transitions.
- Collaborate with local housing authorities and other housing service providers and business partners to access and develop resources to increase housing options for people using transition services.

Activities

- Develop and implement relocation plans for consumers residing in nursing facilities who want to move to the community.
- Train and support transition specialists and peer support volunteers.
- Set up a web-based chat group to connect ILC transition specialists with the Department of Health and Family Services (DHFS).
- Conduct statewide outreach to individuals in nursing facilities and the agencies with which they may come into contact.
- Develop caregiver support groups.
- Train ILC staff statewide to assist individuals in nursing facilities with relocation planning.

Abstract

The Transitions Project will create an effective methodology and practice to reduce and eliminate the existing barriers to relocation from nursing facilities to community living throughout the state of Wisconsin. Funds will also be used for training and to support a cadre of transition specialists and peer support volunteers.

As an Independent Living Center (ILC), Great Rivers provides services to individuals of all ages with all types of disabilities. All of the eight ILCs in Wisconsin have successfully participated in the previously funded Nursing Home Relocation Project (Homecoming) over the past 2 years and bring a great deal of knowledge and expertise to this new project. They have extensive experience in providing outreach to relevant agencies and nursing facility residents who desire community living, and in providing technical assistance on home modifications and assistive technology. Additionally, they have in-depth knowledge of required community resources such as local housing authorities, personal care providers, transportation services, and local, state, and federal funding options. They also have a successful partnership with the Wisconsin DHFS.

The eight ILCs have experience working within Wisconsin's long-term care system, which includes the Community Options Program (COP), Medicaid state plan services, Medicaid Waiver Programs, Family Care, Badger Care, and Pathways to Independence. All ILCs currently have a list of identified residents living in nursing facilities who are waiting for community living. The ILC staff are knowledgeable of the barriers that prevent their relocation and have access to information and services that could reduce or eliminate those barriers. The Transitions Project will identify and recommend how to implement the changes needed to address the relocation barriers and provide the information and support to sustain a successful relocation.

WISCONSIN

Grant Information

Name of Grantee	Department of Health and Family Services Division of Supportive Living		
Title of Grant	Homecoming II		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$800,000	***Year Original Funding Received***	2001

Contact Information

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Long Term Care Policy Analyst
Project Director/Coordinator
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Madison, WI 53707-7851

Subcontractor(s)

The following are recipients of grants to enhance housing opportunities for persons with disabilities who wish to live in the community:

1. NEWCAP: Center for Self-Reliance, Robert Koller, Executive Director, 920-834-4621.
2. Stockbridge-Munsee Community, JoAnn Schedler, Project Director, 715-793-4876.
3. Foundation for Rural Housing, Inc., Char Thompson, Project Director, 608-238-3448.
4. Independent Living, Inc., Patricia Eldred, Director of Development, 608-274-7900.

Target Population(s)

Individuals who are currently in a nursing home or other institution from any target group (frail elderly, physical disability, developmental disability, or serious mental illness) and who meet functional and financial eligibility criteria for available funding sources. The project will give special emphasis to working with individuals who have developmental disabilities or serious mental illness.

Goals

- Facilitate the transition of up to 400 individuals from nursing facilities to a successful community placement during the project period.
- Increase the flexibility and responsiveness of the current system to redirect available resources to enable persons with long-term care needs to have the opportunity to live successfully in the least restrictive setting appropriate to their needs.

Activities

- Identify individuals in institutions who want to move to the community and work with all stakeholders to develop care plans and funding options to enable relocations to occur.
- Develop a systematic process for ongoing identification and relocation of individuals who want to move from institutions to the community.
- Develop strategies to ensure that resources are available to support people to live in the community.
- Develop strategies for recruiting and maintaining a capable long-term care workforce.
- Fund local projects to systematically address housing issues of individuals with disabilities.

Abstract

Wisconsin's nursing home transition project, entitled *Homecoming II*, builds on the experiences of a nursing home transition grant received in 1999. The original projects focused on individuals with physical disabilities and frail elders and the development of relationships with Independent Living Centers as partners in outreach and relocation support. Wisconsin will build on the original *Homecoming* grant by expanding the target groups and increasing focus on system building for future activities.

The *Homecoming II* project will improve community-integrated services in the short term for 400 consumers who are currently in institutions, and over the long term through systems changes that will facilitate the relocation of additional individuals in a more systematic way. Particular attention will be paid to persons with serious mental illness living inappropriately in nursing homes and to persons with developmental disabilities living in Intermediate Care Facilities for Mental Retardation, while continuing the activities that successfully relocated residents who are elderly or have physical disabilities. In the new project, the Independent Living Centers will continue their current role with their own Nursing Facility Transitions Grant from CMS.

The outcomes Wisconsin anticipates for Homecoming II are as follows:

- Up to 400 individuals will be relocated from nursing homes and other institutions.
- Relocated individuals will have most of their needs and preferences met cost-effectively, as determined by consumer outcome interviews.
- Wisconsin has a system in place to use available resources so that people live in the least restrictive setting appropriate to their needs. Resources include outreach and identification, clinical expertise, peer support, and availability of service funding.
- Wisconsin has more local partnerships to provide readily available housing opportunities for individuals with disabilities.
- Wisconsin has an increasing supply of qualified direct care workers to meet the needs of its people with long-term care needs.

ALABAMA

Grant Information

Name of Grantee	Alabama Department of Senior Services, State Unit on Aging		
Title of Grant	Nursing Facility Transportations Program Grant		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$770,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

University of Alabama at Birmingham, Alabama Tombigbee Regional Commission (ATRC) (Area Agencies on Aging [AAA])

Jefferson County Office of Senior Citizens Services (AAA)

Target Population(s)

Persons currently enrolled in or eligible for the Alabama Department of Senior Services (ADSS) Medicaid Waiver program who are hospitalized and are at risk of nursing home placement, and persons recently admitted into Medicaid-eligible nursing home residences.

Goals

- Facilitate hospital-to-home transitions for ADSS Medicaid Waiver-eligible individuals with dementia who wish to remain in the community by implementing the "Hospital-to-Home" program that places ADSS Medicaid Consultants within hospitals.
- Field test a nursing home-to-community transition program for individuals with dementia residing in nursing homes located in the Jefferson County and ATRC AAA regions.

Activities

- Develop and implement an educational program targeting Hospital Discharge Coordinators Training will emphasize (1) the importance of making community living a viable option for persons with dementia, (2) the unique challenges faced by caregivers of dementia patients, (3) the resources available to caregivers in the community, (4) basic problem solving techniques, and (5) the role of ADSS Case Manager in assisting discharge coordinators and family caregivers with obtaining needed resources.
- Implement a consultant service that (1) places an ADSS Medicaid Waiver specialist within the hospital to assist with the identification of patients with dementia who are “at risk” of nursing home placement and (2) assist the Hospital Discharge Planner in the development of individualized home care plans that reduce the risk of nursing home placement.
- Inform all nursing homes in Jefferson County and the ATRC region about the transition project.
- Identify resident characteristics that would appear to predict successful community transition.
- Implement a system for identifying Medicaid-eligible nursing home residents who appear to be candidates for successful transition.
- Transfer a maximum of 10 nursing home residents from each of the two AAA areas from nursing home to home living using enhanced ADSS Medicaid Waiver services.
- Enhance ADSS Medicaid Waiver services by implementing an extensive training system for ADSS Case Managers in problem-solving techniques to assist them in managing the multiple and complex demands faced by caregivers of persons with dementia who are transitioned to the home.
- Provide additional support services through funds initially provided by this grant, but sustained by funding changes to the Medicaid Waiver program by the state of Alabama. These support services may include in-home respite services, home health aid services, nursing home hold days, adult day care, or any other service not currently covered by the waiver but is needed for transition back to the community.
- Evaluate the acceptability and feasibility of the “nursing home-to-home” transition program.

Abstract

The ADSS proposes to collaborate with the state's 13 AAAs, the Alabama State Nursing Home Association, the Alabama Hospital Association, Alabama Medicaid Department, Governor’s Office on Disability, the Olmstead Core Workgroup, and the Dementia Care Research Program of the University of Alabama at Birmingham to enhance support services provided by the Elderly and Disabled Medicaid Waiver program to assist persons with dementia living in the community. The project institutes a comprehensive system to support enduring changes in the delivery of community based assistance for Medicaid eligible persons with dementia. The project targets two populations of Medicaid eligible persons with dementia: (1) community dwelling persons with a recent admission to the hospital and (2) recently admitted Medicaid eligible nursing home residents. We have chosen two AAAs because they provide both rural and urban settings, a significant number of low-income, minority residents, and sufficient staff capacity for program management. Our program will integrate ADSS Medicaid Waiver services into other formal care services and into family caregiving, maximizing the benefit of both formal and informal services available to Medicaid Waiver participants.

ARKANSAS

Grant Information

Name of Grantee	Department of Human Services Division of Aging and Adult Services		
Title of Grant	Your Choice		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$598,444	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Independent Living Centers of Arkansas
Eight Area Agencies on Aging of Arkansas

Target Population(s)

Individuals who are at high risk of entering a nursing facility or individuals currently residing in nursing facilities that wish to return to the community.

Goals

- Develop a working model for a diversionary process from nursing homes.
- Build on the transitional process already underway with Passages, Arkansas' 2000 Nursing Home Transition Grant.
- Establish an ombudsman program for individuals who use home and community based waivers.
- Develop a blueprint for interagency collaboration for identifying, developing, and coordinating access to community housing.

Activities

- Develop an intervention plan for individuals who are at risk of nursing facility placement directly from a hospital.
- Provide public awareness of the array of long-term care services that are available in the state of Arkansas through a community grass roots marketing campaign, development of a website and implementation of a toll-free number.
- Collaborate with the Real Choice and CPASS Grants to develop a statewide web-based consumer information resource, personal assessment form, and directory of services for people who are aging and people with disabilities, including developmental disability and mental illness.
- Develop a single, standardized assessment form to establish eligibility for both nursing facilities and home and community based waivers in the state of Arkansas.
- Establish a Community Bridge Fund with grant funds that will help pay for items that are necessary for an individual to remain in the community or assist individuals to return to the community.
- Collaborate with Arkansas Development Finance Authority (ADFA), which has agreed to set aside $300,000 of its annual HOME program allocation for bridge rental subsidies to be used for those qualifying for home and community based waiver services.

Abstract

"Your Choice" focuses on diverting individuals at high risk of institutionalization by placing social workers in pilot programs in two hospitals in Arkansas, one rural and one urban. Currently, the Division of County Operations determines eligibility for Medicaid long-term care services (nursing home and home and community based services). Eligibility determinations for nursing home care are made post-admission. The average time to process a Medicaid waiver application is 45 days. Because of the 45-day lag time, inpatient hospital providers have historically not been able to arrange for services in the home prior to discharge and found it much easier to arrange for nursing home admission. A collaborative effort will be made with the Real Choice Grant to develop a "fast-track" process to reduce the eligibility wait time for Medicaid waiver applications. Consumers will have quick entry, timely eligibility determination, and consistent medical eligibility criteria and access to services. Data will be complied to show the comparison of nursing facility placements in prior years with those in project years.

Another component of the diversionary process will be the development of a statewide web-based consumer information resource, personal assessment form, and directory of services for people who are aging and people with disabilities, including developmental disability and mental illness. An ombudsman program for persons who receive waiver services will also be developed to assist in the diversion of persons from institutions. Consumers with disabilities and advocates have often expressed concern about a voice for individuals in the community who have difficulties with services they are receiving from a home and community based waiver.

Another initiative of this grant is to build a blueprint for interagency collaboration to identify, develop, and coordinate community housing. The ADFA has agreed to set aside $300,000 of its annual HOME program allocation for bridge rental subsidies. A collaborative effort with AFDA will be made to recruit and identify individuals currently at high risk of being institutionalized, or those currently in nursing homes and capable of living in the community, and to assess the housing and support service needs of those individuals and to link those persons with support service providers.

CALIFORNIA

Grant Information

Name of Grantee	Community Resources for Independence		
Title of Grant	Transitions Independent Living Partnership Grant		
Type of Grant	Nursing Facility Transitions, Independent Living Partnerships		
Amount of Grant	$337,500	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Have not subcontracted with anyone at this time.

Target Population(s)

Native Americans and Hispanic individuals with cognitive, mental/emotional, physical, hearing, vision and multiple disabilities, families, and health clinics statewide.

Goals

- Improve access to services by developing a new transition model and conducting outreach and education.
- Assure consumer direction, involvement, and participation at all levels of the project.

Activities

- Recruit, organize, and train the six to eight member Peer Support Mentor Team.
- Explore other states' assessment tools and develop a consumer-directed assessment tool.
- Develop outreach materials, letters, brochures, and expand media contacts for widest visibility.
- Implement changes to the Community Resources for Independence (CRI) consumer database and develop concurrent database collecting additional information determined necessary for project.
- Begin working with Native American and Hispanic staff members to develop outreach plan to these populations.
- Develop "living" resource list for each county.
- Participate in an evaluation process through a contract with the World Institute on Disability (WID) at the end of the 3-year grant period to determine if people with disabilities will experience substantially greater opportunities for community living and community participation as a result of this project.

Abstract

CRI will develop a replicable statewide program improving community options to assist individuals with disabilities make appropriate transitions from institutions into integrated community settings. Through outreach, training, technical assistance, and public policy recommendations, CRI will design a program to strengthen California's infrastructure to support nursing facility transitions. CRI, an Independent Living Center established in 1976, serves individuals with disabilities in Sonoma, Mendocino, Lake, and Napa Counties (Northern California), representing diverse urban and rural communities.

CRI will form partnerships with key local, state, and federal organizations including CA Department of Health Services, Area Agencies on Aging, State Independent Living Council (SILC), CA Foundation for Independent Living Centers (CFILC), local housing authorities, Coalition of Californians for Olmstead (COCO), Department of Rehabilitation, consumers, and other community organizations. CRI will contract with Independent Living Centers in San Diego, San Francisco, and Grass Valley for training and technical assistance to ensure that statewide issues, barriers, and opportunities are addressed.

CRI will also conduct outreach, education, and training; develop and distribute information and materials; and organize focus groups to alter individual, public, and professional expectations. It will also expand local, state, and federal opportunities and choices for individuals transitioning from nursing facilities into their communities.

A statewide model of transition will be designed, including resources, quality services, and policy recommendations for Independent Living Centers in California. Working with The Access Center in San Diego, ILRC in San Francisco, and FREED in Grass Valley, CRI will develop a proposal to support a statewide funding mechanism for the implementation of this Independent Living Center "Transitions" model.

We will also address barriers to successful transitions in local, state, and federal policy, regulations, and initiatives (i.e., housing, employment, personal assistance services, emergency funding, as well as access to and availability of home modifications, assistive technology, and equipment).

DELAWARE

Grant Information

Name of Grantee	Independent Resources, Inc.		
Title of Grant	Community Works Partnership		
Type of Grant	Nursing Facility Transitions, Independent Living Partnerships		
Amount of Grant	$270,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

None.

Target Population(s)

The population targeted in the Community Works Partnership will be any individual with a disability currently residing in a nursing facility, Intermediate Care Facility, etc., living in New Castle County (northern Delaware) who desires to change their living situation and become more independent in a community setting of their choosing.

Goals

- Put into place a system of public and private groups that will move people from nursing facilities into community living.
- Conduct outreach to identify persons with disabilities residing in nursing facilities who wish to transition into the community.
- Get buy-in from residents, family, and friends with regard to providing ongoing support in the community after they have transitioned.
- Work with partners to coordinate needed services and supplies for transitioning consumers.

Activities

- Compile a list of outreach recipients.
- Develop outreach materials.
- Provide outreach and education to nursing facility residents and their families.
- Meet with nursing facilities staff (social workers and case managers).
- Schedule workshops for interested parties.

Abstract

Independent Resources, Inc. (IRI) will hire two additional staff people to conduct activities for the project. One person will specialize in locating accessible housing and/or modifying inaccessible housing. The other person will specialize in identifying people with disabilities or chronic long-term illness in nursing facilities who wish to live in the community. We will act in partnership with, and with the active participation of, the state agency administering home and community based waivers under Section 1915(c) of the Social Security Act, Division of Services for Aging and Adults with Physical Disabilities (DSAAPH). Together, we will identify 30 individuals with disabilities in nursing facilities that want to live in the community. We are calling this project the Community Works Partnership (CWP) because we are forging alliances with public and private groups to make community living work for people with disabilities currently in nursing facilities.

After identification of individuals who want community living, IRI will work with many public and private organizations to make certain the transition from facility to community is smooth, secure, and lasting. We will locate housing and, if modification to existing housing is necessary, we will secure the necessary materials and volunteer labor to make that possible. IRI has received a HUD grant with the goal of increasing accessible, affordable housing for people with disabilities through outreach and education.

For years, IRI has provided advocacy, peer counseling, independent living skills training and information, and referral services to people with disabilities of all ages on a cross disability, consumer-driven basis. With CWP, we will improve community-integrated services and enable more people to live in the community rather than in institutions.

DELAWARE

Grant Information

Name of Grantee	Delaware Health and Social Services, Division of Services for Aging and Adults with Physical Disabilities		
Title of Grant	Delaware Passport to Independence Initiative		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$566,772	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Medicaid nursing home eligible adults.

Goals

- Identify consumers wanting to participate in transitioning and assess levels of needed supports.
- Provide skills training and resource awareness for transitioning consumers and outreach; identify support services for consumers to utilize after transitioning.
- Increase housing opportunities for community living.
- Reduce institutionalization among persons with disabilities.
- Locate alternative funding streams.
- Provide enhanced community support services.
- Develop and improve workforce recruitment and retention.
- Promote quality enhancement of services delivered.

Activities

- Develop a system to identify candidates for transitioning; determine fiscal resources to transition 15 consumers; evaluate service gaps; identify consumer-driven case management options; and transition interested consumers to the community.
- Develop a resource notebook and identify ways to distribute it to consumers and develop a transition training package in partnership with the Centers for Independent Living.
- Survey housing barriers; expand private and public partnership opportunities; define and formalize interagency partnerships with local and state housing authorities; locate affordable and accessible housing options; and explore alternative sources of funding for housing.
- Develop educational programs to guide system decision making; seek participation of the DE Association of Health Care Facilities and local medical practitioners; and educate hospital discharge teams.
- Align Medicaid policies and practices with best practices for community services; and identify gaps in waiver programs.
- Develop and implement a strategic plan to meet consumer needs before, during, and after the project, and establish a network of trained volunteers to support consumers.
- Identify innovative methods for recruitment and retention of personal assistance workers, and develop training and professional development programs in partnership with other agencies.
- Issue a request for proposals (RFP) to solicit an independent contractor for data collection, evaluation, and final report preparation, and develop a project evaluation tool.

Abstract

This project will identify individuals within long-term care facilities wishing to transition to an integrated community setting and select an initial group of 15 participants. During the assessment and identification process, statewide outreach to educate professional staff and the public about the Initiative and transition-related issues will be implemented. Ongoing training topics will include areas to lay the philosophical foundation for self-determination, independent living, and personal decision making within a person-centered model. Ongoing project data collection and input from stakeholders will provide the foundation for the evaluation process to monitor program effectiveness, allow for flexibility and change, and contribute to lasting improvements of service provision and support. A multidisciplinary interagency Grant Oversight Committee (GOC) will guide all project related activities, information sharing, project updates, and reports to their agency. Critical issues to be examined are the following: affordable and accessible housing availability, transition-related policies and regulations, support services, training, outreach, and sustainability. DSAAPD will coordinate activities with other agencies with Systems Change funding and welcomes the opportunity to interface common efforts, goals, strategies, and partnerships to increase access to services with a continuum of supports.

LOUISIANA

Grant Information

Name of Grantee	Louisiana Department of Health and Hospitals		
Title of Grant	Louisiana Community Choice Access		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$600,000	***Year Original Funding Received***	2002

Contact Information

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Bureau of Community Supports and Services
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Subcontractor(s)

None.

Target Population(s)

Adults in nursing facilities.

Goals

- Enhance outreach to the general public concerning community alternatives through development of media materials and distribution networks.
- Provide systems change training concerning community alternatives to medical providers and institutions.
- Create infrastructure for identification, screening, addressing barriers, transitioning, and quality assurance/monitoring for nursing facility residents and transition at least 150 appropriate persons to community settings.

Activities

- Develop educational materials such as brochures, videos, and compact discs, and update a website to inform interested parties of opportunities to transition to the community from nursing facilities.
- Enhance helpline capabilities to cope with increased requests by adding additional hardware and staff.
- Hire coordinators to ensure statewide dissemination of educational materials, broad public contact, training, and contact of individuals in nursing facilities who indicate an interest in returning to the community.
- Contract for final phase of comprehensive assessment process based on the Residential Assessment Instrument—Home Care (RAI-HC).
- Develop and apply Quality Assurance and Citizens Monitoring processes for grant activities and individuals transitioned under the grant.

Abstract

The Department of Health and Hospitals (DHH) has developed and will implement a statewide initiative to change perceptions among the general public and health care providers regarding appropriate care choices for the elderly and individuals living with disabilities. The initiative will establish processes for transition from institutional care to the community, and will identify and assist 150 appropriate Medicaid Nursing Facility residents to transition to the community. This initiative is designed to work with existing state and local agencies and germane grants in partnership to assure that individuals have meaningful choices in viable community support systems. The grant will fund a serious, concerted attempt to institute true systems change by addressing cultural expectations as well as identification and relocation of nursing facility residents.

MINNESOTA

Grant Information

Name of Grantee	Metropolitan Center for Independent Living		
Title of Grant	Systems Change Grants for Community Living; Nursing Home Transition Grant		
Type of Grant	Nursing Facility Transitions, Independent Living Partnerships		
Amount of Grant	$400,000	***Year Original Funding Received***	2002

Contact Information

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(No project director/coordinator)

Subcontractor(s)

None.

Target Population(s)

Individuals with disabilities currently residing in nursing homes and individuals with disabilities living in community settings with housing needs.

Goals

- Provide continuation of Metropolitan Center for Independent Living (MCIL) and MN DHS collaborations to increase awareness of residents of nursing facilities and their caregivers of possibilities of living interdependently in the community and provide them with information, referrals, and support.
- Promote the availability of affordable and accessible housing for individuals with disabilities choosing to transition from nursing homes to live interdependently in the community of their choice.
- Provide a forum to bring together key informants associated with the issue of accessible and affordable housing for individuals with disabilities (i.e., consumers, policymakers, advocates, architects, contractors/builders, MN Housing Finance Agency (MHFA), and other interested parties).

Activities

- Create a consumer friendly brochure for county staff, consumers, and the general public that will summarize the information regarding programs to help in transitioning to the community.
- Create an easy guide for consumer self-assessment for those desiring to transition from nursing homes/institutions to community-based living.
- Increase awareness of the need for successful nursing facility transition in local communities by working closely with various partners.
- Advocate as a key informant to the appropriate state departments during development of public policy strategy on interdependent, community-based living.
- Develop partnerships with local nursing facility staff and advocates.
- Develop educational and promotional materials to assist with project efforts.
- Develop and analyze a survey instrument to assess housing issues in Region 8.
- Develop a housing assessment model for use in all other regions of the state.
- Present two forums focusing on the issue of accessible and affordable housing.

Abstract

The Metropolitan Center for Independent Living (MCIL), in close collaboration with the Minnesota Association of Centers for Independent living (MACIL) and the eight Centers it represents, will systemically change the way nursing facility transitions are implemented in Minnesota's local communities. By working in partnership with the Minnesota Department of Human Services, and other community partners, MCIL/MACIL is confident their voice, and the voice of the consumers they represent, will be heard.

This project is three-fold. It will (1) increase awareness of residents of nursing facilities and their caregivers of the possibilities of living interdependently in the community and provide them with information, referrals, and support; (2) train CIL and other paraprofessional and professional staff in successful nursing facility transitions; and (3) ensure the availability of affordable and accessible housing for individuals choosing to live interdependently in the community of their choice.

MCIL/MACIL will develop tangible products such as a training manual on successful nursing facility transitions, informational and educational brochures, and a housing survey and assessment model. Other less tangible outcomes include a strong influence on public policy decisions, enhanced public/private partnerships, positive and constructive relationships with nursing facility representatives, and the development of a cadre of community specialists, consumers, and advocates to work in a collaborative effort.

NEBRASKA

Grant Information

Name of Grantee	Department of Health and Human Services, Finance and Support		
Title of Grant	Creating Systems Change in the Transition Process		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$600,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

(Year 1) Eastern Nebraska Office on Aging, Lincoln Area Agency on Aging, and Northeast Nebraska Area Agency on Aging.

(Years 2 and 3) Aging Office of Western Nebraska; Blue Rivers Area Agency on Aging; Midland Area Agency on Aging; South Central Nebraska Area Agency on Aging; West Central Nebraska Area Agency on Aging; and Bailey Lauerman, communications and marketing firm.

Target Population(s)

Current Medicaid clients residing in nursing facilities who meet criteria for potential transition to home and community based settings.

Goals

- Bring Nebraska's long-term care services together as a continuum of care, with components that meet consumer needs at the right time, and a streamlined, seamless method for these components to work together.
- Help older persons and persons with disabilities to have both an awareness of choices in the type of living environment that is most appropriate to them, as well as the ability to exercise those choices.

Activities

- Develop a communication/marketing campaign that both informs candidates and key stakeholders about choices in how and where to live, and also creates a cultural change in the way Nebraskans regard long-term care.
- Conduct a networking campaign through Area Agencies on Aging with the nursing facilities in their territories to enlist nursing facility staff in identifying transition candidates, informing the candidates and key stakeholders about choices in how and where to live, and facilitating successful transitions to home and community based settings.
- Employ specially trained Ombudsman Volunteers to link with every Medicaid client placed in a nursing facility for the purpose of identifying transition candidates and facilitating successful transitions.
- Develop and implement a statewide toll-free number for nursing home transition assistance.

Abstract

Nebraska's project will capitalize on momentum already building in the state around enhancing our long-term care system. A previous 1-year Nursing Facility Transition Grant has allowed us to conduct qualitative research which revealed weaknesses in both the message sent to consumers about long-term care options, as well as the mechanism through which we offer alternatives to nursing facility placement. As a result, we have developed marketing materials and strategies we believe will be effective with targeted audiences, and have also devised strategies to expand and better link our home and community based services into a more cohesive system.

This project has the potential for significant and sustainable impact on Nebraska's long-term care system, both lowering costs for our Medicaid program and, perhaps most importantly, creating greater awareness and better options for consumers.

To assure statewide acceptance of this revolutionary (for Nebraska) plan for cultural and systems shift in long-term care, the project is divided into two phases. In the first year, the Department of Health and Human Services, Eastern Nebraska Office on Aging, Lincoln Area Agency on Aging, and Northeast Area Agency on Aging will operationalize the plan. During the second and third years, the project will expand statewide.

NEW JERSEY

Grant Information

Name of Grantee	Resources for Independent Living, Inc. (RIL)		
Title of Grant	Nursing Facility Transitions		
Type of Grant	Nursing Facility Transitions, Independent Living Partnerships		
Amount of Grant	$400,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Eleven Independent Living Centers (ILCs) in addition to RIL

Target Population(s)

Individuals under the age of 65 currently living in nursing facilities who have the desire and capacity to live in community-based housing situations.

Goals

- Incorporate direct consumer input into the planning, implementation and phasing of infrastructure changes.
- Provide adequate information, training, and support to individuals transitioning out of nursing facilities into the community.
- Assist people with disabilities in exercising choice in the services and supports they need as well as directing these services and supports in a manner consistent with his or her stated preferences.

Activities

- Transition the Olmstead Stakeholders Task Force to the New Jersey Systems Change Advisory Council.
- Form a Systems Change Management Team comprised of staff from all agencies.
- Develop an Advisory Panel that will provide guidance and direction to RIL staff.
- Utilize ILC staff to educate individuals with disabilities in nursing facilities about their options for community services and supports.
- Provide independent living skills training to people in nursing facilities.
- Recruit and hire one Community Living Specialist in Year 1 and one part-time Community Living Specialist in Years 2 and 3 of the proposal.
- Participate in the development of an individualized Independent Living Plan that will detail consumer goals, objectives, timelines, and areas of responsibility for every transitioning individual.
- Develop a community assessment tool to be used in conjunction with the DHSS comprehensive needs assessment.
- Develop mentoring and peer support programs with volunteer consumers in the community.
- Develop and conduct training for all the Community Choice Counselors to increase the ability of staff to deal effectively with people with disabilities who are under age 65.
- Develop a mentoring program that will match individuals leaving nursing facilities with trained peer mentors from local ILCs.

Abstract

The overall goal of this project is to conduct an assessment of individuals with disabilities who are under age 65 and reside in nursing facilities, and transition 200 individuals to the community over the 3-year grant period. Staff will coordinate an assessment process of 3,000 individuals with disabilities now residing in nursing facilities and help identify the types of community supports and services needed to transition individuals to the community. The project will recruit, hire, and train one full-time Community Living Specialist and one part-time Community Living Specialist.

Consumer involvement in planning and direction are critical elements of the project. Consumer advocates will be instrumental in the transition of the Olmstead Stakeholders Task Force to the New Jersey Systems Change Advisory Council and the formation of an RIL Advisory Panel. Consumers will also participate in mentoring and peer support programs.

NEW JERSEY

Grant Information

Name of Grantee	Department of Health and Senior Services		
Title of Grant	Young Adult Nursing Facility Resident Transition Initiative		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$600,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Barbara Parkoff, Principal SP Consultants, L.L.C. 23 Clive Hills Road Edison, NJ 08820	732-494-8268	Barbara.parkoff@verizon.net

Target Population(s)

Children and adults under the age of 65 with disabilities or a long-term illness.

Goals

- Collaborate with grant partners (the NJ Division of Disability Services, Independent Living Centers, and the Rutgers University Center for State Health Policy) to assist individuals with disabilities under age 65 to transition from a nursing facility to a community setting.
- Maximize consumer-direction and consumer-control of personal assistance services.
- Enhance our outreach and technical assistance efforts to assure that individuals obtain quality services and exercise meaningful choices.
- Partner with consumer advocacy associations, public housing authorities, and social service agencies to expand the existing infrastructure.
- Link transitioned individuals to social and economic activities of community life commensurate with their capacity.
- Adapt existing material for multimedia to include information specifically for individuals with disabilities to ensure accuracy and ease of comprehension for community living.

Activities

- Provide select Community Choice Counselors with more intensive training on the needs of persons under age 65 with the expectation that they will work exclusively on these transitions.
- Conduct a training program in disabilities for all Counselors to increase their ability to assist people with disabilities in the transition to the community.
- Expand collaboration with Independent Living Centers by meeting on a monthly basis for the first 6 months of the grant, and quarterly thereafter, to share ideas and information.
- Perform assessments in partnership with staff from Independent Living Centers.
- Transition or divert 240 individuals who have a disability or long-term illness to the community setting of their choice.
- Continue participation by Department of Health and Senior Services staff on the Governor's Stakeholders Task Force on Olmstead.
- Expand website and information guides to include community-based housing options listing services, waiver programs, and the range of services available for those with any disability as well as the elderly. Create links to websites related to disability issues.

Abstract

The New Jersey Department of Health and Senior Services, Division of Consumer Support (now the Division of Aging and Community Services) began the Community Choice program on August 1, 1998. It is designed to identify appropriate Medicaid nursing facility (NF) residents and help them find community-based alternatives.

Community Choice has been successful in transitioning a large number of beneficiaries in nursing facilities to the community, primarily individuals over age 65. We need to try a different approach to work with the 3,000 children and adults under age 65 who have a disability or long-term illness and remain in nursing facilities. Barriers to community re-entry include a lack of adequate, affordable, and accessible housing and a lack of understanding of their special needs and of the social and economic activities of community life they desire.

This grant will permit New Jersey to

- collaborate with grant partners (the NJ Division of Disability Services, Independent Living Centers, and the Rutgers University Center for State Health Policy) and other partners to transition or divert 240 individuals who have a disability or long-term illness to the community setting of their choice;
- organize a housing workgroup that identifies factors that inhibit the creation of housing, finds solutions to create needed housing, and provides incentives and assists developers interested in new housing; and
- identify housing developers willing to work with consumer groups and faith-based organizations, towns, cities, and service providers to build housing designed or modified to meet the needs of disability communities.

NORTH CAROLINA

Grant Information

Name of Grantee	North Carolina Department of Health and Human Services		
Title of Grant	Transitions		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$600,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Linda Kendall Program Director L.H. Kendall Consulting Services PO Box 28814 Asheville, NC 28814	828-712-4003	lkfields@mindspring.com

Target Population(s)

Adults with disabilities who are residents of North Carolina nursing facilities who wish to move back into the community.

Goals

- Design and implement a program that supports transition assessment and assistance for individuals in nursing facilities who are Medicaid-eligible or who will be Medicaid-eligible within 6 months who wish to return to their communities.
- Build the infrastructure and capacity to sustain the transition effort beyond the grant period for current residents of nursing facilities who have the desire and the capacity to transition with support services of their own.
- Work in conjunction with the other Systems Change grant efforts to provide a continuum of services for people with disabilities who wish to reside in the community.

Activities

- Raise awareness among nursing facility staff, hospital discharge planners, health and human service providers, consumers and their families about community living options, *Transitions*, and how to learn more about community options in their areas.
- Determine the most effective method(s) of identifying successful candidates for community living and identify the services and supports most critical to achieving and sustaining *Transitions*.
- Provide transition assistance to approximately 80 nursing facility residents in order to help them achieve their community-living goals.
- Strengthen the ability and capacity of the Independent Living Rehabilitation Program (ILRP) to assist nursing facility residents who choose to transition by providing more resources and services.
- Evaluate the costs and benefits of transitioning to the community for nursing facility residents assisted by the *Transitions* program and create a plan for sustaining the program beyond the grant period.

Abstract

The NC Division of Medical Assistance's primary partners in this program are the North Carolina Division of Vocational Rehabilitation's statewide ILRP and Centers for Independent Living (CIL). The program, called "*Transitions*," will utilize the experience of ILRP Counselors/Service Coordinators to help identify the needs and goals of nursing facility residents interested in transitioning to community living, facilitate residents' development of transition plans, and coordinate supports and services needed for successful transition. Pathways CIL and its fully functional satellite office, Western Alliance CIL, will train peer mentors in western service areas to support transition candidates and help them fully reintegrate into their communities.

In the first year of the grant, the Asheville and Rocky Mount ILRP regional offices will pilot the program. The results of a program evaluation will be used to refine the transition model before statewide expansion of *Transitions* in the second and third years of the grant. The success of *Transitions*, however, will be highly dependent upon active community partners. Examples of partners who have committed to be active participants in the pilot areas include:

Western Alliance Center for Independent Living, Asheville. Western Alliance will help provide individuals who transition into the community with donated computers, online support, training, and technical assistance to facilitate participation in an online community support network. They will complement ILRP services by responding to individual requests for Center core services including information and referral, advocacy, independent living skills training, peer counseling, and identification of mentors and other informal supports.

Citizens Together Advocacy Group, Rocky Mount. This advocacy group for persons with disabilities is a major community partner for ILRP in the Rocky Mount area and will be active in helping identify informal community supports such as peer mentors who can provide support and encouragement to help individuals readjust to community living.

Grant funding will pay for program staff and evaluation. More importantly, however, grant funds will be used for transition expenses not normally covered by public assistance programs such as utility deposits, furniture, household goods, and clothing. Grant funds will be also used to develop and distribute educational materials about community services and supports, and the *Transitions* program. Materials will be targeted to nursing home staff, hospital discharge planners, service providers, consumers, and families and will include written and video formats.

OHIO

Grant Information

Name of Grantee	Ohio Department of Job and Family Services		
Title of Grant	Ohio Access Success Project		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$600,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

To be determined.

Target Population(s)

Identified nursing home residents who are good candidates to change their living arrangements to a community setting.

Goals

- Identify and support the successful transition of targeted consumers living in nursing homes in Ohio to integrated community settings.
- Identify and share resources and linkages in the community that assist successful community transition.
- Evaluate the nursing home transition process.

Activities

- Create a transition protocol, which will serve as an individualized planning instrument to identify nursing facility residents who want to and who are good candidates to change their living arrangements to a community setting.
- Provide assistance to nursing home residents transitioning to the community with transportation and housing assistance as well as application for enrollment onto PASSPORT or the home care waiver.
- Conduct follow-up visits as a component of the transition plan, no less often than one visit every 6 months in the first year after the individual has moved to the community. Follow-up feedback will be provided to the state and to members of the Olmstead Consumer Task Force.
- Identify and build a base of resource information that will support people on an ongoing basis, particularly in the area of housing.
- Provide results of an evaluation to Ohio's key stakeholders, including the Olmstead Consumer Task Force.

Abstract

The goals of this grant are to identify and support the successful transition of targeted consumers living in nursing homes in Ohio to integrated community settings, identify and share resources and linkages in the community that assist successful community transitions, and evaluate the nursing home transition process. Follow-up feedback will be provided to the state and to members of the Olmstead Consumer Task Force. To facilitate this process, the transition protocol will identify nursing home residents who are interested and are good candidates to move to a community residence. The protocol will be developed with input from the Ohio Olmstead Task Force.

As Ohio is working through the process of transitioning consumers into the community, the grant will build a base of resource information, which will support people on an ongoing basis. A housing coordinator is included in the project design for Ohio's Real Choice Systems Change Grant. That housing coordinator will also be used to support the activities of the Nursing Facility Transitions Grant. Another component of building this resource base is the use of peer counseling from consumers who have been successfully transitioned.

Finally, those consumers that have been relocated to the community will receive follow-up visits by the contractor as a component of the transition plan. Follow-up feedback will be provided to the state and to members of the Olmstead Consumer Task Force.

RHODE ISLAND

Grant Information

Name of Grantee	Department of Human Services, Center for Adult Health		
Title of Grant	Transitioning to the Rhode to Independence		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$600,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Any institutionalized person in Rhode Island.

Goals

- Provide information on community service options, for which they are eligible, to institutionalized individuals of all ages and their families.
- Help institutionalized individuals, who indicate interest, to transition from an institution to a suitable community living arrangement with all necessary supports based on needs and preferences.
- Enhance the home and community based system and develop capacity to serve individuals with multiple and/or complex needs including significant physical, behavioral, and/or cognitive challenges.

Activities

- Expand the target population to anyone residing in an institutional setting.
- Bring in service coordinators from the elderly service network and Independent Living Centers to aid in transitioning activities.
- Leverage state infrastructure to support private transitional efforts through referrals and communications support.
- Develop wraparound program proposals for assisted living settings.
- Establish a 1-day habilitation program specializing in people with severe cognitive disabilities.

Abstract

Rhode Island estimates that there are approximately 400 people currently placed in an institutional setting who would likely benefit from discharge to a more integrated community setting if their needs could be met. Some of these people went to a nursing facility following a hospitalization and did not realize community supports are available. Others had some supports in place but not enough to maintain their health and safety. Still others fell through the cracks in the delivery system and were unable to qualify for services they needed in the community.

This statewide program will build upon Rhode Island's 1998 "Date Certain" Nursing Home Transition Program. It will be directed and monitored by a diverse oversight committee made up of consumers, state and quasi-state agencies, private agencies, and service providers. The Rhode Island Housing Resource Commission will serve as the critical link to housing resource opportunities statewide.

The Shared Vision for Long Term Care developed by a group of Rhode Island state agencies, community providers, nursing homes, and consumers is that Rhode Islanders will have a dynamic long-term care system that supports high quality, independence, choice, and coordination of services with the necessary public and private funding. Implementation of this proposal will be a significant step toward making this vision a reality.

SOUTH CAROLINA

Grant Information

Name of Grantee	Department of Health and Human Services, Office of Senior and Long-Term Care		
Title of Grant	South Carolina Home Again		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$600,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

None.

Target Population(s)

All populations in nursing facilities, with the exception of clients diagnosed as solely mentally retarded.

Goals

- Develop community partnerships with nursing homes and advocates.
- Develop targeting mechanism to identify clients and community needs.
- Develop transitional service package.
- Evaluate success of project and modify for post-grant ongoing efforts.

Activities

- Begin dialogue with area nursing facilities to lay groundwork for successful participation.
- Develop the comprehensive assessment instrument to be used in identifying and transitioning clients to the community.
- Expand the dialogue with HUD and local housing authorities in the target areas and develop a housing database.
- Initiate Community Transition Nursing and the bundled mental health service package.
- Begin targeting potential transition clients.
- Expand housing partnerships to include new HUD grant recipients for additional commitments.
- Use the comprehensive assessment instrument to identify potential transition clients.
- Assist a projected 20 residents with community relocation.
- Implement newly developed transitional services as needed and identified in the care plan.
- Conduct a year-end evaluation to determine progress and success.

Abstract

This project is directed in joint partnership with two state agencies, the SC Department of Mental Health (DMH) and the SC Department of Disabilities and Special Needs (DDSN). This grant was prepared with the objective of identifying and transitioning nursing home clients wanting to reside in the community, as well as implementing system changes needed indefinitely. The target population for this grant includes the elderly, individuals with disabilities, and clients with mental health conditions, excluding those solely diagnosed with mental retardation.

Newly hired grant staff will be primarily responsible for developing a comprehensive assessment instrument for targeting appropriate transition clients. The state intends to use the instrument with a transition team comprised of a community transition nurse (RN), the nursing facility social service worker and other nursing facility staff, the CLTC case manager (or DDSN Service Coordinator), and the client/family.

For transition clients with immediate needs, the state intends to utilize grant funds to assist with the short-term provision of rent deposits, furniture procurement, groceries, etc. Transition clients will be immediately enrolled into a waiver and then offered expanded supports. The RN will address pertinent medical issues and provide intensive caregiver/client training.

Given the intended transition of clients diagnosed with mental illness, it will be necessary to develop a package of relevant mental health services easily accessible in the community. This process will utilize supports already available and expand them in scope and frequency in recognition of transition anxiety.

Working in collaboration with the previously approved Real Choice for Systems Change grant, the nursing home transition project plans to utilize “South Carolina Access” and “South Carolina Choice.” “South Carolina Access” will be a statewide information and referral system database. “South Carolina Choice” is a demonstration waiver to test an enhanced method of offering self-directed care to clients served by Community Long Term Care in the Spartanburg area. It will provide greater options with regard to the types of services and providers allowed to receive Medicaid reimbursement.

UTAH

Grant Information

Name of Grantee	Utah Independent Living Center		
Title of Grant	Independent Living Partnership Grant for Nursing Home Transition		
Type of Grant	Nursing Facility Transitions, Independent Living Partnership		
Amount of Grant	$400,000	***Year Original Funding Received***	2002

Contact Information

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3445 South Main Street
Salt Lake City, UT 84115-4453

Subcontractor(s)

Five Independent Living Centers (ILCs): Options for Independence CIL, Active Re-Entry ILC, Tri-County ILC, Central Utah CIL, Red Rock CIL

Association for Independent Living of Utah

Target Population(s)

Individuals of all ages statewide with significant physical disabilities, representing various ethnic and socioeconomic groups living in nursing homes. Individuals with severe dementia, mental illness, or mental retardation will not be targeted through this proposal. Targeted individuals will be further identified by expressing their desire to live elsewhere.

Goals

- Transition 260 people with primarily physical disabilities from nursing homes to more integrated settings located throughout Utah.
- Improve the community support infrastructure statewide by providing an effective and efficient means through which participating state and local agencies, along with advocacy agencies, can exchange timely information on transition issues needed for nursing home residents to move to integrated community living.

Activities

- Establish a Transition Steering Committee consisting of the directors of six ILCs.
- Provide skill training statewide through a network of ILCs to 260 long-term care residents living in 78 nursing homes, both while they are in the nursing home and throughout their transition to community living.
- Establish a peer network of volunteer mentors in each ILC service area comprised of consumers who have successfully transitioned to community living.
- Organize six local Advocacy Alliances, facilitating open communication between state, local, and advocacy organizations.
- Develop a single coordinating entity through which agencies can disseminate information to promote community integration.

Abstract

The Utah ILC will partner with five other ILCs strategically located throughout the State of Utah to bridge a substantial gap in services available to significantly physically disabled residents of nursing homes that receive Medicaid funding. This ILC network will provide the mechanism to implement one-to-one skill building transition services to participants while still living in the nursing home and will assist participants to reintegrate to less restrictive community settings. Six public and private partnerships will be developed to bridge information and service gaps in Utah's community service infrastructure. Sustainability and a consumer-driven service structure are features built into the overall program.

WYOMING

Grant Information

Name of Grantee	Wyoming Department of Health, Aging Division		
Title of Grant	Project Out		
Type of Grant	Nursing Facility Transitions, State Program		
Amount of Grant	$600,000	***Year Original Funding Received***	2002

Contact Information

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6101 Yellowstone Road, Room 259B
Cheyenne, WY 82002

Subcontractor(s)

Wyoming Independent Living Rehabilitation, Inc.
305 West 1st Street
Casper, WY 82601

Wyoming Services for Independent Living
190 Custer Street
Lander, WY 82520

Target Population(s)

Institutional residents who could reside in a community setting.

Goals

- Incorporate stakeholder participation for plan development.
- Conduct a needs assessment process.
- Develop new community services and support infrastructure.
- Develop transition services to prepare individuals for a change in placement.
- Perform data collection which is individualized and tied to individual program plans.
- Identify outcomes measurement and target dates.
- Develop a quality assurance program.
- Develop resources to be used in nursing facility transition.
- Review, revise and update the plan every 2 years or as needed.

Activities

- Subcontract with two Wyoming Independent Living Centers to provide the transition services using Independent Living Specialists also working as case managers when appropriate.
- Develop a multidisciplinary assessment tool.
- Establish a collaborative effort with social workers, discharge planners, and medical professionals to assess potential clients for transition to the community.
- Develop a coordinated housing strategy on a statewide basis and local strategies to secure accessible, affordable housing for individuals transitioning out of nursing facilities.
- Develop a transportation voucher system to allow transitioned clients transportation to medical, social, religious, and employment appointments.
- Educate consumers, families, and partners who provide services within communities.
- Develop statewide transition services to prepare individuals for a change in placement.
- Conduct monitoring and Quality Assurance activities to be completed through a contract with the University of Wyoming.

Abstract

The purpose of this project is to develop a model in Wyoming for assisting nursing home residents who desire to transition into a less-restrictive environment/community living. The project will identify existing supports and barriers to transitions, develop infrastructure within the state, and develop pilot projects at two centers for independent living. These two ILCs will assist 10 individuals in transitioning from nursing homes in the first year of the project, 30 individuals in Year 2, and 45 in Year 3. They will also conduct education and outreach to communities, professional service providers, and consumers. The Department of Health will develop statewide transition services to prepare individuals for a change in placement and evaluate project consumer satisfaction and cost-effectiveness of the transition program. The grant will be utilized to identify and develop adequate resources and authority to implement long-term care services and supports “in the most integrated setting.” The Aging Division will subcontract with the two centers for independent living in the state in a collaborative effort to include multiple partners in the process of developing and implementing transition plans for nursing home residents. Working with consumers, private service providers, and multiple government agencies, “Project OUT” will identify barriers and the costs associated with transitioning residents from nursing homes. The project will develop proposals for improved funding for housing, transportation, and community health and support services.

Ultimate outcomes of the project are an increase in new and/or changes in Medicaid waivers/waiver slots and enlargement of the provider base; Housing and Urban Development (HUD) Section 8 Voucher changes statewide for housing; State of Wyoming Department of Transportation commitments for improved transportation programs for individuals with disabilities; and state general funds to allow for the sustainability and continuation of the Aging Division’s Olmstead efforts.

ALABAMA

Grant Information

Name of Grantee	Alabama Medicaid Agency, Long Term Care Division		
Title of Grant	Sweet Home Alabama: Under Construction		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,000,000	***Year Original Funding Received***	2001

Contact Information

Marilyn Ferguson, Director	334-242-5009	mferguson@medicaid.state.al.us
Anita Charles, Project Manager Project Development Unit Long-Term Care Division Alabama Medicaid Agency 501 Dexter Avenue Montgomery, AL 36103	334-353-4122	acharles@medicaid.state.al.us

Subcontractor(s)

Alabama Department of Senior Services	Caprice Chattom	334-353-8320
Alabama Department of Mental Health and Mental Retardation	Anne Evans	334-242-3706
Volunteer and Information Center	Camilla Prince	334-264-4636
Governor's Office on Disability	Barbara Crozier	334-353-0355

Target Population(s)

Persons with disabilities regardless of age or type of disability.

Goals

- Enhance access to home and community based services through improved information dissemination and service coordination.
- Create and expand system-wide opportunities for consumer choice and control over home and community based services.
- Expand resources for home and community based services through effective planning, advocacy, and education.

Activities

- Develop a community-based information and referral clearinghouse through collaborative public/private partnerships.
- Develop and implement a required Service Coordination Core Training Module to cross-train Medicaid service coordinators in basic competencies and information.
- Complete and implement recommendations from a comprehensive study of the feasibility of a single point of entry and/or coordination for home and community based services.
- Train, implement, mentor, and support person-centered planning (PCP) for consumers with developmental disabilities.
- Establish infrastructure for consumer input for consumers with mental retardation and/or developmental disabilities.
- Expand the Psychiatric Rehabilitation model to all community mental health centers and all units of state hospitals over a 3-year period.
- Develop, implement, and evaluate a person-centered assessment tool and process as a basis for a consumer-directed system of senior services.
- Establish a permanent Disability/Aging Policy Advisory Group within the Medicaid Agency's Long Term Care Division to formalize the mechanisms for ongoing consumer input and enhanced coordination of services.
- Develop advocacy and informational materials to educate consumers and family members, policymakers, and others regarding the state's Olmstead Plan.
- Establish an Outreach and Education Unit within the Medicaid Agency's Long Term Care Division.

Abstract

Our proposal was developed in conjunction with the state's Olmstead planning process. This process is comprehensive, addressing the needs of people with disabilities and their families regardless of age or type of disability. It is also consumer-based, substantially involving people with disabilities and family members in planning and decision-making. The Olmstead Core Workgroup is a 40-member group, comprising state agencies, advocates, providers, and consumers and family members, with the Alabama Medicaid Agency serving as lead agency.

The Workgroup has drafted a unifying theme as a title for the Olmstead plan, designed to catch the imagination of the state's citizenry and policy makers: *Sweet Home Alabama*: *Under Construction*. It is an apt metaphor for the work we must do to build a cohesive system of supports that is predicated on community, real choice, and consumer direction. The architects of the proposed systems changes are its stakeholders, with special emphasis on the substantial and meaningful participation of people with disabilities and family members. The proposed grant activities are our building blocks, targeted to achieve enduring systems change in three areas: access, consumer choice/control, and expanded resources for home and community based services.

ARKANSAS

Grant Information

Name of Grantee	Department of Human Services Division of Aging and Adult Services		
Title of Grant	Real Choice for Enduring Change in Arkansas		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,025,000	***Year Original Funding Received***	2001
Amount of Supplemental Grant	$360,000	***Supplemental Award Received***	2002

Contact Information

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Subcontractor(s)

Partners for Inclusive Communities/University of Arkansas for Medical Sciences

Area Agency on Aging of South West Arkansas

Target Population(s)

Adults age 19 and older.

Goals

- Achieve a better balance of spending between institutions and home and community settings.
- Increase the availability of in-home workers.
- Improve or maintain the health of elderly persons who are dual-eligibles.
- Increase consumer control over their services.

Activities

- Identify successful strategies to recruit and retain in-home workers, including those that focus on wages, benefits, training, and the establishment of a career path.
- Establish a worker registry.
- Develop a replicable model for a voluntary Medicaid/Medicare integrated system that efficiently manages the costs of services.
- Provide technical assistance regarding consumer self-determination practices to consumers and advocacy organizations.
- Develop an assessment process based on consumer preferences.

Abstract

The Real Choice project will address a number of problems Arkansas experiences in delivering long-term care services. Relevant agencies have come together with consumer groups and other public and private partners to plan for systems change that will promote informed consumer choice and higher quality services. The project will address issues related to access, availability, quality, value, and consumer participation.

The Real Choice grant for Arkansas will address the need for a single point of contact for home and community based care, timely and flexible eligibility determination, ease of access to services, and appropriate determination of services people want and need. Strategies we intend to employ are the use of federal options over more restrictive state options; a feasibility study to integrate Medicare and Medicaid services for seniors; training staff across divisions of the Department of Human Services (DHS) to promote understanding of alternatives available; an education outreach program to community resource staff; development of new assessment tools to determine optional settings for people entering the system and those already institutionalized; a study to explore the options for providing insurance to front line workers; a public awareness campaign to elevate the status of such occupations with the general public; development of a state worker registry; and strengthening of individual consumers and consumer advocacy groups in effective action at the law and policy-making levels.

Significant and sustainable outcomes will include a system that encourages greater consumer control and choice and services that will enable people to enjoy improved overall health and long-term care in their communities for a longer period.

DELAWARE

Grant Information

Name of Grantee	Delaware Health and Social Services		
Title of Grant	Assistive Technology Access: Infrastructure for Community Living		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,200,000	***Year Original Funding Received***	2001

Contact Information

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Director, Professional Services
Division of Developmental Disabilities Services
Jesse Cooper Building, PO Box 637
Dover, DE 19903

Subcontractor(s)

Delaware Assistive Technology Initiative University of Delaware	Beth Mineo Mollica, Ph.D.	302-651-6836
Center for Disabilities Studies University of Delaware	Donald Unger, Ph.D.	302-831-6735

Target Population(s)

People with one or more disabling conditions. A more specific subpopulation is individuals with a disability currently receiving services through various state agencies.

Goals

- Increase awareness and knowledge of assistive technology (AT) at all levels.
- Streamline and improve access to funding options.
- Expand the range of assistive technology access options and alternatives.
- Establish a comprehensive tracking system for assistive technology.

Activities

- Conduct a needs analysis.
- Conduct an awareness campaign and specific training activities for various target groups.
- Develop a website.
- Revise policies that decrease access to assistive technology and expand funding options for assistive technology.
- Design and implement a tracking system for assistive technology.

Abstract

AT often makes it possible for people with disabilities to move from institutional to community living arrangements or to continue to live in their own homes as their support and service needs change. Numerous studies and stakeholder polls reveal that Delaware residents with disabilities encounter barriers in their attempts to obtain the AT they need. With this project, the State of Delaware will strengthen its support infrastructure for people with disabilities by increasing access to AT devices and services. Doing so expands the options afforded to consumers—a central tenet of person-centered planning—and enables the service infrastructure in Delaware to become increasingly consumer responsive.

Building on several extensive planning processes undertaken in the past year (involving consumers, providers, state agencies, and advocates)—and using a groundbreaking initiative led by the Delaware Division of Developmental Disabilities Services as a model—a Work Group comprising key stakeholders developed a 3-year plan. Grant activities over the 3 years will lead to: significant increases in awareness of the benefits of technology options; opportunities to explore technology options prior to making purchase decisions; provider sophistication in facilitating technology selection and use; consumer sophistication in selecting and using AT; the comprehensibility and comprehensiveness of policies impacting AT access; consumer and provider access to a range of supports that facilitate efficient and appropriate AT access; and accessibility of state information and services for people with disabilities.

The activities of this project will improve stakeholder awareness, knowledge, and skills relative to AT and to the infrastructure supporting technology exploration, acquisition, and use. These improvements will help ensure that AT will become a readily available component of community-based supports and services in the years following project completion.

FLORIDA

Grant Information

Name of Grantee	Florida Department of Management Services Americans with Disabilities Act Working Group		
Title of Grant	Real Choice Partnership Project		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,000,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Health Management Associates (Medicaid Waiver Analysis)
United Way of Palm Beach County—Model Community (Healthy Community) pilot site serving Palm Beach County (urban/rural mix)

Gulf Coast Jewish Family Services, Inc.—Model Community (Healthy Community) pilot sites (2) serving Hillsborough and Pinellas Counties (urban) and Pasco County (rural)

University of Florida, Shimberg Center for Affordable Housing—Affordable and Accessible Housing Demographic Research (a component of a comprehensive coalition-driven research agenda)

Target Population(s)

Children and adults of any age who have a disability or long-term illness, who currently rely on long-term support systems, and who may be at risk due to insufficient community supports and/or who may be inappropriately placed in a restrictive setting.

Individuals of any age residing in three regional pilot project sites who have a disability or long-term illness, and who are eligible for services or at risk of institutionalization.

Goals

- Create operational linkages among key stakeholders that result in improved communication, and better coordination of services for people with disabilities and long-term illnesses.
- Improve the delivery of services to consumers by increasing access to providers and streamlining Medicaid services provided through four major waiver programs: the Aged and Disabled Adult Waiver, the Project AIDS Care Waiver, the Traumatic Brain Injury and Spinal Cord Waiver, and the Assisted Living for the Elderly Waiver.
- Create a comprehensive single point of contact/inquiry to obtain information and links to state and local resources (Clearinghouse on Disability Information).
- Implement three pilot projects to develop community capacity to assist people with disabilities and long-term illnesses to live in integrated community settings of their choice when appropriate.

Activities

- Identify unnecessary barriers in state or federal policies and regulations that hinder or limit the effectiveness of waiver programs, and develop recommendations and implement strategies to address these barriers.
- Expand the implementation of Florida's statewide Clearinghouse on Disability Information to function as the single point of data collection and information access on all aspects of the project.
- Establish a statewide educational campaign on the Clearinghouse program, and develop a consumer feedback mechanism to track consumer satisfaction with the Clearinghouse services.
- Analyze the benefits and costs of a statewide automated and accessible benefits screening program for professionals and consumers.
- Create local grassroots long-term care resource networks in three demonstration areas, which will provide technical assistance and local community resources to address barriers and share best practices.
- Create a housing initiative involving the disability and aging communities, housing administrators, and providers to increase housing choices for people with disabilities and long-term illnesses. This initiative will:
  - Establish partnerships and cross-train on the housing needs of people with disabilities and long-term illnesses and how to access housing resources;
  - Develop an effective tool to assess the need for home modifications and assistive technology;
  - Work with public housing agencies to submit mainstream voucher applications to HUD to increase the number of Section 8 vouchers available for people with disabilities and long-term illnesses; and
  - Coordinate existing housing education initiatives to ensure that people with disabilities and long-term illnesses are included.

Abstract

Florida's Real Choice Partnership Project is designed to implement improvements in community long-term support systems that will enable people of all ages with disabilities or long-term illnesses to live and participate in their communities. The project is organized around four primary goals or objectives: create operational linkages among the key state agency stakeholders and service providers; streamline the delivery of services to consumers by increasing access to providers and coordinating services covered under Medicaid Waiver Programs; create a comprehensive single point of contact/inquiry for people with disabilities and/or long-term illnesses, caregivers, and service providers to obtain information and links to state and local resources (Clearinghouse on Disability Information); and develop community support networks and resources to assist people with disabilities and long-term illnesses to live in an integrated community setting.

GUAM

Grant Information

Name of Grantee	Department of Public Health and Social Services Division of Public Health		
Title of Grant	Real Choice Program		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$673,106	***Year Original Funding Received***	2001

Contact Information

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PO Box 2816
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Subcontractor(s)

Department of Integrated Services for Individuals with Disabilities
The Guam Developmental Disabilities Council

Target Population(s)

Persons with disabilities and long-term illnesses.

Goals

Increase community inclusion for persons with disabilities through comprehensive community services planning and reform.

Activities

- Consolidate state plans from all service and advocacy agencies into a coordinated comprehensive systems change plan to be used as a blueprint to move from an agency-centered service model to a person-centered model.
- Develop a cadre of professionals who have been trained in person-centered systems of service.
- Design and develop a universal screening and tracking database and related forms.
- Setup and maintain an information system.
- Design and develop a screening and tracking form and a database for an individualized budgeting program.

Abstract

The Guam Real Choice Program will address the challenges that the current service delivery of care system faces. The one most often-repeated concern is the fragmented nature of the system that provides services to persons with disabilities. There are a host of governmental and nongovernmental organizations that provide services for individuals with disabilities. These services are offered based on the respective agency's perception of what services may be needed and the resources it has available to provide those services. This agency-centered model is useful but often does not meet all the needs of the individual and the family. Another concern is that consumers may not have been involved in the planning and development stages prior to implementation of the service.

The Guam Real Choice Program, along with the major stakeholders in the services delivery arena including consumers, will develop a comprehensive system of services and supports that will be person-centered in all aspects. One important component of this endeavor will be to develop a system to accurately identify individuals with developmental disabilities. The island's Chief Executive, Legislators, and others can use this registry in developing related policies. Another focus area for the project is to develop an on-island training capacity to ensure a readily available pool of support resources for consumers. Additionally, it is also critical to develop a program that provides health care clinicians with the appropriate knowledge base to ensure a holistic continuum of care across the life cycle. It is critical that public awareness also be addressed to ensure successful community inclusion of persons with disabilities.

HAWAII

Grant Information

Name of Grantee	Department of Human Services		
Title of Grant	Hawaii Real Choices Partnership		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,350,000	***Year Original Funding Received***	2001

Contact Information

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www.RealChoices.org		

Subcontractor(s)

University of Hawaii Center on Disability Studies	Robert A. Stodden	808-956-9199

Target Population(s)

Persons who are aging and those with disabilities who require long-term supports to function in their community of choice.

Goals

- Involve all stakeholder groups and maximize consumer participation in a collaborative systems change process through consumer-majority collaborative bodies responsible for developing policies, procedures, and practices.
- Enhance access to long-term care services, promote consumer choice and self-determination, and improve service quality by developing and demonstrating a cross-agency, cross-disability web-based single entry point (SEP).
- Provide primary/secondary consumers and agency personnel with essential attitudes, skills, and knowledge for achieving increased consumer choice and self-determination through use of the web-based SEP.

Activities

- Establish and support a governing council and workgroups with broad stakeholder representation.
- Support the governing council and its workgroups to develop and submit background and language for legislation and program guidelines enabling desired systemic changes.
- Develop and implement a web-based SEP and develop strategies to ensure sufficient and enduring resources to maintain the web-based SEP beyond the end of Hawaii ACCESS Project funding.
- Assess training and technical assistance needs of participating stakeholder groups, and develop and implement technical assistance activities to meet identified needs.
- Conduct ongoing evaluation of effectiveness of training and technical assistance activities.

Abstract

The Hawaii Real Choices Partnership will involve all key stakeholder groups in developing, demonstrating, and institutionalizing one of the nation's first cross-agency web-based Single Entry Point (SEP) that will provide consumers with in-depth, up-to-date information on ALL their available options, including those offered by private as well as public agencies.

This innovative SEP will employ the latest computer networking and web technologies to provide the following consumer-friendly features: an interactive assessment process to help consumers identify services for which they are eligible; a unified database showing all long-term care services offered by the state, counties, and private organizations, with open slots listed according to geographical location; and a quality assurance component that will identify service gaps by tracking service requests and allow consumers to rate the services they receive.

To maximize consumer input into all aspects of the project and promote collaboration and coordination among all stakeholders, a collaborative systems improvement process, as demonstrated to be effective in numerous other systems change efforts, will be implemented. This process will be used to guide the activities of a partnership governing council, which will have directive authority over the project and will establish work groups to address critical topics.

The council and work groups will be chaired by a consumer (co-principal investigator for the project) and will have at least 51 percent consumer membership (consumer members will include primary consumers, family members or others concerned for their well-being, and representatives of consumer and family organizations). Other council members will include the heads of the public and private service providing agencies, including the DHS Director, serving as principal investigator, heads of four DHS divisions, two Department of Health divisions, and the Executive Office on Aging.

The overall objective of the Hawaii ACCESS Project is to design and implement effective and enduring improvements in community long-term support systems for all children and adults with disabilities or long-term illness, reflecting increased access to information, choice, and quality services and supports consistent with their community living preferences and priorities.

IDAHO

Grant Information

Name of Grantee	Department of Health and Welfare Division of Family and Community Services Idaho State University Institute of Rural Health		
Title of Grant	Real Choices		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,102,148	***Year Original Funding Received***	2001

Contact Information

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www.isu.edu.irh		

Subcontractor(s)

Idaho State University Institute of Rural Health	Dr. Beth Stamm	208-282-4074

Target Population(s)

All people with disabilities and long-term illness.

Goals

- Increase access in all forms.
- Increase availability and adequacy of services.
- Increase or maintain value of services across the system.
- Increase or maintain quality of services across the system.

Activities

- Conduct a statewide anti-stigma campaign.
- Conduct a needs and resources assessment.
- Conduct an economic analysis of current service utilization.
- Implement a community development project.
- Conduct an effectiveness study to test and refine a community-based plan.

Abstract

This project will create enduring systems change in two phases: Phase 1—a statewide anti-stigma campaign and a needs and resources assessment, culminating in a plan for change; and Phase 2—an effectiveness study to test and refine the plan. There are four objectives: increase access in all forms, increase availability and adequacy of services, increase (or maintain) the value of services across the system, and increase (or maintain) the quality of services across the system.

The objectives will be achieved by an anti-stigma campaign that will pave the way for more successful community integration. A statewide assessment of needs and resources will establish a baseline of needs and resources. An economic analysis of the current system, including the Medicaid program, will seek to maximize appropriate funding strategies and leverage available funds. A community development project to examine the political and fiscal feasibility of addressing inadequate access to resources will approach this as a community development problem, not a health care problem, and an effectiveness study will determine the quality and value of the project. The final product will be a plan for statewide implementation, to obtain consumer and stakeholder input, and a monitoring system for continuous quality improvement.

ILLINOIS

Grant Information

Name of Grantee	Illinois Department of Human Services		
Title of Grant	Illinois Systems Change Project		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$800,000	***Year Original Funding Received***	2001

Contact Information

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http://www.state.il.us/agency/dhs/olmweb.html (Olmstead website)

Subcontractor(s)

Franklin-Williamson Human Services
(Southern IL Grant Project – Fiscal Agent)
902 West Main Street
West Frankfort, IL 62896

Southern Illinois Center for Independent Living
(Southern IL Grant Project – Program Agent and Project Coordinator)
100 North Glenview, PO Box 627
Carbondale, IL 62903

Northwestern Illinois Area Agency on Aging
(Rockford Grant Project – Fiscal Agent)
2576 Charles Street
Rockford, IL 61108-1605

Access Services Northern Illinois
(Rockford Grant Project – Program Agent)
7399 Forest Hills Road
Loves Park, IL 61111

NAMI member
(Rockford Grant Project – Project Coordinator)
4312 Alpine Court
Rockford, IL 61107

Illinois Statewide Independent Living Council
(Homeownership Coalition Project)
122 South 4th Street
Springfield, IL 62701

Target Population(s)

People with physical disabilities, people with developmental disabilities, people with mental illness, and elderly people with all types of disabilities.

Goals

- Create a system that fosters ongoing communication between the various agencies and community service delivery agents (CSDAs), including Area Agencies on Aging, Case Coordination Units, Mental Health Networks, and Centers for Independent Living (CILS) in Rockford and Southern Illinois, and establish processes whereby the CSDAs use self-assessment to identify areas of change, inform all partners of the needs for change, and modify procedures and policies on an ongoing basis.
- Create more effective strategies for developing, locating, and maintaining affordable, accessible housing resources.
- Identify and develop tools for consumers and community service delivery agents to assist people, if they choose, to successfully transition from institutional settings to appropriate community settings.
- Establish a framework of successful long-term community supports for people once they have transitioned from institutional settings into the community.

Activities

- Develop a Community Partner Fund that will pay for the costs of the Community Service Delivery teams in two areas (Rockford and Southern Illinois).
- Provide start-up grants to individuals to enable them to move into the community in Rockford and Southern Illinois.
- Pay for a consultant to work with agency staff to develop a format and procedural guidelines for developing person-centered plans.
- Pay for a contractor to make information system changes.
- Provide funding for any technical assistance and training in areas such as assistive technology and other areas identified by the CSDAs.

Abstract

This grant will enable the Illinois Department of Human Services to enhance the existing system of long-term supports and services by emphasizing a consumer-driven approach to community integration with the Systems Change Project. The project will focus on Southern Illinois and Rockford.

The Systems Change Project will foster ongoing communication between the various state agencies and CSDAs and establish processes whereby the CSDAs use self-assessment to identify areas in need of change, inform all partners of the need for change, and modify procedures and policies on an ongoing basis. It will create more effective strategies for developing, locating, and maintaining affordable, accessible housing resources and assistive technology. The project will identify and develop tools for consumers and CSDAs to assist people who choose to move to successfully transition from institutional settings to appropriate community settings and will establish a framework for successful long-term community supports for people once they have transitioned.

Putting consumers at the center of all efforts to redesign systems and improve access to community-based living opportunities is key to Illinois' ability to sustain any advances achieved in this project. The outcome is a coordinated system of long-term support that is person-centered and provides an array of services based on the persons' strengths, desires, and needs.

This project will lay the groundwork for an enhanced quality of life for individuals at risk of, or currently living in, institutional settings. Its most significant outcome will be to enable individuals to remain in or return to the community.

A Consumer Task Force will be involved in this project and has been since its inception. It is made up of people with different types of disabilities or parents of people with disabilities. A number of partnering agencies will also be involved, as part of a state Inter-Agency Team. They include: DHS Offices of Rehabilitation Services, Developmental Disabilities, and Mental Health; Clinical Administrative and Program Support; Child Care and Family Services; Department on Aging; the Illinois Housing Development Authority; the Department of Public Aid; and the state's Medicaid funding authority. The Team will serve as the primary vehicle of coordination among and between the government partners, CSDAs and consumers.

IOWA

Grant Information

Name of Grantee	Iowa Department of Human Services, Division of MH/DD		
Title of Grant	Iowa's Real Choice Program		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,025,000	***Year Original Funding Received***	2001
Amount of Supplemental Grant	$360,000	***Supplemental Award Received***	2002

Contact Information

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Subcontractor(s)

University of Iowa, Center for Disabilities and Development, Iowa City, IA
Primary Contact Person: Bob Bacon, Director, Iowa's University Center for Excellence on Disabilities.

Target Population(s)

Persons with disabilities and long-term illnesses currently living in institutional settings and those at risk of entering institutions.

Goals

- Move the disability services system away from the traditional medical model of evaluation and placement of individuals toward a system that is driven by meaningful and informed consumer choices and is responsive to consumer-identified needs.
- Develop and provide coordinated transition and community support systems to facilitate movement from institutional to community settings and support individuals living in integrated community settings to avoid institutional placement.
- Design an individualized, consumer-centered process to assess individual preferences and abilities that will allow consumers to make informed choices about their living environment, the services they receive, the types of support they use, and the manner in which services are provided and funded.

Activities

- Identify systems for identification of all persons with disabilities currently living in institutional settings and those at risk of entering institutions.
- Identify and train Community Living Specialists to assist consumers with transition activities and support them in community living.
- Develop an evaluation process to monitor systems change efforts.
- Develop and implement an individualized assessment tool and process that identifies strengths and barriers and emphasizes personal choice and preferences.
- Provide information to individuals with disabilities and long-term illnesses to assist them in accessing needed resources, services, and supports in the most integrated setting appropriate to their needs and consistent with their preferences, including information on individual rights, self-advocacy, and appeal rights.
- Provide information to parents and other family members, guardians, and direct service staff on the service system and living options, individual rights, informed choice, advocacy, and appeal rights.
- Provide information and training to service providers, service coordinators, medical professionals, and policy makers.
- Identify and pursue needed policy changes to increase the flexibility of and simplify access to disability-related services and funding.
- Establish an information and referral system to assist individuals to access services and supports before they are at imminent risk of institutionalization.
- Establish and implement a coordinated system of transition services and community-based supports for individuals accessing less restrictive living options.
- Establish and implement a coordinated system of crisis prevention and intervention services to prevent unnecessary institutional admissions.

Abstract

The grant will be used to develop and improve community support systems by establishing a flexible, consumer-centered, individual assessment process emphasizing consumer preferences and by developing a coordinated system of transition and community support services.

The project will use the expertise and experiences of numerous state agencies, local governments and providers, consumers and their family members, and advocates of the disability system as part of The Oversight and Implementation Committee for the Iowa Plan for Community Development. A steering committee was developed in January of 2001. The "Olmstead Real Choices Consumer Taskforce," as it has been known since a name change in 2002, has been operational since June of 2001 and has been involved in development of the original and amended grant applications. More than 50 percent of the membership is made up of people with disabilities who are also consumers of disability-related services or family members of adults and children with disabilities.

KENTUCKY

Grant Information

Name of Grantee	Kentucky Cabinet for Health Services		
Title of Grant	Real People: Real C.H.O.I.C. E.S—Citizen Monitoring, Housing Options and Investing in Creative Educational Solutions		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,000,000	***Year Original Funding Received***	2001

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Subcontractor(s)

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University of Kentucky/IHDI	Kathy Sheperd-Jones	859-257-1714
Eastern Kentucky University/TRC	Elizabeth Wachtel	859-622-2262
Kentucky Housing Corporation	Natalie Hutcheson	502-564-7630

Target Population(s)

The general target population is individuals with disabilities. Each of the three major initiatives is targeting a specific population:

Citizen Monitoring Initiative. Individuals with mental retardation/developmental disabilities that are served by Supports for Community Living waiver providers throughout the state. The target population will expand to other individuals with disabilities in years two and three of the grant.

Housing/Nursing Home Transition Initiative. Individuals with disabilities residing in Louisville/Jefferson County (urban) and Murray/Calloway county (rural).

Workforce Initiative. Individuals with disabilities who receive services from providers trained under this initiative.

Goals

- Develop a system of citizen oversight in quality and consumer satisfaction for Kentucky's system of long-term supports by piloting an initiative for persons with mental retardation and other developmental disabilities.
- Increase individuals' ability to make an informed choice about where they will live, increase timely access to existing affordable community housing options and increase the stock of new affordable and accessible housing options while piloting an initiative that transitions individuals with disabilities to the community from nursing homes and other long-term care facilities.
- Improve the stability and quality of personnel and services to individuals with disabilities or long-term illnesses through the development of a competent and dedicated workforce.

Activities

Workforce Initiative. Create a consortium to develop recommendations for the development of curricula. Develop and implement seven curricula to train community-based direct service, supervisory, and administrative staff. Place curricula in the Kentucky Virtual University system for use statewide.

Housing/Nursing Home Transition Initiative. Develop pilot projects in two regions of the state (urban and rural) to assess the availability and accessibility of housing and service options for individuals transitioning out of institutions into the community. Develop a marketing plan to inform discharge planners, community advocacy groups, and individuals about the pilot project.

Citizen Monitoring Initiative. Recruit and train consumers and family members to participate in a pilot project patterned on the existing state-funded Core Indicators Project. Recruit volunteer personal advocates for participants served by the Supports for Community Living waiver program.

Abstract

The citizen monitoring initiative has three components: (1) developing a protocol and training volunteer advocates, (2) recruiting and training two-person interview teams to solicit consumer satisfaction, and (3) engaging consumers and family members of services and supports to enhance current standard survey instruments.

The workforce initiative will develop a comprehensive credentialing system based on a common set of standards and training methods. This will be accomplished by hiring a full-time project director and the establishment of a consortium of institutions of higher education, persons with disabilities, and community service providers.

The housing and nursing home transition initiative (conducted by the Center for Accessible Living, a Center for Independent Living) will establish two pilot projects in an urban and rural site to assist individuals with disabilities making the transition from a nursing home or other institutional setting to the community. The initiative will support the development of protocols and resources necessary to make this transition. Additionally, two specific projects at the state level involving the state housing finance agency (Kentucky Housing Corporation) will support this local effort. Grant funds will be used to develop a “standard plans” publication incorporating universal design principles, as well as to provide home modification funds to qualified individuals with disabilities through an existing program (the Kentucky Assistive Technology Loan Fund).

MAINE

Grant Information

Name of Grantee	Maine Department of Human Services Bureau of Medical Services		
Title of Grant	Quality Choices for Maine		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,300,000	***Year Original Funding Received***	2001

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Subcontractor(s)

Edmund S. Muskie School of Public Service	Danny Westcott	207-228-8038

Target Population(s)

Generally, no specific target population. Some demonstrations will target specific populations, as yet undetermined. One project (evaluating wraparound services provided in schools) targets children with serious emotional disabilities.

Goals

- *Person-Centered Services*. Maximize options for choice and control of personal assistance services across programs. Provide more consumers with the administrative support infrastructure necessary or desired to exercise greater choice and control over personal assistance and other long-term services. Develop, demonstrate, and evaluate a model of flexible funding that enables consumers to access services from multiple state departments. Increase the effectiveness of services targeted to children with emotional, behavioral, or mental health needs in public schools.

- *Quality*. Identify and implement quality indicators for measuring quality of life and quality of care for children and adults with disabilities receiving long-term services and supports. Demonstrate the feasibility and efficacy of interdepartmental collaboration on quality improvement for long-term services and supports.
- *Access*. Increase access to information about services and eligibility; housing; qualified direct care workers; recreational, social, and cultural activities; and transportation services.
- *Data*. Improve planning and implementation of services by integrating data across departments.

Activities

- Conduct a comparative analysis of Maine's PAS policies, develop recommendations for change.
- Develop an independent service organization.
- Conduct a flexible funding demonstration.
- Evaluate the wraparound services program underway in Portland Public Schools.
- Identify and implement quality indicators measuring quality of care and quality of life.
- Identify and conduct two interdepartmental collaborative quality improvement projects.
- Develop a website providing information about services, resources, and eligibility.
- Conduct two to three demonstrations for improving access to housing services.
- Develop a direct care workers' guild.
- Develop a resource inventory for recreation services, replicate a monthly calendar of low-cost events, and develop a Universal Access Guidelines Tool Kit.
- Conduct two to three demonstrations for improving access to transportation services.
- Develop a detailed design for generic infrastructure to support integrating data across multiple departments and programs.

Abstract

Maine has already developed a good community services system with a wide array of community living supports. Quality Choices for Maine seeks to take this system to the next level, where consumers have more choice and control; where community-relevant quality management structures are built into Maine's community-based living options and incorporate consumer perspectives; where identified gaps are addressed (access to information, direct care workers, housing, transportation, and recreation); and where integrated interdepartmental data support interdepartmental collaboration.

The grant's focus is largely interdepartmental. It will be used to develop consistency across programs and the infrastructure for supporting a shared interdepartmental vision for serving persons with disabilities, as well as to address access barriers common to multiple population groups.

Quality Choice for Maine directly responds to and continues the work performed under Maine's Olmstead initiative, which has been a collaborative process involving representatives from five departments (Human Services, Behavioral and Developmental Services, Education, Labor, and Corrections) and a broad cross-section of consumer representatives.

MARYLAND

Grant Information

Name of Grantee	Department of Mental Health and Hygiene		
Title of Grant	Increasing Access, Service Availability, and Quality in Maryland's Long-Term Care System		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,025,000	***Year Original Funding Received***	2001
Amount of Supplemental Grant	$360,000	***Supplemental Award Received***	2002

Contact Information

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Subcontractor(s)

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

Target Population(s)

People of all ages with disabilities. One grant initiative is designed specifically for children with serious emotional disturbances.

Goals

- Permanently increase the availability of attendant care services.
- Provide information and assistance to consumers in acute care hospitals to aid decision-making and assist with transitions back to the community.
- Assess the quality of community-based long-term care services and use that information to focus on quality improvement efforts in the future.
- Improve community-based service delivery to children with serious emotional disturbances.

Activities

- Develop a pilot project to provide outreach to persons in hospitals to inform them of community-based long-term care options to prevent unnecessary institutional placement. The project will include working with a hospital discharge planner to inform individuals of community-based services and programs at the point of discharge from the hospital. This initiative also includes funding for the development of educational materials to inform individuals about community-based programs in Maryland.
- Target efforts to increase the community long-term care workforce. This includes hosting provider job fairs across the state targeted to direct care workers where technical assistance with completion of the provider applications and specific qualifications can be provided.
- Develop a capitated demonstration program to better serve children with serious emotional disturbances (SED).
- Develop performance measures for community-based long-term care programs. This includes development and implementation of consumer satisfaction surveys for Maryland's community-based programs.

Abstract

The Real Choice Systems Change Grant will build on Maryland's commitment to providing home and community based services to individuals in the community. The funding will enable Maryland to address a number of issues in delivering long-term care services. Maryland is in the process of developing a Consumer Advisory Board (CAB) that builds on the consumer workgroup established to develop the Real Choice Systems Change grant initiatives in the summer of 2001. The CAB will offer advice and recommendations in the process of the implementation of the grant initiatives. The CAB will work collaboratively with the other Maryland grant awardees.

The grant includes four initiatives:

1. Implementation of a pilot project to provide outreach and information to persons of all ages with disabilities in acute care hospitals to ensure that they have comprehensive information about community-based long-term care options and how to access them, particularly when planning for discharge from acute care settings.
2. Focus on implementing activities designed to attract and retain long-term care direct care workers and mitigate the long-term care worker shortage.
3. Development and implementation of a managed care demonstration program to provide coordinated long-term care services to children with SED who would otherwise likely "fall through the system cracks" and languish in long-term care facilities or psychiatric hospitals. Development and implementation oversight would be grant-funded. Services would be state-funded.
4. Development of quality indicators for long-term care services, a comprehensive satisfaction survey, and survey approach to be administered to home and community waiver participants and establishment of a quality measurement and improvement process that would be maintained after the grant period concludes.

MASSACHUSETTS

Grant Information

Name of Grantee	Center for Health Policy and Research University of Massachusetts Medical School		
Title of Grant	Massachusetts Real Choice Systems Change: Enhancing Community Based Services		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,025,000	***Year Original Funding Received***	2001
Amount of Supplemental Grant	$360,000	***Supplemental Award Received***	2002

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Subcontractor(s)

None at this time.

Target Population(s)

Individuals with disabilities and long-term illnesses.

Goals

- Improve coordination and collaboration among agencies in the development of long-term support systems' policy studies, program re-design options, and related pilot-testing activities.
- Plan for an integrated information infrastructure that will involve developing state-of-the-art tools for client functional assessments, streamlining the eligibility determination process for long-term care services, and enhancing service coordination options.
- Develop, implement, and evaluate new community-based service coordination and delivery system models.
- Develop meaningful and sustainable mechanisms for involving consumers in the planning and program development process.
- Develop systems for quality monitoring and continuous quality improvement of home and community based long-term care services.

Activities

- Implement interagency policy coordination and program development.
- Assess existing functional assessment tools used by Massachusetts and by other states.
- Evaluate funding options for community-based long-term services.
- Integrate funding models.
- Use pilot programs for community-based long-term care delivery models.
- Integrate acute and long-term supports through coordinated care strategies.
- Implement early intervention and prevention for individuals at risk of functional decline and institutionalization.

Abstract

Partnerships. This proposal builds upon existing relationships and initiatives involving state agencies and disability advocacy and advisory groups. Leadership for activities under this grant will be provided by representatives from the Executive Office of Health and Human Services (EOHHS), the Division of Medical Assistance (DMA), and the Massachusetts Rehabilitation Commission (MRC), with support from the University of Massachusetts Medical School (UMMS).

Coordination of activities between the leadership team and the other key state agencies involved—the Departments of Mental Health (DMH), Mental Retardation (DMR), and Public Health (DPH), and the Executive Office of Elder Affairs (EOEA)—will be accomplished through an Interagency Steering Committee and a Working Group for Community Long-Term Care. Consumer input into policy evaluation and the design and implementation of infrastructure changes will be assured through a working partnership with the disability community and the establishment of a Consumer Task Force and integrated policy working groups that include representation from consumers, providers, and state agencies.

Outcomes. The primary outcomes of this grant will be sustainable improvements in the state infrastructure responsible for long-term care policy coordination and program implementation; a streamlined functional assessment, eligibility determination, and service coordination system; recommendations for standardized quality assurance measures/tools; and field-tested models of coordinated, culturally appropriate, community-based long-term care services that respect consumer preferences and needs.

MICHIGAN

Grant Information

Name of Grantee	Department of Community Health, Long Term Care Programs		
Title of Grant	Michigan's Real Choice Systems Change Grant		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,000,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

To be identified through RFP processes during the second year.

Target Population(s)

The first two initiatives target the general LTC population: working age adults with disabilities and elderly adults. The Consumer Cooperative Initiative targets individuals with developmental disabilities or mental illness within a pilot community.

Goals

The grant has three distinct components: the LTC Outcomes and Evaluation Systems Initiative, the Virtual Organization Initiative, and the Consumer Cooperative Initiative.

- LTC Outcomes and Evaluation Systems (OES)
  - Strengthen consumer/family input into the LTC OES
  - Develop a model for vertically integrated OES across state and local agencies
  - Improve outcomes through the use of quality indicators across LTC settings (nursing facilities, home care, and acute/primary care)
- Virtual Organization (VO) Initiative
  - Use modern information technology and systems design to support an LTC delivery system that empowers consumers
  - Provide consumers opportunities to use assistive technologies
  - Use e-business technologies within system administration
  - Obtain real-time feedback on satisfaction, cost/benefit analyses, and performance improvement efforts
- Consumer Cooperative Initiative
  - Develop organizational governance to ensure consumer control of the cooperative
  - Establish process to ensure consumer control over access and management of services and supports

Activities

- Include consumers on HCBS site monitoring teams.
- Select/develop quality indicators for use across LTC settings.
- Develop a method for assessing consumer satisfaction.
- Develop web-based options for determining eligibility and accessing services.
- Develop practice guidelines for use of assistive technologies.
- Contract with a community mental health board to pilot the consumer cooperative model.
- Develop the organizational structure and operations for the cooperative.
- Conduct a participatory evaluation of the cooperative.

Abstract

The grant proposal builds upon Michigan's plan for developing an integrated LTC system, as described in the Michigan LTC Report and Recommendations. The LTC Outcomes and Evaluation System Initiative seeks to strengthen our quality assurance and improvement systems by expanding the roles of consumers and family members in system design, implementation, and evaluation; by developing outcomes and quality indicators for the continuum of services; by developing effective methods for assessing consumer satisfaction; and by supporting quality improvement initiatives in local agencies.

The Virtual Organization Initiative will develop a model for administering an integrated system of long-term care, in which access and service delivery are coordinated across primary/acute care, home and community based services, and nursing facilities. The VO is a business model that allows consumers to use telephone or web technology to identify and arrange services, communicate needs and satisfaction with services, and allows providers to electronically link into a full service network to better serve customers.

The Consumer Cooperative Initiative will develop a model in which consumers and family members will collectively assume responsibility for their outcomes and take control of the resources needed to achieve them. The Co-op will allow members to design and obtain the services they prefer, with more creativity, responsiveness, and cost-effectiveness. This model offers an exciting advancement in systems changes in support of consumer-directed services.

MINNESOTA

Grant Information

Name of Grantee	Department of Human Services Continuing Care for Persons with Disabilities
Title of Grant	Pathways to Choice: Minnesota's System Change Initiative Grant
Type of Grant	Real Choice Systems Change
Amount of Grant	$2,300,000 ***Year Original Funding Received*** 2001

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Target Population(s)

People with disabilities and chronic illnesses of all ages who are underserved such as people from communities of color, people who are low income, people with severe disabilities, and people from tribal nations.

Goals

- Develop a model for consumer-designed and driven quality assurance and improvement functions to be implemented within the long-term care delivery system in Minnesota.
- Assure that consumers have access to timely, consistent, accurate information that supports self-determination and informed choices.
- Consumer-driven quality assurance and improvement functions will be integrated into every aspect of the project to assure that frequent and accurate customer feedback and information are obtained and used effectively to correct or prevent problems as they are identified, and that quality improvement is assured.

Activities

- Recruit and convene a 15-member quality design commission comprising 51 percent primary consumers.
- Develop a model for consumer-driven quality assurance and quality improvement.
- Develop a model for information, referral, and assistance (IR&A) and create three regional IR&A networks to provide service to target populations.
- Develop training materials to be used for and with the IR&A networks.
- Develop an automated consumer feedback system to evaluate and measure consumer satisfaction with the service delivery system and consumer quality of life outcomes.

Abstract

Minnesota intends to create an exemplary delivery system of services for people of all ages with disabilities or long-term illnesses. The state has a comprehensive set of traditional, prescriptive services, and in recent years has built a partial patchwork of consumer-centered service options. To transform Minnesota's services array into a replication model for other states, a fundamental change in thinking is needed. Minnesota proposes a strategy that uses new sources of leadership, new forms of service organizations, and new methods of training to instill a consumer-centered philosophy throughout the system network. The strategy includes:

Quality assurance and improvement. The state will create a quality assurance and improvement model that is consumer designed, directed, and evaluated. A consumer quality commission will be an ongoing element and will provide continual design, direction, and evaluation of the other project strategies. This quality commission will be used to provide direction for many of DHS' quality assurance ideas.

Information, referral, and assistance. The state will develop a central information system with accurate and consistent information with outreach tailored to underserved populations. Features include updating the state's website so that consumers, advocates, providers, and agencies receive the same information in a useful, easily understood manner; organizing county-level information networks with localized, detailed information and assistance; and initiating a 1-800 number system that ties together state and local information and connects people needing additional help with advocates and providers.

Since the grants have been awarded, DHS is moving forward with implementing a 211 system. The grants will be used to support this system. The grants will also be used to initiate some local networks to provide more intensive one-on-one assistance and advocacy efforts—in partnerships with counties, consumers, and private/public strategies.

MISSOURI

Grant Information

Name of Grantee	Department of Social Services		
Title of Grant	Flexible Choices for Independence		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,000,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

University of Missouri-Kansas City	Dr. Christine Rinck	816-235-1760

Target Population(s)

Consumers of all ages who have a disability or long-term illness.

Goals

- Streamline the system to assure easy and quick access to needed services and supports.
- Assure that the infrastructure and process reflects consumer choice and consumer input.
- Foster interagency coordination and collaboration.
- Assure informed choices at all stages of care so that consumers can make good decisions about their lives.
- Enhance linkages at critical points to assure successful transitions to community living.
- Conduct research on small demonstration projects to identify best practices and projects that should be replicated.
- Establish a quality assurance mechanism that relies on consumer input and is data-driven.

Activities

- Develop resources for training on informed choices for a wide audience.
- Train consumers on how to discuss informed choice with other individuals with a disability or long-term illness.
- Identify perceptions of consumers, providers, service coordinators, and staff agency staff.
- Examine length of hospital stays and the number of persons transferred from hospitals to nursing homes, who stay longer than anticipated, and conduct a pilot that attempts to address each of the factors found in the study, to determine what strategies are most successful in facilitating living in community settings.
- Develop and pilot a quality assurance process that can be used for all participating agencies.
- Develop and pilot a standardized application process and referral system.

Abstract

The objective of Flexible Choices for Independence is to enhance the lives of people with a disability or long-term illness through systems change to allow them to live in the most integrated community setting, exercise meaningful choices about their lives, and obtain quality services. The outcome of the activities of this grant will be that people with a disability or long-term illness will have a significant voice in choices about their life and be able to shape the services that they receive. In addition, services will be more consumer-driven and better serve people with a disability or long-term illness.

NEBRASKA

Grant Information

Name of Grantee	Nebraska Department of Health and Human Services Finance and Support		
Title of Grant	Real Choice for Nebraskans		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,000,000	***Year Original Funding Received***	2001

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Subcontractor(s)

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University of Nebraska Medical Center Munroe Meyer Institute	Barbara Jackson, Ph.D.	402-559-5765

Target Population(s)

Children and adults of all ages with physical disabilities, developmental disabilities, or behavioral health problems.

Goals

- Implement a consumer-directed model of services coordination and services delivery.
- Improve consumer access to, and information about, supports and services.
- Develop a system that allows consumers from various disability systems to access and receive needed services.
- Implement a quality management system that ensures the health and well-being of consumers through continuous consumer-directed monitoring and improvement.
- Make available to consumers and agencies a comprehensive, statewide resource database of health and human services.

Activities

- Gain consensus of consumer task force on choice definition, risk, and guiding principles for systems development.
- Market Real Choice philosophy to internal and external target audiences, and articulate what it means in practice.
- Analyze current services coordination across systems to determine steps needed to implement consumer-directed approach and transdisciplinary model.
- Set uniform standards, practices, and methods pertaining to collection, management, use, and promotion of data for resource directories across local and state agencies and organizations.

Abstract

Nebraska's current service delivery system comprises programs that provide services and supports through consumer-directed, as well as state-directed, philosophies and variations in between. Many of these programs operate in isolation from one another, even though consumers often need services across programs. Consumers and policymakers have become aware of, and are advocating for, system-wide adoption of a consumer-directed philosophy.

Nebraska is struggling with the challenge of moving from an inspection and certification-based philosophy to one that gives consumers more responsibility in monitoring and quality assurance. In the realm of consumer-directed services, the state's process of identifying, approving, and monitoring providers must be revisited to ensure that consumers have real choices, are provided with full disclosure, and are provided necessary safeguards. For consumers to have real choices, consumers need to have easy, consistent, and timely access to information on available programs, resources, and services.

Nebraska proposes to implement a consumer-directed philosophy across populations—children and adults of all ages with physical disabilities, developmental disabilities, or behavioral health problems—with consumer choice and risk defined and incorporated into services, delivery, regulations, quality assurance, and practices. Consumers, agency, and program staff, will collaborate to design and implement effective and enduring improvements in a culturally competent community long-term service and support system. They will also collaborate to identify quality measures and to design and implement a sustainable quality management system to monitor the efficiency of services in achieving the client outcomes desired and the delivery of services in a manner that meets consumers' expectations and preferences.

Consumers, services coordinators, providers, and other stakeholders participating in long-term support systems will have needed information about services and supports at the right time to effectively make informed choices regarding services that are appropriate, effective, and user responsive through improved access to long-term support systems.

Through consumer role enhancement, skill building, training, and support, consumers will have the necessary skills, knowledge, and supports to successfully live in the most integrated community settings chosen; exercise meaningful choices; and obtain quality services.

Services coordinators across programs will embrace a consumer-directed philosophy and have the necessary knowledge and skills to effectively support consumers, exercising meaningful choices in obtaining quality services through services coordination role redefinition, skill building, training, and support.

NEW HAMPSHIRE

Grant Information

Name of Grantee	Department of Health and Human Services		
Title of Grant	Facilitating Lifespan Excellence (FLEX)		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,300,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

University of New Hampshire Institute on Disability	Mary Schuh	603-228-2084
Institute on Health Law and Ethics Franklin Pierce Law Center	Michelle Winchester	603-228-1963

Target Population(s)

Older adults and persons with disabilities.

Goals

- Fill identified gaps and address identified weaknesses in the current long-term support system.
- Identify barriers to real choice and consumer-directed services and recommend reforms.
- Develop educational and technical assistance activities and strategies for implementing consumer-directed services.
- Develop a comprehensive evaluation strategy that uses both empowerment evaluation methods and summative evaluation methods within and across all project components.
- Develop creative dissemination strategies designed to support change and empower consumers.

Activities

- Develop and support management and advisory structures that support completion of project objectives and partnerships with other state initiatives for permanent systems change.
- Implement, using an RFP process, specific model projects that will develop solutions to barriers to consumer choice and integrated community living.
- Implement a mentorship pilot project for persons with developmental disabilities.
- Implement a mobile unit to bring assistive technology and durable medical equipment to citizens in their homes and communities.
- Develop a Policy Resource Center to identify and analyze barriers to consumer-directed services and to make recommendations for actions to reduce or eliminate these barriers.
- Establish a community laboratory to implement projects to improve community long-term care systems.
- Provide peer supports to persons with mental illness.

Abstract

Governor Jeanne Shaheen, with support and leadership from the New Hampshire Department of Health and Human Services, Granite State Independent Living, the University of New Hampshire Institute on Disability, Franklin Pierce Law Center, numerous consumer groups, and other stakeholders proposes to “improve health and long-term care service systems and supports for people with disabilities and long-term illness to live in the community.”

This proposal, developed collaboratively by the disability and aging communities, is designed to create and implement improvements in community long-term care systems. Several specific projects are proposed, each of which is designed to fill an identified gap or weakness in the current infrastructure of long-term supports. These projects will then be implemented in one model community or region that will serve as a laboratory for change.

In addition we will develop a policy center to review all laws and regulations that create barriers to full community integration and to make recommendations for change. The Policy Center will also provide education and training to the public, legislators, providers, and advocates. The project will be led by a consumer advisory council that has broad cross-disability representation across all age spans.

NEW JERSEY

Grant Information

Name of Grantee	New Jersey Department of Human Services		
Title of Grant	New Jersey Real Choice Systems Change Project		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,000,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Boggs Center UCE, University of Medicine & Dentistry of NJ
Rutgers Center for State Health Policy

Target Population(s)

Multiple populations of persons with disabilities, including elderly persons, persons with developmental disabilities, people with serious mental illness, children with disabilities, and people with adult-onset disabilities. Residents at the state's developmental centers, psychiatric hospitals, and nursing facilities are the initial priority populations as we redesign and enhance our long-term care system to increase community options.

Goals

- Expand community-based services and supports to be offered as an alternative to institutional placements.
- Increase the use of consumer-directed service models throughout the long-term care system.
- Increase the stock of affordable, accessible housing for people with disabilities.
- Increase the availability of personal care assistant (PCA) workers and offer a backup system of emergency PCA services.
- Develop and pilot an objective assessment for consumers with developmental disabilities and a process to involve consumers in the decision making for long-term care services.

Activities

- Create an interactive housing website for use by persons of all ages with disabilities.
- Hold a statewide housing summit to showcase innovative practices and to stimulate creative planning for future housing options.
- Provide “seed money” for innovative housing projects through a competitive RFP process.
- Develop and pilot a personal care assistant (PCA) registry and rapid response PCA backup system.
- Develop an educational program for case managers and other front line staff on the benefits of consumer-directed service models.
- Develop a set of quality measures for community-based and consumer-directed services.
- Conduct an evaluation of New Jersey’s systems change efforts resulting from the grant.

Abstract

New Jersey’s Real Choice System Change Grant is designed to make enduring changes in our system of long-term care for people of all ages, with a wide variety of disabling conditions. Through a series of pilot programs and contracts, we will seek to address issues related to access, quality, adequacy, availability, and responsiveness of our system of community-based care. The grant activities build on current ongoing state efforts and seek to deal with gaps in service and areas of weakness identified by our Olmstead Stakeholder Task Force.

In addition to the activities and projects identified above, New Jersey will be working on a variety of infrastructure improvements, including working with the state Board of Nursing on increasing delegation to paraprofessional workers, and reviewing 1915(c) home and community based waivers to determine where improvements or enhancements may be needed. New Jersey will also develop a transition curriculum on consumer direction for secondary school students with disabilities; conduct a “needs assessment” in the area of accessible, affordable housing; and do further work on front line staff recruitment and retention.

The Real Choice Systems Change Grant efforts will be monitored and guided by an Advisory Council composed of consumers, family members, advocates, providers, and government agency representatives. Consumer involvement throughout the project is seen as critical and essential to its success. A program manger will be hired to help make sure that all contracts are carefully monitored, all deliverables received, and that the project stays on track.

The anticipated benefit of undertaking these grant-funded activities is an improved and effective system of long-term community supports and services that provides maximum flexibility and choice to persons with disabilities in New Jersey.

NORTH CAROLINA

Grant Information

Name of Grantee	NC Department of Health and Human Services		
Title of Grant	Direct Care Workforce Recruitment and Retention		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,600,000	***Year Original Funding Received***	2001

Contact Information

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NC Department of Health and Human Services
Office of Long Term Care
2001 Mail Service Center
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Subcontractor(s)

Institute on Aging UNC at Chapel Hill *(Will assist with data analysis)*	Bob Konrad	919-966-2501
Paraprofessional Healthcare Institute *(Coaching supervision train the trainer)*	Sara Joffe	718-402-7157
NC Board of Nursing Raleigh, NC *(Geriatric nurse aide curriculum development)*	Polly Johnson	919-782-3211

Target Population(s)

All populations needing home and community based services.

Goals

- Reduce institutional bias in the state's long-term care system.
- Improve the size, stability, and quality of the state's direct care workforce to address the current workforce crisis, and expand this workforce to better meet the personal care and home management needs of persons with disabilities now and in the future.

Activities

- Design and implement a consumer-directed care model.
- Develop new competency-based job categories to provide a career ladder for direct care workers in home and community based settings.
- Develop educational and marketing materials for use with the media, the general public, schools, and nontraditional populations, etc., to promote employment opportunities and enhance the image of, and appreciation for, direct care workers.
- Compile annual turnover data from home care agencies and assisted living facilities, using a uniform methodology to track the workforce over time.
- Collect, compile, analyze, and disseminate data specific to North Carolina's direct care workforce.

Abstract

Grant activities will focus on several major areas: reducing institutional bias, developing a career ladder for direct care workers, implementing public education and awareness efforts to promote recruitment and retention of direct care workers, and designing a consumer-directed care model and related accountability requirements, reimbursement policies, and policies covering fiscal intermediaries for clients.

Addressing direct care workforce issues will require a multi-pronged approach. First, we will examine options for increasing the availability and affordability of health care insurance coverage for direct care workers, as well as other benefits, including flexible work schedules, child and eldercare, and participation in retirement and other benefit plans.

To retain direct care workers, a career ladder is needed. Our project will develop competency-based training models with related wage recommendations that recognize incremental development of specialized competencies (e.g., working with persons with complex medical needs, developmental disabilities, dementia and other cognitive impairments; and development of mentoring skills, supervisory skills, effective communication skills, etc.). We will also perform a classification analysis of current state job categories for direct care workers and recommend any changes needed and payment levels based on competency level of worker. Finally, we will develop curricula, in-service, and continuing education programs in support of core and specialized training (including supervisory training and mentoring) and develop appropriate training outlets, opportunities for web-based training, etc.

To recruit and retain direct care workers, it is necessary to enhance the image of this workforce. We will implement a range of public education and awareness efforts to promote information about direct care worker opportunities (paid and volunteer) focused on home and community care. These efforts will include the development of promotional and training materials for use in high school allied health programs. We will also convene a Task Force of direct care staff to get input on recruitment, retention, and marketing efforts, developing public service announcements, video spots, feature articles, flyers for use with the media, general public, high schools, Hispanic and nontraditional populations, disabled population, Job Corps, etc.; and conduct job fairs to address the image and importance of this workforce. Additionally, we will promote the development of a direct care worker association in the state, and compile and disseminate information about innovative strategies being used to address recruit and retain direct care workers.

We will also collect and analyze data about the direct care workforce that will inform our efforts to recruit and retain workers.

OREGON

Grant Information

Name of Grantee	Oregon Department of Human Services		
Title of Grant	Advancing Consumer Direction Through Enhanced Infrastructure		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,000,996	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Oregon Technical Assistance Corporation—Person Centered Planning Pilot Projects
Oregon Health & Sciences University, Center For Self Determination, Pilot Brokerage Project and Consumer-Run Drop-In Center Survey.

Target Population(s)

Adults and children with disabilities, with a particular focus on persons with psychiatric disabilities for several initiatives (e.g., person-centered planning, development of a pilot brokerage, increasing residential capacity).

Goals

- Increase affordable, accessible housing.
- Promote informed choice and consumer self-determination.
- Provide training to consumers and family representatives, service coordinators and service providers.
- Increase the availability of personal assistants and contract registered nurses (CRNs).

Activities

- Provide local assistance to consumers and other stakeholders in planning for needed housing; leveraging resources, developing partnerships; and providing funds for deposits, furnishings, and rent subsidies.
- Revise the planning used by the mental health system to a person-centered process promoting consumer choice, self-determination, and community integration.
- Provide funding to add and strengthen consumer-run drop-in centers throughout Oregon.
- Provide training to consumers concerning the ADA, the Olmstead decision, self-advocacy, assessing care needs, protection from abuse, and self-directing care.
- Develop a statewide recruitment effort for personal assistants.

Abstract

The *Advancing Consumer Direction Through Enhanced Infrastructure* grant is intended to refocus and reorient people with disabilities and the workforce towards the outcome of maximizing consumer self-determination. A grant coordinator and two housing staff will coordinate the efforts of four main workgroups composed of consumers, family representatives, stakeholders, and agency staff in implementing 24 specific goals identified in the grant. The grant will pilot a consumer-run brokerage in one Oregon County and assist in the development and strengthening of drop-in centers demonstrating new models of consumer-directed choice. Cross-disability and cross-discipline events and conferences conducted during the grant period will foster new partnerships and service integration. Many educational and training activities are planned to change service provider culture across the range of services to adopt consumer-directed approaches, to enhance the skills of the personal assistance workforce, and to increase the number of nurses trained to support persons with disabilities living in the community.

SOUTH CAROLINA

Grant Information

Name of Grantee	Department of Health and Human Services		
Title of Grant	Options for Community Living		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,300,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

University of South Carolina School of Medicine	Kathy Mayfield-Smith	803-898-4564
University of South Carolina School of Public Health	Carol Cornman	803-777-5337

Target Population(s)

SC Access targets persons of all ages with a disability or long-term illness, their families, and caregivers. *SC Choice* targets elderly and disabled HCB waiver beneficiaries (i.e., seniors and working age adults with physical disabilities), adults with mental illness, and children with severe emotional disabilities in two geographic regions of the state.

Goals

- Improve accessibility to comprehensive, up-to-date information about services and resources in the community for older adults and persons of all ages with disabilities.
- Increase options for consumer-directed care.

Activities

- Develop software to support web-based information and referral (I&R) system.
- Collect statewide data for I&R resource directory.
- Make necessary changes in policies and procedures to afford increased consumer choice and control in services across three agencies.
- Implement two pilot sites to test new I&R system and consumer-directed models.

Abstract

The SC Department of Health and Human Services (SCDHHS) is partnering with the SC Department of Mental Health and the Continuum of Care for Children to develop a project known as *Options for Community Living.*

There are two components under the *Options for Community Living* grant*: SC Access* and *SC Choice. SC Access* will develop, implement, and maintain a database of comprehensive information and assistance services for children and adults of any age with a disability, long-term illness or need. *Access* will be housed at the South Carolina Department of Health & Human Services and will be available online in real time at local, regional, and state levels to agencies and organizations serving persons with disabilities, including the Aging Network, Medicaid waiver programs, disability agencies, and consumer and advocacy groups.

SC Choice will create the infrastructure to support more consumer-directed services, including the development of support coordination, fiscal intermediaries, and the use of cash equivalencies. This program will be piloted in two areas of the state, across disability groups, and will enable the consumer, in consultation with a support coordinator, to perform many of the duties currently performed by a case manager.

State and local advisory committees will assist with the design and implementation of *SC Access* and *SC Choice*, including the development of consumer satisfaction measures.

TENNESSEE

Grant Information

Name of Grantee	Department of Mental Health & Developmental Disabilities		
Title of Grant	Housing within Reach		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,768,604	***Year Original Funding Received***	2001

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Subcontractor(s)

Foundations Associate	Michael Cartwright	615-256-9002
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Target Population(s)

Individuals with mental illness who are currently in need of permanent, safe, affordable, quality housing and support service options.

Goals

- Design and implement a more effective, consumer-directed and accessible housing resource system for persons with mental illness.
- Reduce the stigma of mental illness, thereby providing a more welcome environment for these residents in community neighborhoods.

Activities

- Hire four consumer housing specialists in targeted communities (Chattanooga, Jackson, Memphis, and Nashville).
- Develop and maintain a housing resource website that is accessible statewide and, specifically, through hardware installed in drop-in centers in targeted communities.
- Facilitate annual week-long housing academy and multiple semi-annual housing summits.
- Develop a statewide anti-stigma media campaign and television commercial spots.
- Conduct a research initiative to evaluate efforts to meet the housing needs of consumers.
- If sufficient funds are available, provide for a statewide housing hotline.

Abstract

This project will make a long-term change in housing and support services access for people diagnosed with serious and persistent mental illness. All too often these individuals are ostracized, stigmatized, and left to fend for themselves—unwelcome within the communities in which they live. Key project goals include designing and implementing a more effective, consumer-directed, and accessible housing resource system for people with mental illness; increasing the number of persons in quality, affordable housing; and reducing the stigma of mental illness statewide.

Project goals will be addressed through multifaceted activities, including employment of four consumer housing specialists in targeted communities; the development of a housing resource website accessible throughout the state; hardware strategically installed at key community drop-in centers to promote access to the website; facilitation of an annual weeklong housing academy and biannual housing summits; formation of a statewide housing hotline; development of a high-quality anti-stigma mass media campaign, and a research initiative to evaluate efforts of meeting the needs of consumers as they transition to community-based housing and supports.

These activities will result in an enduring change to the state's current mental health housing system by increasing the availability and accessibility of housing resources for consumers and providers; increasing consumer involvement in housing development and their choice in housing decisions; increasing opportunities to live in the most integrated and preferred community setting; and changing community attitudes to decrease stigma and create a more welcoming environment. The grant funds will be supplemented by additional in-kind funding of over $400,000. This modest investment will produce a sustainable change in available community supports that enable individuals with mental illness to live and participate fully in their communities.

VERMONT

Grant Information

Name of Grantee	Agency for Human Services		
Title of Grant	Vermont Real Choice Systems Change Grant		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$2,000,000	***Year Original Funding Received***	2001

Contact Information

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Subcontractor(s)

Information and Assistance—Flint Springs Consulting

Para Professional Caregiver Association—Community of Vermont Elders (COVE)

Target Population(s)

Elders (age 60 and over), younger persons with physical disabilities, adults with mental illness, and adults with developmental disabilities.

Goals

- Improve and coordinate mechanisms across systems to provide consumers with easy access to independent, consistent, and accurate information, and assistance in navigating service delivery systems.
- Identify best practices to foster self-determination, self-advocacy, and recovery among consumers and develop methods for expanding availability of those practices.
- Create a valued, adequately reimbursed, and well-trained workforce across the three systems.
- Expand Vermont's 1115 Waiver to increase use of home and community based services and eliminate the Medicaid bias toward nursing homes.
- Research the option and implement a pilot project for providing direct funding for supports and services to people with developmental disabilities and their families.

Activities

- Assess current information and referral system. Identify gaps and deficiencies and identify measures to improve access to information and assistance.
- Develop training materials and provide statewide and local training, and develop ongoing capacity by recruiting a pool of self-advocates and family members.
- Implement a counseling program to discuss placement options to ensure that consumers applying for admission to a nursing home are informed about all their available options.
- Establish a paraprofessional organization.
- Amend 1115 Waiver.
- Research and propose necessary legislative and regulatory changes to permit direct consumer funding.

Abstract

Vermont's Department of Aging and Disabilities, Division of Developmental Disabilities, and the Division of Mental Health will work collaboratively to increase community integration, real choice and control for elders, younger adults with physical disabilities, people with developmental disabilities and their families, and adults with severe mental illness.

The three systems that are partners in this Real Choice proposal have evolved separately and differ in the amount of community integration, choice, and control offered to the populations they serve. Consumers continue to experience lack of choice and control over their service options. The goals of the Real Choice Systems Change Project are to effect enduring systems that:

- promote continued progress toward community integration of services, and
- promote real choice about how, where, and by whom services and supports are delivered.

The project objectives are to:

- provide consumers with the tools to exercise real choice—good information, technical assistance, and advocacy skills;
- increase access to home and community based services for persons of all ages with physical disabilities; and
- increase consumer control through a direct consumer funding option for those receiving developmental services.

To address the identified problems, the project will undertake activities to:

- create an accessible cross-age and disability system to provide information and assistance;
- provide self-advocacy skills to consumers and families, and training for providers to promote facilitation of consumer self-advocacy;
- create a stable, valued, appropriately trained and compensated workforce by developing a paraprofessional association and implementation of other recommendations;
- expand the 1115 waiver to eliminate the institutional bias and create equal access to home and community based care; and
- create a pilot that can be replicated statewide for direct consumer funding for developmental services.

VIRGINIA

Grant Information

Name of Grantee	Department of Medical Assistance Services Long Term Care & Quality Assurance		
Title of Grant	Consumer Choices for Independence		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,025,000	***Year Original Funding Received***	2001
Amount of Supplemental Grant	$360,000	***Supplemental Award Received***	2002

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Subcontractor(s)

Virginia Institute for Developmental Disabilities	Dr. Fred Orelove, Director	804-828-3908
Virginia Tech Center for Gerontology	Dr. Karen Roberto, Director	540-231-7657
Virginia Geriatric Education Center	Dr. Iris Parham, Director	804-828-1565

Target Population(s)

Beneficiaries of Virginia's home and community based services waivers, and their families and caregivers.

Goals

- Ensure that individuals and their families and caregivers may realize full and meaningful participation, choice, and control of needed supports through Virginia's Medicaid waivers:
  - through development of a paperless assessment process;
  - by providing the right information at the right time to individuals and their caregivers so they can make key life decisions, manage their services, and manage their conditions or disabilities for the most positive outcomes possible;
  - through the implementation of consumer-directed services as included in Virginia's waivers; and
  - by addressing gaps in quality assurance and satisfaction for community-based waiver services through the development of performance, outcomes, and satisfaction measures for continuous quality improvement and use.

Activities

- Develop a paperless assessment process for people who request admission to Virginia's Medicaid waivers.
- Ensure the ability of beneficiaries and families to make informed choices about home and community based services by providing:
  - a "RoadMap" to services offered by the Commonwealth to promote "one stop shopping" for information;
  - an interactive website that will allow individuals and caregivers to search for resources and information across life spans, disabilities, diagnoses, desired outcomes, and geographic locations; and
  - an introductory video that provides an overview of available resources, supports, and services. To the extent possible, persons with disabilities will be hired to develop and be featured in the video.
- Provide training on consumer-directed services as included in Virginia's waivers. This will be accomplished through an agreement with the Virginia Institute for Developmental Disabilities (VIDD) at Virginia Commonwealth University.
- Develop performance, outcomes, and satisfaction measures for continuous quality improvement and use. This will be accomplished through an agreement with the Center for Gerontology at Virginia Tech.

Abstract

Virginians of all ages with disabilities and long-term illnesses have, in multiple forums, related their hopes and dreams to become active participants in communities and to exercise greater choice and control over the decisions that have an impact on their lives. When the Consumer Task Force met to discuss an application for a Real Choice Systems Change Grant, waiver consumers once again stated their desire to have supports available to live, work, go to school, play, grow old in their own neighborhoods, and to be instrumental in the design of those supports. The Department of Medical Assistance Services (DMAS), in coordination with a Consumer Task Force, and a wide range of agencies and organizations, developed the Grant application to create enduring and effective improvements to Home and Community Based Services (HCBS) in Virginia.

Successful project implementation will lead to increased ease of access to services available through waivers, methods for informing consumers about choices and options for support, greater understanding and use of consumer-directed services, and increased consumer satisfaction with, and quality of, services.

DMAS will work with affected individuals and their caregivers and partner with individuals within the disability community as well as with the Virginia Institute for Developmental Disabilities at Virginia Commonwealth University and the Center for Gerontology at Virginia Tech to accomplish the above goals. The grant activities will be coordinated through a steering committee made up of state agencies and members of the advisory task force. A consumer task force of individuals and their caregivers and providers will provide direction throughout the 3 years of the grant activities.

ALASKA

Grant Information

Name of Grantee	Department of Health and Social Services, Division of Mental Health and Developmental Disabilities		
Title of Grant	Real Choice Systems Change Project for Community Living		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

To be determined.

Target Population(s)

Children and adults with developmental disabilities, children with complex medical conditions, adults with physical disabilities, and seniors in need of in-home and long-term care.

Goals

- Integrate self-determination into the existing waiver service system.
- Enhance access to care coordination.
- Improve access to services through systems reform and the creation of a self-directed case management system.

Activities

- Develop data that links level of need, service mix, and costs in order to develop individual budgets for participating recipients.
- Determine the service mix related to meeting the level of need.
- Establish a reimbursement methodology for individual budgets.
- Develop a system for purchasing services through fiscal intermediaries or service brokers.
- Improve quality by developing an evaluation process that includes outcome measures.
- Deliver services using case management models.
- Address provider capacity issues by assessing the role of traditional providers and allowing family members to be paid providers.

Abstract

This project will design and implement enduring improvements in Alaska's long-term care system for the target population that will result in better participation by recipients in planning and controlling the services they receive.

Particular attention will be paid to developing a consumer-driven care coordination system. The roles, performance, and training of care coordinators will be assessed and refined as needed. The project will design and implement reforms necessary to ensure coherent and timely access to needed services and supports. Reforms will be made to eligibility determination, plans of care, and billing procedures.

By linking a person's level of need, service mix, and costs, an individual budget can be developed and placed under the control of the recipient. Funds from the project will be used to pilot and evaluate this process for self-directed care

CALIFORNIA

Grant Information

Name of Grantee	California Department of Social Services		
Title of Grant	IHSS Enhancement Initiative		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

California State University, Sacramento		
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Project Specialist	Sandie Sutherland	916-278-5737
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Target Population(s)

Approximately 300,000 Medicaid-eligible aged, blind, and disabled individuals in the In-Home Supportive Services Program (IHSS), as well as roughly 250,000 care providers.

Goals

- Develop training, educational materials, and other methods of support to aid IHSS consumers to better understand IHSS and to develop skills required to self-direct their care.
- Identify training and other support needs of IHSS care providers and create materials, tools, and work aids that will enable those providers to improve the quality of care they render to the consumer.

Activities

- Convene stakeholder task force meetings.
- Conduct program review and needs assessment.
- Inventory and acquire relevant existing training and educational materials.
- Address the gaps in educational and training tools.
- Design new tools (and modify any existing tools being adapted) and test these tools and dissemination methods.
- Provide training for trainers.
- Develop a final report and release of new materials and training for trainer's manual.

Abstract

Although the vast majority of Medicaid consumers in the IHSS program recruit, hire, train, and supervise their own care providers, there is no statewide assistance or training available to support them in undertaking these potentially difficult responsibilities that are critical to service delivery.

To accomplish the project's goals, grant funds will be used to finance extensive needs assessments of IHSS consumers and providers. Based on those assessments, project staff will locate, obtain, or design training and educational materials, work aids, and other supportive resources. Grant funds will also be used to fund a diverse stakeholder taskforce that will routinely advise the state on the project.

The expected improvements enabled by grant funding will make the IHSS program more effective, with higher consumer satisfaction, greater provider participation and retention, and improved quality of care.

By January 2003, all California counties must, by law, have implemented an employer of record for employer/employee relations with IHSS providers including collective bargaining. As of January 1, 2003, almost all of California's 58 counties have established a Public Authority (PA) that, by law, must make consumer and worker training available. Counties and PAs will sustain the materials, work aids, and other products developed under this project. This assures that the grant-funded products of this project will be an enduring aspect of the IHSS program throughout the state. The products of this project would also be available to be shared with other states that have programs similar to IHSS.

COLORADO

Grant Information

Name of Grantee	Department of Health Care Policy and Financing		
Title of Grant	Systems Change for Real Choices		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,120,147	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

The Center for Research Strategies, LLC 225 E 16th Avenue, Suite 1150 Denver, CO 80203	Kaia Gallagher, Ph.D.	303-860-1705

Target Population(s)

Persons of all ages with a disability or long-term illness.

Goals

- Expand opportunities for consumers to live in the community by increasing the number and quality of community-based options.
- Expand opportunities for consumers to live in the community by increasing consumer and provider knowledge of community-based options.
- Improve the funding system to better meet consumers' individual needs for services.
- Decrease the fragmentation among state systems involved in coordinating long-term care.

Activities

- Contract with Center for Research Strategies to design and conduct a service capacity survey and a sample-based statewide needs assessment for community-based care with an emphasis on rural areas of Colorado.
- Develop and implement a rural seed-money grants program to develop community-based care options.
- Conduct a feasibility study of community-based respite care and develop recommendations for pilot programs.
- Develop an education campaign on community-based options targeted to consumers.
- Identify best practices in service delivery and conduct a symposium on best practices for consumers, service providers, and state agency staff.
- Improve the mental health client assessment tool and conduct a training session for mental health case managers on the newly created assessment tool.
- Analyze current funding streams, review other states' funding models, and develop options for a funding system that allows the money to follow the consumer.
- Review existing quality assurance programs in long-term care and identify key elements of an effective community-based quality assurance system.
- Develop policy recommendations regarding an updated quality assurance system for community-based services.
- Create web-based application forms for community-based services to be used across state systems.
- Conduct training sessions on web-based application forms for case managers across state systems.

Abstract

Colorado's overall objective is to improve and expand sustainable community-based support services to allow children and adults of any age who have a disability or long-term illness to live in the most integrated setting appropriate to their individual needs. In order to meet this goal effectively, Colorado will work in partnership with a consumer task force consisting of a diverse group of consumers, advocates, and service providers to implement all activities. The consumer task force will provide advice to agency staff and subcontractors on all project goals through monthly meetings of the full task force or meetings of one of four subgroups related to the four major goals of the project. We anticipate that the research and policy recommendations that follow from the project activities will build upon past and current efforts by the state to improve and expand community-based services and will inform future efforts by the state to meet this goal.

COMMONWEALTH OF NORTHERN MARIANA ISLANDS

Grant Information

Name of Grantee	Governor's Council on Developmental Disabilities		
Title of Grant	Real Choice Systems Change		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

CNMI Center for Independent Living
Northern Marianas College

Target Population(s)

Persons with developmental disabilities.

Goals

- Implement systems change in CMNI long-term care service delivery.
- Improve the resources available for assistive technology.
- Provide better information about services available and support for persons with disabilities.
- Increase the availability and quality of personal assistance workers.
- Develop a framework for fee-for-service personal assistance and respite services.

Activities

- Renovate a building to house and support the CNMI assistive technology program.
- Conduct a demonstration of newly available assistive technology equipment.
- Provide technical assistance in the use and support of assistive technology.
- Establish support groups for persons with disabilities.
- Develop a one-stop resource/information center.
- Conduct a needs assessment and demonstration of the feasibility of fee-for-service personal assistance services.
- Provide fee-for-service personal assistance services based on demonstration findings.
- Coordinate development of a education and certification program for personal assistance workers through CNMI Northern Marianas College.
- Provide transportation services for persons with disabilities.
- Develop a fee-for-service respite care program.
- Provide funding for increased self-advocacy in the legislative process.

Abstract

The Governor's Council on Developmental Disabilities (GCDD) will conduct a needs assessment and develop or implement model programs for long-term care planning to facilitate community living. These programs will include assistive technology demonstrations, respite care and personal assistance services, nursing facilities, and assisted living and hospice programs. GCDD will conduct needs assessment surveys and provide recommendation for accessible transportation services supporting inclusive living, including school busing, taxicab and public transportation modifications, and voucher and financial support methods.

To address longer term needs, the Task Force believes it is necessary to develop personal assistance capacity among the local community. Capacity development will include development of an assistive care certificate curriculum that will target CNMI family caregivers and other local job-seekers to fill longer term demand.

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

CONNECTICUT

Grant Information

Name of Grantee	Connecticut Department of Social Services		
Title of Grant	Real Choice Systems Change Grant		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Center for Excellence in Developmental Disabilities, Education, Research & Services	Mary Beth Bruder	860-679-1500

Target Population(s)

Persons with disabilities of all ages living in communities in Connecticut.

Goals

- Build capacity within the State of Connecticut to support informed decision making, independent living, and a meaningful quality of life for persons with disabilities across the life span.
- Assist three communities in Connecticut to become models of support for opportunities and choices for persons with disabilities across the lifespan.

Activities

- Collaborate with the Connect to Work grant (Medicaid Infrastructure Grant) and the Connecticut Association of Personal Assistants (CTAPA) in their efforts to increase the workforce of personal assistants throughout the State of Connecticut, including development of a strategic marketing/recruitment plan, and develop outreach and recruitment materials.
- Work with state agencies to enhance their capacity to provide services by including persons with disabilities and their families as partners and decision makers in service design and delivery.
- Develop training materials and provide technical assistance to state agencies regarding embedding training information, materials, and activities within state agency orientation and training.
- Collaborate with training coordinators on revising existing training systems.
- Develop and disseminate information and resources for the general public on the Real Choice System Change Grant and increase public awareness of inclusion in the community, including handouts or Question-and-Answer sheets, a media tool kit for persons interested in advocating within their own communities or statewide, and an interactive, accessible website on project activities and findings.

Abstract

The Real Choice project will build the capacity within the state of Connecticut to support informed decision-making, independent living, and a meaningful quality of life for persons with disabilities across the life span. The project will (1) conduct a statewide assessment and (2) build capacity in three specific communities concurrently over a 3-year period.

First, the Real Choice project will conduct a statewide assessment of the 169 towns in the state to determine the level of inclusion available in those communities. This assessment will examine the extent to which persons with disabilities living in Connecticut are able to receive an inclusive education (including early intervention), participate in community life, seek and obtain employment and housing, and generally access the supports and services they need in a manner that enhances their fullest community participation and independence. We will produce a report summarizing the opportunities and barriers experienced by persons with disabilities and their families across the state and develop a resource inventory.

Second, we will select and build capacity through technical and financial assistance in three specific communities (one rural/regional, one urban, and one suburban community) that are already demonstrating good progress in this area. The grant provides for $75,000 across these communities to be awarded in order to strengthen an already demonstrated commitment to community inclusion in all aspects of community life. We will do this by developing a task force in each community that includes consumers, families, and representatives of the public sector, the private sector, and the private, nonprofit sector. We will also assess areas of need in each selected community and develop a community action plan. Other methods of building capacity in each of the three target communities include facilitating expansion of the paraprofessional workforce; increasing the availability of affordable, accessible and safe housing; building collaborative partnerships that will assist with implementation; developing peer support networks; and providing targeted training to disseminate information and resources to community leaders and other community members.

DISTRICT OF COLUMBIA

Grant Information

Name of Grantee	Department of Health, Medical Assistance Administration		
Title of Grant	DC Coordinating Community Care Options for Individuals who are Disabled or Aging (DC C^3ODA)		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

To be determined by the RFP process.

Target Population(s)

Elderly and adults with physical disabilities, ages 18 to 64 years.

Goals

- Create the infrastructure to build a cost-effective HCBS system.
- Create mechanisms to ensure full community participation in the project and to coordinate policy decision-making across district government agencies.
- Improve the flow of HCBS information to consumers and streamline the eligibility determination process.
- Build an accessible continuum of services.
- Construct the infrastructure necessary to ensure appropriate use of services.
- Provide a single point of entry for home and community based services through development and implementation of a Resource Center that will provide options counseling, eligibility determination, and channel individuals to the most effective and medically appropriate setting.

Activities

- Develop a Real Choice Systems Change Advisory Committee that is composed of consumers, providers, and various representatives of district government agencies.
- Develop and implement a resource center or single point of entry for home and community based services that provides long-term care options counseling, self-determination, Medicaid and other publicly-funded eligibility, channeling of individuals to the most effective and medically appropriate setting, and effective management of cost of services.
- Expand services to include assisted living, targeted case management for particular populations, an independent provider/consumer-directed form of attendant care services, and expanded coverage of assistive technology.
- Increase the number of new waiver providers and continue a current rate-setting analysis.
- Develop a long-term care information systems software package to improve the quality of care and to ensure proper levels of service utilization.

Abstract

The DC C^{3}ODA project will address strategies for responding to the desires of the elderly and individuals with physical disabilities to live in and receive services in appropriate home and community based settings. The project will focus on the development of the infrastructure to build a cost-effective HCBS system and address issues related to establishment of an Advisory Committee to ensure community and government participation in the decision-making process, information dissemination to consumers, streamlining the eligibility determination process, access to services and other publicly funded programs, and building capacity for access, adequacy, availability, appropriateness, and quality of services along the continuum of care.

The DC C^{3}ODA program will develop a resource center that will serve as a single point of entry for accessing the long-term care system and providing consumers with the tools and supports to manage their care. The system will maximize the ability of HCBS to target individuals at high risk for institutionalization, empower individuals to make informed choices about their long-term care options, and channel those in need of long-term care services to the most effective and medically appropriate settings of their choice. The project will also establish a care coordination system that incorporates financial incentives for providers in order to increase flexibility, improve quality of life and care, and control costs.

Significant and sustainable outcomes will include a system that fosters greater consumer control and choice; service provision that will enable the elderly and individuals with physical disabilities to be integrated into the social mainstream; and methods to allow individuals to be appropriately served in the settings of their choice and to have control over the delivery of those services.

GEORGIA

Grant Information

Name of Grantee	Georgia Department of Human Resources		
Title of Grant	Real Choice Systems Change Grant		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Valdosta State University
Georgia State University
Janet Rechtman and Associates
Brown Consulting
Georgia Governor's Council on Developmental Disabilities
Alice P. Lin, Ph.D.
The Technical Assistance Collaborative
Georgia Consumer Network

Target Population(s)

Individuals of all ages who have a disability or long-term illness.

Goals

- Address system barriers to community integrated living.
- Develop an ongoing mechanism for consumer involvement in all aspects of the integrated community service delivery system for elderly people and people with disabilities.
- Develop a process for effective communication and collaboration to enhance planning and implementation of integrated community service system change.
- Sustain an accessible integrated community service system for elderly people and people with disabilities.

Activities

- Develop a medication administration certification program for adoption by the Division of Mental Health, Developmental Disabilities and Addictive Diseases.
- Develop strategies that will enhance the ability to recruit, retain, and improve the direct care workforce that supports elderly people and people with disabilities in community-integrated settings.
- Evaluate the effectiveness of supported housing for adults with serious mental illness.
- Develop training programs for peer supporters to enhance transition of individuals from institutions to community-integrated settings.
- Develop and implement actions for improved communication with elderly people, people with disabilities, and family members and advocates and to improve communication and coordination among state agencies.
- Support the development of a single point of access for people with mental illness and developmental disabilities as specified in HB 498.

Abstract

The Real Choice Systems Change Grant represents Georgia's commitment to design and implement effective and enduring improvements in community long-term support systems. These improvements will enable individuals of all ages who have a disability or long-term illness to live and participate in their communities.

The project will address system barriers to community-integrated living, develop an ongoing mechanism for consumer involvement in all aspects of the integrated community service delivery system for people of all ages and disabilities, develop a process for effective communication and collaboration to enhance planning and implementation of integrated community services system changes, and sustain an accessible integrated community service system.

This project represents Georgia's commitment to enact real systems change by effectively changing the provision of services to people of all disabilities and ages. The project's products will be accomplished by building on current initiatives, such as the work on direct care staff improvements. The Supported Housing Demonstration Project training and evaluation will be supplementary to the current housing initiative funded by a Center for Mental Health Services grant. This grant will build synergies with current Centers for Medicare and Medicaid Services initiatives, such as the Nursing Home Transition grants previously awarded.

INDIANA

Grant Information

Name of Grantee	Family and Social Services Administration		
Title of Grant	Indiana Real Choice Systems Change Grant		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

HealthEvolutions—to staff the Governor's Commission on Home and Community Based Care

Various entities selected for "minigrants."

Target Population(s)

Children, adults, and senior citizens.

Goals

- Develop community capacity in the areas of community living arrangements, housing, transportation, supported employment, and caregiver support.
- Develop systems that support consumer choice and consumer-directed care.
- Develop innovative systems that identify and propose solutions to eliminate barriers to service.

Activities

- Create the Governor's Commission on Home and Community Based Services (the Commission) to develop short- and long-term strategies to create or expand community capacity for persons at risk of being institutionalized, or for those currently in an institution or nursing home.
- Have task forces of the commission address current system barriers and best practices, incentives for change, partnership recommendations for system change, recommendations for strategies on community capacity building (both short- and long-term), process for implementing short-term strategies, and evaluation criteria to measure effectiveness of change.
- Issue mini-grants to create community partnerships, to provide incentives for public/private partnerships, and to encourage innovation at the community level between community stakeholders.

Abstract

The Indiana Family and Social Services Administration (FSSA) is using this funding to create an enduring infrastructure to support consumer-directed and controlled community-based services and supports for persons with disabilities in Indiana. The federal funds will be used to implement the following objectives:

- **Support the Governor's Commission on Home and Community Based Care.** Major responsibilities of the Commission include oversight and monitoring of Olmstead and related ADA grants and activities. The Commission will also provide a forum for interaction with consumers and advocates.
- **Integrate and coordinate all systems change grants.** A demonstration project consisting of portions of each grant will use local partners and create new ways to provide services and supports in Indiana communities.
- **Restructure the state's quality assurance system.** Direction and oversight will be provided for the restructuring of the system to include consumer complaints, safety, protection, and advocacy.
- **Form state public/private partnerships.** The Commission will implement a series of 10 mini-grants to local communities to demonstrate innovative ways of delivering services and supports.

KANSAS

Grant Information

Name of Grantee	Department of Social and Rehabilitation Services, Resource Development		
Title of Grant	Kansas 21st Century Long-Term Care Project		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Topeka, KS 66612

Subcontractor(s)

Request for Proposal has been issued; subcontractor has not been identified yet.

Target Population(s)

Individuals of all ages with disabilities or long-term illness.

Goals

- Develop a strategic plan to guide future systems change.
- Investigate the potential of improved screening instruments for functional eligibility determination and de-institutionalization.
- Enhance the Diversion project by providing short-term case management services to divert individuals who are at-risk of institutional placement upon discharge from a hospital.
- Provide technical assistance to expand capacity to deliver community-based services based on currently identified needs, and needs articulated in the strategic plan, including increasing the systems' flexibility to accommodate both the unique needs of consumers and the state.
- Develop and present effective education materials among the broad range of service providers and other long-term care stakeholders.

Activities

- Convene a strategic planning task force comprised of relevant stakeholders to develop a 3-year action plan to articulate a philosophy and direction for systems change.
- Implement new or modified long-term care level of care screening tools.
- Establish a technical assistance pool to provide technical assistance to local service providers in developing local resources to meet the needs of individuals to remain in (or return to) and participate in the community.
- Conduct professional development/continuing education programs aimed at changing referral patterns from institutional dependence to the fullest possible participation in the community.

Abstract

The Real Choice Systems Change project seeks to build upon the incremental improvements in long-term care, which Kansas has implemented through Medicaid home and community based services waivers. The primary purpose of the project is to make home and community based services as accessible to individuals with disabilities or long-term illness as institutional care.

A Strategic Planning Committee including consumer, provider, funding, and regulatory stakeholders will address legal, regulatory, and policy barriers to a community-first long-term care system, including funding issues, capacities of service providers to provide access to necessary supports and services, and employment related issues. The 3-year action plan seeks to expand self-determination by providing additional control over supports and services for all individuals with disabilities or long-term illness based on the premise of self-determination, independent living, and personal autonomy.

LOUISIANA

Grant Information

Name of Grantee	State of Louisiana Department of Health and Hospitals		
Title of Grant	Real Choice for Louisiana		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Mary Perrault
Governor's Office of Disability Affairs
365 N Fourth Street
Baton Rouge, LA 70801

Target Population(s)

All populations with disabilities.

Goals

- Support the planning process of the Consumer Task Force (CTF) and the Disability Services and Supports System Planning Group (DSSSPG).
- Develop and implement consumer direction in Home and Community Based Services (HCBS) waivers.
- Develop and implement a Workforce Development Project.
- Develop and implement Housing Pilot Projects.

Activities

- Provide staff, meeting space, educational opportunities, and consultants to support and inform the CTF and DSSSPG as they continue to recommend programmatic direction.
- Encourage participation in CTF and DSSSPG activities by assisting with expenses of consumers.
- Hold a series of public forums in all regions of the state to obtain consumer input.
- Develop and implement programming, training materials, and project evaluation materials to enable implementation of consumer direction in HCBS waivers.
- Develop competency training curriculum and career ladder recommendations aimed toward professionalizing direct care staff.
- Develop guidelines for establishing local coalitions to address housing issues.
- Establish regional housing networks in three regions and a statewide housing network to develop collaborative partnerships to identify and implement strategies to overcome housing barriers.

Abstract

The ultimate outcome of the proposed activities will be to identify and implement enhancements to the long-term care services infrastructure that will dramatically move Louisiana away from a reliance on institutional care. By demonstrating cost efficiencies, improved consumer satisfaction and outcomes, and increased integration of a full continuum of long-term care services, the proposed project will play a role in producing enduring systems change to benefit all citizens of Louisiana.

The vehicles to achieve this shift will begin with a collaborative process to both inform consumers about the options for long-term care systems change and to obtain their input into the planning process. Other systems change capabilities to be developed through this grant will enhance the array of available services and the way in which they are delivered, focusing on consumer direction, direct care staff professionalism, and local housing coalitions.

MISSISSIPPI

Grant Information

Name of Grantee	Department of Mental Health		
Title of Grant	Person Centered Planning		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

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Region 13 Gulf Coast Mental Health Center	Jeff Bennett	228-865-1700
Region 15 Warren Yazoo Mental Health	Steve Roark	601-638-0031
The University of Southern Mississippi Department of Curriculum, Instruction & Special Education	Dr. Linda McDowell	601-266-5135
The University of Mississippi Department of Psychology	Dr. Paul Deal	662-915-7383
NAMI Mississippi 411 Briarwood Drive, Suite 410 Jackson, MS 39206	Teri Brister	601-899-9058

Target Population(s)

Transition individuals who are between 17 and 26 years of age who have a serious mental illness or dual diagnosis (mental illness/substance abuse or mental illness/mental retardation).

Goals

- Demonstrate a model for systems change by training stakeholders in the Person Centered Planning (PCP) process and applying the PCP process in three selected mental health regions.
- Document improvements in the quality of supports based on the PCP model by measuring satisfaction among individuals receiving services, support providers' acknowledgment of increased positive outcomes, and cost effectiveness of the PCP model.
- Collaborate with the current support systems of Mental Illness Management (MIMS) and Intensive Case Management and future support models being considered in Mississippi.

Activities

- Review the MIMS and Intensive Case Management systems and introduce the PCP process to meet the needs of adolescents and adults with mental illness or/or dual diagnosis.
- Build consensus among the stakeholders (professionals and individuals receiving services) for use of the Person Centered Planning process in three Community Mental Health Regions: Region 6 (Greenwood), 13 (Gulfport), and 15 (Vicksburg).
- Train professionals and peer specialists from each of the three participating Community Mental Health Regions to use the Person Centered Planning model.
- Implement the PCP model in the three participating Community Mental Health Regions and conduct ongoing evaluation of the effectiveness of the model.
- Incorporate evaluation findings into the model and revise as necessary.
- Publish and disseminate findings of the implementation of the model.

Abstract

The Mississippi State Department of Mental Health in collaboration with the Division of Medicaid and the Office of the Governor, propose a pilot with the Real Choice Systems Grant to introduce the Person Centered Planning process to MIMS and Intensive Case Management by providing a Regional Support Coordinator and other support staff to create effective, enduring improvements in Mississippi community long-term support systems. The project would demonstrate that this alternative approach increases the possibility that transition individuals 17 to 26 years of age, who have a serious mental illness or dual diagnosis, can self-manage their illness and participate in their community to the best of their ability with the support necessary to allow them to achieve their expressed goals and accomplish their highest level of independence.

MONTANA

Grant Information

Name of Grantee	Department of Public Health and Human Services		
Title of Grant	Montana Real Choice Systems Change		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Support and Techniques for Empowering People (STEP), Inc.
Joan Grauman, Evergreen Center 406-248-2055 joang@step-inc.org

Montana Home Choice Coalition
Michael O'Neal, AWARE, Inc. 406-459-0281 ONeil_Michael@msn.com

Western Transportation Institute, Montana State University—Bozeman
Lisa Ballard 406-994-6529 Lballard@coe.montana.edu

Target Population(s)

All persons with disabilities in Montana.

Goals

- Modify the long-term care system to create a system designed for individualized funding and choice.
- Support consumers, their families, and providers with information, training, and technical assistance for their participation in the new system.
- Identify accessible and affordable housing options.
- Develop and implement a coordinated transportation system.

Activities

- Redesign Montana's contracting and billing system to promote individualized funding and choice in service delivery and rewrite Oracle software program to meet these requirements.
- Revise existing curricula for parents, advocates, and self-advocates to reflect changes in the Montana Developmental Disability Program and provide training and technical assistance in its use.
- Establish HomeChoice Mortgage Home Ownership Pilot project in four cities.
- Identify existing homeownership curriculum materials to meet needs of people with disabilities or develop such materials, and provide to existing home ownership networks.
- Develop at least 16 community housing opportunities for people with disabilities annually.
- Assist at least 10 individuals/families with disabilities to obtain home ownership through partnering with existing home ownership networks.
- Provide training and technical assistance on the housing development process, supportive housing concepts, home buying assistance, universal design, and housing advocacy.
- Assist two communities in developing coordinated transportation plans that meet the specific needs of the disabled population and other persons with transportation problems.
- Plan for and build or support two coordinated transportation models that can be replicated statewide.
- Identify Intelligent Transportation Systems technologies and other coordination tools and develop system requirements for a statewide transportation computer system.

Abstract

Three programs or divisions within the Montana Department of Public Health and Human Services will collaborate to build systems to promote real choice in Montana. The Developmental Disabilities Program will completely change the way that services are offered to persons with developmental disabilities. The Program will become one in which services are funded for an individual based on that person's needs. Each person will be able to purchase and pay for their own services from their choice of qualified providers. Extensive training, consulting, and information will be presented to families and consumers to inform them about systems change, and a software system will be created to implement the individualized services system.

The Addictive and Mental Disorders Division will coordinate the development and use of accessible and affordable housing in four communities in Montana with the Montana HomeChoice Coalition. The coordinator will work with local, state, and federal resources to find affordable and accessible housing for all persons with disabilities.

Montana Vocational Rehabilitation will coordinate with the Montana Transportation Partnership and the Western Transportation Institute to develop and implement a coordinated transportation system in two communities in Montana. The system will provide transportation services to all persons with disabilities and will provide a replicable model for the state.

NEVADA

Grant Information

Name of Grantee	Nevada Department of Human Resources		
Title of Grant	Real Choices: Improving Community Services and Supports for Special Needs Children in Nevada		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Project manager to be hired.

Subcontractor(s)

None.

Target Population(s)

Children with Special Health Care Needs (CSHCN) aged 0 to 22 in Nevada and their families.

Goals

Improve community-integrated, family-focused services and supports for CSHCN in Nevada.

Activities

- Complete a comprehensive, statewide needs assessment of the nature and magnitude of challenges facing CSHCN and their families in Nevada.
- Evaluate service delivery models and statewide planning approaches developed and implemented in other states.
- Develop a comprehensive set of public policy recommendations, proposals, and strategies aimed at improving community-based services and supports for CSHCN and their families in Nevada.
- Establish a Nevada Advisory Council on CSHCN.
- Implement a statewide media campaign on issues and challenges facing CSHCN and their families in Nevada.
- Implement three community-based pilot projects in urban northern (Reno metro area), urban southern (Las Vegas metro area), and rural-frontier regions of Nevada.

Abstract

Nevada seeks to improve community-based services and supports for children with special health care needs. The primary goal of these activities is enduring systems improvements in Nevada that will increase access to community-based programs, services, and supports for CSHCN and their families.

This project was developed with the consultation of the following state agencies: the Nevada State Department of Human Resources (DHR), three divisions and one office within the DHR - Division of Health Care Financing and Policy (DHCFP), Division of Mental Health and Developmental Services (DMHDS), the Nevada State Health Division (SHD), the Community Connections office; and the Nevada State Department of Employment, Training, and Rehabilitation (DETR). Project activities were also developed with the broad, collaborative input of parents of CSHCN, private service providers, advocacy groups, and treatment professionals in Nevada. The project will be administered by the Nevada State Health Division and will be coordinated with an ongoing, legislatively-mandated initiative within the DHR to develop a "Strategic Plan for Services to Persons with Disabilities" in Nevada.

The project will address two well documented needs in Nevada—the absence of a coordinated system of community-based and family-focused programs, services, and supports for CSHCN in Nevada, and an essentially nonexistent statewide resource planning system for CSHCN and families in Nevada. Activities will result in (1) generation of data during Years 1 through 3 of the proposed budget period that provide a better understanding of the nature and magnitude of challenges facing CSHCN in Nevada; (2) development of a permanent data collection system during Year 1 that allows state policymakers, service providers, advocates, and families of CSHCN to evaluate service delivery models and planning approaches developed in other states and regions; (3) development of public policy initiatives and a long-term strategic plan that provides concrete solutions to the medical care and service needs of CSHCN in Nevada; (4) implementation of a statewide multimedia campaign on issues affecting CSHCN and their families in Nevada; (5) establishment of a permanent Nevada Advisory Council on Children with Special Health Care Needs that will guide project activities and serve as an ongoing forum for issues addressing community based services and supports for CSHCN once the funding period of the proposed project has been completed; and (6) development and implementation a multi-community demonstration during Year 2 of the proposed budget period that is based on "lessons learned" from activities in Year 1 of the project.

NEW MEXICO

Grant Information

Name of Grantee	Human Services Department, Medical Assistance Division		
Title of Grant	Individual Choices		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

*Contact Information**

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Subcontractor(s)

None.

Target Population(s)

All populations with disabilities.

Goals

- Establish a statewide Service Delivery Options Training Program (SDOTP) to provide individuals with resources and information on how to access services and make meaningful choices about their living environment and their provider of services.
- Establish a statewide Network for Long-Term Care Policy Change (NLTCPC) program to provide training to consumers, family members, and other advocates on the skills necessary to help create and sustain systems change.

**Grantee did not provide updated contact information for this edition.*

Activities

- Develop a training curriculum to assist consumers, caregivers, and providers in learning how to maximize utilization of social support services and combine those services with medical services to achieve the best health and social support outcomes.
- Create a train-the-trainers model with a core training curriculum with information on current systems and processes as well as new models of services delivery.
- Develop a curriculum to train consumers, families, and other advocates throughout the state with skills to help create and sustain systems change.
- Create a train-the-trainers model to help participants receive training to help them understand state systems that fund services and supports and how to impact those systems to initiate change.

Abstract

New Mexico is reforming its Medicaid long-term care service system, and this project will provide an important testing ground for strategies to provide individuals with resources and information on how to access services and make choices about their living environment and their provider of services. The project will include training on consumer-directed selection/management of providers and an advocacy and leadership training program for individuals with disabilities to lead systems change. This training will include the History and Philosophy of Disability, Public Policy (including the philosophical underpinnings of self-directed and community supports), State Policy Systems (including the State Legislature), Current Service Delivery and Available Resources, and Community Development and Organizing Strategies.

New Mexico plans to submit an 1115 waiver to integrate long-term care services and expand consumer choice opportunities to shift the existing bias from institutional services to community-based services and individual choice. This project's strategies will be integrated into the Medicaid 1115 Global Funding waiver that is projected to begin in 2003. The Individual Choices strategies will be implemented prior to the start of the 1115 waiver to enable consumers to better understand the 1115 waiver and make appropriate choices for care.

NEW YORK

Grant Information

Name of Grantee	New York Department of Health		
Title of Grant	Real Choice Systems Change Grant		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

The Real Choice Systems Change Grant is being used by the New York State Department of Health and the Office of Mental Retardation and Developmental Disabilities. The Department of Health has not identified subcontractors at this time. The Office of Mental Retardation and Developmental Disabilities has identified the Self-Advocacy Association of NYS, Inc as a subcontractor. A certain number of person-centered planning experts will also be identified as subcontractors.

Target Population(s)

The Department of Health's project will target individuals of all ages and disabilities. The Office of Mental Retardation and Developmental Disabilities will focus on transitioning persons with developmental disabilities from Intermediate Care Facilities (ICFs) to more integrated residential settings.

Goals

- Divert individuals who can live in the community from nursing home care; transition persons with developmental disabilities from intermediate care facilities (ICFs).
- Develop partnerships that foster collaboration between long-term care stakeholders in the community who are involved in advocating for, arranging for, or providing long-term care services. The partnerships will enhance existing information, assistance, and advocacy (IA&A) systems or develop new ones.
- Promote consumer independence, freedom of choice, and the ability to live in the most integrated setting appropriate to their needs.
- Identify barriers that impede individuals from living in the most integrated settings appropriate to their needs and develop recommendations for systems change.

Activities

- Fund consortia of long-term care stakeholders who will provide consumers, caregivers, and professionals, regardless of payer source, with comprehensive and unbiased information on available long-term care services and programs.
- Provide assistance to consumers in obtaining needed services.
- Provide advocacy services when needs are not being appropriately met.
- Partner with the Self-Advocacy Association of NYS to provide information and peer mentoring to residents of participating ICFs/DD.
- Help ICF residents, who so choose, to transition to more integrated community settings through a person-centered planning process.

Abstract

New York will conduct two related projects, each designed to help individuals with disabilities live in the most integrated setting appropriate to their needs. The Office of Mental Retardation and Developmental Disabilities (OMRDD) will focus on transitioning persons with developmental disabilities from ICFs to residential settings. The Department of Health (DOH) in partnership with other state agencies will focus on diverting individuals from nursing homes. DOH will award grant funds to applicants to develop new, or enhance existing, IA&A systems which will facilitate entry into community-based care by providing consumers, caregivers, and human services professionals with accurate and impartial information and assistance in accessing New York State's broad spectrum of long-term care services. Proposals must demonstrate cooperation and planning between government, providers, consumers, and other appropriate long-term care stakeholders. Applicants from private and/or public community-based organizations, as well as consumer organizations will be sought who have the capacity and experience to provide ongoing IA&A to persons, regardless of disability, age, or payer.

NORTH DAKOTA

Grant Information

Name of Grantee	State of North Dakota		
Title of Grant	Real Choice Systems Change in North Dakota		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$900,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

None.

Target Population(s)

All ages.

Goals

- Identify current strengths and challenges in the North Dakota system of care for persons with a disability.
- Combine, compress, or piggyback services and resources where possible given the existing resources.
- Improve access to information about home and community service options.

Activities

- Develop requests for proposals for innovative projects in rural communities based upon a review of research and service delivery currently underway.
- Issue the request for proposals for pilot projects that will demonstrate creative changes in service delivery.
- Demonstrate creative changes in service delivery without additional costs through simplified access to services, consumer involvement in development and management of services, and consumer-directed fiscal planning for services.

Abstract

The Governor's Commission on the Olmstead Decision received $900,000 that will be used to ensure the consumer is actively involved in decision making regarding development and implementation of services. Multiple systems are involved in providing services to persons with disabilities, therefore, memorandums of agreement and policies must be created that empower the consumer to have a strong voice in service decision.

The first phase of the project is a white paper on the current system and meta-analysis of current studies of the systems of care. That portion will be completed in April of 2003. Because North Dakota has an aging population and the majority of services for persons with a disability tends to be within long-term care facilities, studies involving payment and services in long-term care facilities are especially informative to this project.

Specific tasks, such as improved access to information and greater consumer input into development of services will be achieved through pilot projects in rural North Dakota. A request for proposals will be sent out to develop creative projects that will assist persons with a disability to direct their other services.

Early analysis of data indicates a need for system changes in the areas of finance, outreach, transportation, workforce, service gaps, and service coordination. The pilot projects will be expected to address these areas.

Currently, there are multiple telephone numbers one would need to have to access all the possible services available. One project is aimed at a simplified access system for services.

The Governor's appointed commission is the governing body for the grant. A project coordinator will oversee the day-to-day operation and report to the Commission.

OHIO

Grant Information

Name of Grantee	Ohio Department of Job and Family Services		
Title of Grant	No Wrong Door		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Ohio Department of Aging

Target Population(s)

Adults.

Goals

- Increase consumer choice and control by giving consumers consistent, reliable, and up-to-date information about services and supports available to them regardless of their point of contact with the formal delivery system.
- Improve access to housing for adults receiving community-based supports and services.
- Promote consumer involvement in state-level decision making on policy issues affecting Ohioans with disabilities.

Activities

- Develop a web-based, comprehensive information system that provides information on all benefits and services available for adults with disabilities.
- Provide information and training targeted at professional agency staff who are working directly with consumers on the use of the No Wrong Door Internet site.
- Increase housing options for people with disabilities by working with consumers identified for transition through the state's System's Change Nursing Facilities Transition grant and by working with public housing authorities on identifying available housing.
- Catalog all existing housing programs for inclusion in the No Wrong Door project.
- Work directly with public and private community service organizations and consumers to resolve housing-related problems, and bring together representatives from community services agencies and housing assistance agencies to address system-level issues.
- Provide ongoing financial support to the Ohio Olmstead Task Force.

Abstract

No Wrong Door is designed to give consumers consistent, reliable, and up-to-date information about services and supports available to them regardless of their point of contact with the formal delivery system. A consumer desiring to access services through a County Department of Job and Family Services, an Area Agency on Aging, an Alcohol Drug Addiction and Mental Health Board, or a County Mental Retardation/Developmental Disabilities Board should have access to the same information. There would be "no wrong door" into the system.

This objective can best be accomplished by the creation of a centralized body of information that is accessible to all agencies and all consumers equally. This information on services and supports will be both comprehensive and reliable. Reliability becomes an issue even with the simple passage of time. What is reliable today is history tomorrow. The problem with printed guides to services and supports is that they are often outdated before they can be printed. For that reason, this centralized body of information should be available in electronic form over the Internet to ensure that it remains reliable and can be easily updated.

We recognize that not all consumers have access to Internet-based information sources. We will build mechanisms into the project to ensure that information on services and supports is widely available through public and private sector agencies that serve people with disabilities.

Training professional agency staff that work with consumers is an equally important step in ensuring that consumers have the opportunity to make informed choices. During the community forums, we heard consistently that even when consumers were in contact with professional agency staff, often these staff had an incomplete understanding of the forms of assistance available to consumers and the eligibility requirements for accessing services and supports. If professionals themselves lack access to reliable information, consumers are ultimately denied the right to make an informed choice. Therefore, the No Wrong Door project will also include information and training targeted at professional agency staff who work directly with consumers.

An additional, but important concern is the difficulty consumers encounter in finding suitable housing. Ohio will hire a housing coordinator to work with consumers as well as public and private providers of housing to increase consumer choice.

OKLAHOMA

Grant Information

Name of Grantee	Oklahoma Department of Human Services, Aging Services Division		
Title of Grant	Real Choice Systems Change in Oklahoma		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor

Long Term Care Authority of Tulsa Deborah Karns, Director	918-583-3336	dkarns@ltca.org

Target Population(s)

Frail elderly and adults with physical disabilities.

Goals

- Promote accountability of the service delivery system to consumers, providers, and policy makers.
- Produce available, reliable, appropriate, and quality personal assistance services.
- Create supports for consumer transitioning from institutional settings into community living.
- Develop a new service delivery infrastructure to support a specialty managed care program model.

Activities

- Develop the Oklahoma Real Choice Partnership with consumers and advocates from the CD-PASS project.
- Develop and implement supports for Continuous Quality Improvement in the service delivery system through the involvement of consumers and family in oversight and quality monitoring.
- Develop and deploy software tracking of quality indicators.
- Evaluate and make recommendations for change to the state's personal care program to include services that require nurse delegation of tasks and additional skilled nursing.
- Attain detailed knowledge of nursing facility transition service requirements and costs by transitioning 50 consumers.
- Prepare a section 1915(b)(c) waiver in order to pilot the concepts of a model specialty managed care program in a rural area of the state.

Abstract

Oklahoma's Real Choice project will build on the achievements of the first year in our CD-PASS grant by promoting accountability of the service delivery system to consumers and the state through a Continuous Quality Improvement system. It will create supports for consumer transitioning from institutional settings back into the community. It will also develop a specialty managed care program model of service delivery, which relies on managed care principles but applies them in a manner that serves people with disabilities and long-term illnesses more flexibly and effectively and will provide consumer choice of providers in rural Oklahoma.

PENNSYLVANIA

Grant Information

Name of Grantee	Department of Public Welfare		
Title of Grant	Real Choice Systems Change Grant		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

In the process of obtaining an administrative subcontractor.

Target Population(s)

Older Pennsylvanians, adults with disabilities and children.

Goals

- Develop better methods to manage the overall system in support of community living.
- Develop a system of access to home and community based services and supports for people of all ages that is cross-disability, comprehensive, understandable, and responsible to the needs of local communities.
- Develop expertise and capacity to effectively serve individuals across the broad spectrum of disabilities and long-term illnesses.

Activities

- Support the Home and Community Based Services Stakeholder Planning Team through training opportunities, mentoring for certain individuals, reimbursement for travel, attendants, and other costs for members who are either consumers themselves or family members of consumers.
- Evaluate existing outreach and education efforts.
- Develop comprehensive materials regarding HCBS.
- Develop curriculum to train local agency staff, community, and state/local government personnel.
- Fund demonstration projects that support better access and streamlined eligibility processes.
- Evaluate the feasibility of an Independence + project.
- Write and submit the proposal (upon approval of the administration).
- Examine and make recommendations regarding barriers to home and community based services and supports.

Abstract

This grant program will address the identified weaknesses or barriers of Pennsylvania's current long-term home and community based system of care through the implementation of specific strategies designed to provide the foundation for enduring and effective systems change. Specifically, involvement of individuals with disabilities, older individuals, families, and advocates will be the keystone of this program. The Home and Community Based Governance Structure will play a vital role in the overall management of the grant program, while the existing expertise of agency staff and community providers will be tapped to capitalize on available knowledge of promising practices in the implementation of home and community based services and supports. Attention will be given to improving Pennsylvania's system of access, developing better informational materials that are culturally competent, and performing a feasibility analysis of an Independence + demonstration to begin to address the existing barriers by allowing for a consumer-directed cross disability approach that is driven by need rather than diagnosis.

RHODE ISLAND

Grant Information

Name of Grantee	Department of Human Services, Center for Adult Health		
Title of Grant	Rhode Island Real Choices Systems Change Grant		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Elders, adults with disabilities, and children with special needs.

Goals

- Expand capacity to provide services.
- Increase informed choice for consumers.
- Improve the integration of health and support services.

Activities

- Develop a web-based benefits screener and resource directory.
- Develop a service tracking software application.
- Host a conference on community-based services across the long-term care continuum for all populations.
- Conduct a survey and needs assessment of consumers throughout the long-term care continuum.
- Analyze Medicare data to identify acuity patterns of individuals likely to become dually Medicare/Medicaid eligible.
- Provide behavioral specialist consultation to noninstitutional residences, and develop training modules on working with individuals' behavioral problems.
- Seek consultative services to assist in the assessment of a cohort of youth with serious emotional disturbances who transition to the community.
- Track and analyze residential and community-based systems of care.

Abstract

The principle objective of this grant is to construct the enduring system changes that will allow all Rhode Islanders meaningful choice and control about where they reside and that will help them gain access to the services they need. Rhode Island has a long history of developing new policy initiatives by bringing together various interested parties to identify relevant concerns, barriers, and roadblocks regarding health and social support services. The state, in collaboration with consumers, advocates, providers, and other representatives of the private sector, has been developing the foundation for the infrastructure that will help realize substantial improvements in health care and community support services.

Current efforts to improve care and services for persons needing long-term care in Rhode Island are shaped by three goals:

1. to expand capacity to provide services,
2. to increase informed choice for consumers, and
3. to improve the integration of health and social services.

To address these goals, we will conduct the above activities aimed at implementing long-term change and sustained improvement. Each activity addresses one or more of the project goals.

TEXAS

Grant Information

Name of Grantee	Texas Health and Human Services Commission		
Title of Grant	Texas Real Choice Grant: Creating a More Accessible System for Real Choices in Long-Term Care Services		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Heart of Texas Council of Governments
Heart of Central Texas Regional Access Group

Texoma Council of Governments
Texoma Area Information and Access Center

Target Population(s)

Consumers of all ages with disabilities, and children with disabilities and/or special health care needs.

Goals

- Develop and implement a “system navigator function” at the community level using two access models.
- Evaluate the effectiveness of the navigator function by tracking the number of persons successfully diverted from institutions or transitioned from institutions into the community and by gauging consumer satisfaction regarding accessibility of the system.

Activities

- Define the local role of system navigators.
- Implement the use of system navigators through two local access models.
- Select up to two demonstration sites in regions of the state where local access planning is actively underway and where a commitment of community collaboration to reach across all ages and population groups is clearly evident.
- Implement (local/regional) system-wide training on "family/person-directed planning."
- Provide state-level technical assistance and program coordination.

Abstract

Texas administers numerous long-term services and programs across several state agencies. Many more related support services are operated within and without the health and human services system. Over the years, the state has implemented various improvements to, and increased the capacity of, long-term services and supports, yet the system remains fragmented and difficult to access.

Thanks to strong and committed consumer participation, Texas is becoming more focused in its efforts to improve the long-term care system for persons of all ages with disabilities. While stakeholders have offered many differing opinions regarding the need for a "single point of access" versus "multiple points of access," everyone agrees that better system coordination and consumer navigation is needed.

Texas will evaluate the use of system navigators by testing two models: (1) navigators located within a "single access point"; and/or (2) navigators located across multiple, but highly coordinated access points. The target population for the Texas Project will be consumers of all ages with disabilities and children with disabilities and/or special health care needs.

Two Texas communities have been selected to implement the two models and both will work to:

- designate and place system navigators, and implement the operational features of the chosen community model;
- coordinate and integrate this model with any existing other access system or project in the community that has similar goals;
- develop and implement training for navigators and person/family-directed planners and/or other applicable staff;
- develop and implement, as appropriate, common intake, referral, assessment, and follow up protocols;
- develop and implement a valid, reliable client-tracking mechanism, and methods for gauging consumer satisfaction;
- develop methods for, and evaluate, personal and system outcomes; and
- make adjustments to system design according to evaluation results.

UTAH

Grant Information

Name of Grantee	Department of Human Services		
Title of Grant	Real Choice Grant		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

None at this time.

Target Population(s)

Children, their families, and adults of any age that have a disability or long-term illness.

Goals

- Increase public awareness and support for people needing Utah's redesigned long-term care system.
- Stimulate the development of enhanced community options to better support individuals with disabilities and/or long-term illnesses.
- Increase coordination among state agencies by establishing an intradepartmental and intra-divisional vehicle to design and foster implementation of long-term care strategies.
- Increase the capacity of informal caregivers and natural supports to provide care, which facilitates community integration and choice of residence.
- Increase opportunities for consumers to exercise their choice in long-term care community integration.
- Conduct continuous evaluation and change of the Utah long-term care system.

Activities

- Provide for a statewide long-term transactional website and 1-800 number to enable consumers, family members, friends, advocates, or providers to learn about long-term care resources, whom they are available from, and how to access them.
- Simplify and streamline the eligibility and assessment process to determine long- term care need and eligibility.
- Develop a multi-media campaign to advise the public about the role that caregivers play in assisting individuals with disabilities of long-term illness to receive support in a community setting of their choice and enable individuals to identify themselves as caregivers.
- Develop training modules that teach caregiver skills appropriate to various stages or levels of care being provided, develop a peer-counseling program for caregivers, and create a new 1-800 access point for caregivers to obtain emergency relief from their caregiver duties.

Abstract

The Real Choice Grant will re-design Utah's long-term care system to enable children, their families, and adults of any age that have a disability or long-term illness to meaningfully participate in the choice of their care, location, and residence. The Department of Human Services, Divisions of Aging and Adult Services, Services for People with Disabilities, Substance Abuse/Mental Health, as well as the Department of Health's Divisions of Healthcare Finance and Health Systems Improvement, have come together with consumer groups and other public and private partners to create a seamless long-term care service system for consumers and their families.

The Real Choice Grant awarded to Utah will address the need for long-term care user and provider information to include a 1-800 information and referral number, a transactional website that includes an eligibility wizard, a common eligibility process/assessment tool, and an information/public awareness campaign that will include training on newly developed resources. The goal is to create a no wrong door approach for the consumer. In addition, the Real Choice Grant will address the need to increase the capacity of informal caregivers through a public relations campaign, training, supports, respite, and recognition, which will facilitate community integration and choice of residence. Finally, the Real Choice Grant will assist in coordination of governmental, community and private providers to educate and encourage the participation of consumers/families on policy and advisory boards as well as attend state and national conferences on long-term care issues.

Utah is committed to ongoing evaluation in order to sustain lasting changes to the long-term care system. Outcomes will include improved and coordinated service delivery that offers the necessary tools for consumers to make informed choices about all aspects of their care.

WASHINGTON

Grant Information

Name of Grantee	Department of Social and Health Services		
Title of Grant	Community Living Initiative		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

None at this time.

Target Population(s)

Individuals with disabilities served by the Washington State Department of Social and Health Services (DSHS).

Goals

- Enhance skills needed for self-directed care and community living for individuals with disabilities, caregivers, and case management staff.
- Improve coordination of services and transition to community living by developing and implementing cross-system case management coordination models.
- Increase consumer-directed service payment options such as vouchers or cash and counseling through development of consumer assessment tools and necessary automation.

Activities

- Develop materials for education and training to teach self-directed services through locally planned and sponsored forums, including consumers and families of individuals with developmental disabilities.
- Provide a Community Living Conference for 500 consumers, families, staff, caregivers, and advocates to share information, training, and solutions to community living issues.
- Support discharge and transition processes for long-term psychiatric hospital residents who can appropriately live in community settings by coordinating services and increasing community options.
- Replicate successful models of case management coordination for individuals with multiple disabilities most at risk for institutionalization through development of criteria and evaluation tools.
- Provide consumer-directed service payment options such as vouchers or cash and counseling by developing a community-based case mix payment model as the foundation.
- Create a quality assurance, outcome measurement tool that will be integrated with the new automated assessment tool funded by DSHS.

Abstract

The Real Choice Systems Change Grant in Washington State will allow for the development of educational materials and training to enhance skills for individuals with disabilities to self-direct services. Consumers, families, providers, and others will share information developed by the grant, along with training opportunities, at a Community Living Conference for 500 in 2004. The materials from the conference will also be made available for those who cannot attend, and distributed to local agencies and providers for wider consumer access.

On a larger systems level, criteria and evaluation tools will be developed for cross-systems case management coordination models. Teams of multidisciplinary agencies in the community, along with consumers and families, will define successes and challenges with transitions to community living. This will include the coordination of multiple social and health systems to support individuals with disabilities to live in the community. Additionally, the grant will provide assistance with transition from state psychiatric hospitals and the appropriate system changes to increase community living options.

Consumer-directed services payment options, such as vouchers and cash and counseling methods, are systems changes that will result from the development of a community based case mix payment model, more accurately reflecting the care needs of individual consumers. Further, the Real Choice grant will fund the development of a quality assurance, outcome measurement tool that is vital to the development of a consumer-directed service delivery model.

WEST VIRGINIA

Grant Information

Name of Grantee	Department of Health and Human Resources		
Title of Grant	West Virginia: Real Choice!		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,313,996	***Year Original Funding Received***	2002

Contact Information

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Project website under construction.

Subcontractor(s)

WVUCED	Dr. Sherry Shuman	304-293-4692

Target Population(s)

Individuals of any age who have a disability or long-term illness.

Goals

- Empower consumers to plan, direct, and evaluate community long-term supports and services with agency, public, and private partners.
- Educate multiple audiences statewide regarding community-based living issues.
- Restructure and/or enlarge long-term support systems.
- Provide consumers the freedom to choose from a variety of options for community living.
- Improve and expand the quality of services and supports.

Activities

- Develop and maintain an ongoing Real Choice Partnership group (60 percent consumers/ advocates) with successfully working subcommittees.
- Develop trainings with consumers/advocacy groups and disseminate curriculum on community-based issues to raise awareness at multiple levels.
- Construct, advertise, and maintain a toll-free line and website, and develop a Resource Directory.
- Review and make recommendations regarding Medicaid State Plan and waivers to enhance their compatibility for fully supporting community-living.
- Within the framework of an inclusive community template, review, analyze, and recommend solutions for increasing transportation accessibility, recreational/leisure opportunities, educational supports and services, and accessing employment.
- Fund community-based mini-projects to serve as community support models.
- Utilize the Plan, Do, Study, Act (PDSA) model to monitor change effort success.

Abstract

The West Virginia Real Choice Project will attempt to create enduring improvements in community long-term support systems so that individuals of any age who have a disability or long-term illness have the choice and necessary supports to live and participate in their communities. The Real Choice grant will develop an infrastructure that helps agencies, providers and consumers make the necessary system-level changes that will support people with disabilities in the community.

The Real Choice Partnership includes consumers and advocates (60 percent), public and private service providers and Points of Contact from eight state agencies. This 28-member group meets quarterly to review the activities and recommendations of its four working committees. These committees include: Policy; Practice; Services; and Legislative Affairs. Real Choice Partnership members may serve on one or more committees. Consumer members are also recruited for each committee.

The Real Choice staff will convene meetings, collect data or resources for committee work, and produce reports and recommendation summaries. An Oversight Commission serves as the monitoring body for Project activity, partnership recommendations, and ongoing modifications in the Real Choice plan of action. It develops and executes an agenda to gain the buy-in of policymakers for enduring systems change.

A one-stop toll-free electronic information resource that builds knowledge for providers and empowers consumers will be created. Project staff will develop a curriculum and provide consumer-led training that prepares stakeholders for the new self-determination disability paradigm. Consumers will receive self-determination training that assists them in being informed participants in committee work, policy, and practice-development and in legislative impact.

Several community-based mini-projects will be funded as subcontracts of the project to demonstrate transportation, recreation/leisure, and peer service models that can later be presented as successful methods of providing community supports.

WISCONSIN

Grant Information

Name of Grantee	Department of Health Family Services, Division of Supportive Living		
Title of Grant	Real Choices for Real Life		
Type of Grant	Real Choice Systems Change		
Amount of Grant	$1,385,000	***Year Original Funding Received***	2002

Contact Information

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Subcontractor(s)

Deloitte Consulting, Divya Nidhi, 608-283-3030—software development for Children's Long Term Care Functional Screen.

Northern Area Agency on Aging, Richard Sicchio, 715-365-2525—conducted focus groups and surveys regarding the factors that influence elder decision-making regarding long-term care.

ARC Wisconsin—operates Guardian Mentor program.

Target Population(s)

- Elders—for elder consumer choice components.
- Persons with developmental disabilities in state institutions—guardian mentors.
- Persons with mental illness who have long-term care needs—clarifying needs of long-term care consumers with mental illness.
- Children with disabilities and their families—development of Children's Long-Term Care Functional Screen.
- Persons from any disability groups who have long-term care needs—consumer-directed personal care, workforce activities.

Goals

- Ensure that, to the extent possible, long-term care funding follows the person.
- Identify and fund ways to enhance the aspects of consumer choice that are important to elderly consumers.
- Make existing Medicaid home care benefits more flexible and responsive to consumer choice.

- Improve ability to meet the needs of consumers of long-term care who have a mental illness.
- Assist guardians of persons with developmental disabilities to fully understand choices and opportunities available in noninstitutional settings.
- Develop and maintain a workforce that is competent and committed to meeting the needs of consumers and their families in the long-term care system.

Activities

- Examine and revise, as possible, administrative and statutory barriers to allowing long-term care funds to follow the person based on individual choices and preferences.
- Conduct forums to identify elder preferences and provide funds and technical assistance to counties to better meet the needs and preferences of elder consumers.
- Contract with a software developer to adapt the existing adult automated functional screening tool for use with children and for other purposes as found feasible.
- Develop a consumer-directed personal care option—initially as part of home and community based waivers and ultimately under the State Plan.
- Define long-term care needs of consumers with mental illness and develop methods to better meet those needs (e.g., a potential 1915 (c) waiver).
- Employ guardian mentors at state centers for persons with developmental disabilities to help address concerns of guardians and overcome their reluctance to consider community placements for their wards.
- Fund training and technical assistance activities related to workforce recruitment and retention.

Abstract

In 1997, Wisconsin engaged in a comprehensive planning process to redesign its long-term care system. The broad objectives established for this redesign are to

- increase consumer choice and access to services in a comprehensive, flexible and cost-effective long-term care system for the future; and
- enhance the value of the system by improving long-term care quality through a focus on health and social outcomes.

To achieve these objectives, Wisconsin is piloting a managed care pilot project called Family Care for persons with physical and developmental disabilities and frail elders. Parallel redesigns are underway for children and persons with serious mental illness. While these broader reforms are being piloted, Wisconsin intends to proceed incrementally toward the goals of redesign. The state will use grant funds to develop some of the building blocks needed to enhance its strong foundation of comprehensive, care managed community-based services for people who are frail elderly or adults and children with lifelong disabilities.

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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Family Caregiver Alliance
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Target Population(s)

Caregivers of individuals with adult-onset cognitive impairment.

Goals

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.

Activities

- Establish an Advisory Committee comprising representatives of key government agencies, consumers, provider and academic entitities, 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

Contact Information

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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.

Goals

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.

Activities

- 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 (NYS) 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

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Subcontractor(s)

To be determined by an RFP process during first year of grant.

Target Population(s)

Caregivers of in-home care recipients.

Goals

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.

Activities

- 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 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

Contact Information

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Subcontractor(s)

Yet to be determined.

Target Population(s)

Working age adults and elderly persons with disabilities.

Goals

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.

Activities

- 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

Rhode Island currently has six 1915(c) Home and Community Based Waivers for elderly persons and younger adults with disabilities, only one of which includes respite services. The purpose of this project is to enable DHS 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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Yulanda Tyree, Project Coordinator RSA Union Building 100 N. Union Street PO Box 301410 Montgomery, AL 36130-1410	334-240-8437	*not yet available*

Subcontractor(s)

Alabama Family Ties
Censeo Research, Inc.

Target Population(s)

Caregivers of children 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 caregivers of children with serious emotional disturbance.

Activities

- 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 stand-alone, 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 caregivers 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 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

Contact Information

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Subcontractor(s)

University of Arkansas Center of Excellence on Developmental Disabilities, Partners for Inclusive Communities

Target Population(s)

Caregivers of children with special health care needs.

Goals

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

Activities

- 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.

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.

Activities

- 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 multi-agency 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.

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 and/or serious emotional disturbance.

Goals

The goal of this study is to position the state of Michigan to provide respite as a Medicaid-covered mental health service.

Activities

- 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 developmental disabilities (DD) as a specific population, and collect data on family and child satisfaction with respite services and caregiver well-being.
- 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 (MSHCF), 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 position the state of Michigan to provide respite as a Medicaid-covered mental heath service. 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 covered 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 Partnership Panel on Respite will be expanded to 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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Subcontractor(s)

To be identified.

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.

Activities

- 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

Contact Information

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Subcontractor(s)

None at this time.

Target Population(s)

Children with special health care needs and their families.

Goals

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.

Activities

- 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 assuring 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

Contact Information

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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 and their families.

Goals

The State of Illinois, Department of Human Services, Division of Mental Health provides residential treatment services to children and adolescents with serious emotional disturbance through the Individual Care Grant (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.

Activities

- Develop a set of recommendations for the Individual Care Grant (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 serious emotional disturbance (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

Contact Information

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Subcontractor(s)

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.

Goals

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

Activities

- 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 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 psychiatric residential treatment facility (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 CMHS 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

Contact Information

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Subcontractor(s)

Yet to be awarded.

Target Population(s)

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

Goals

- 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.

Activities

- 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 workgroups 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

Contact Information

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Project Director

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Subcontractor(s)

To be determined by an RFP process in first month of the grant.

Target Population(s)

Children with serious emotional disturbance (SED).

Goals

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.

Activities

- 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 10-year demonstration grant proposed in the President's FY2004 budget to operate an HCBS waiver for children with serious emotional disturbances.

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

Contact Information

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Subcontractor(s)

Alicia Smith and Associates

Target Population(s)

Families of children with serious emotional disturbance (SED).

Goals

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.

Activities

- 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.

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)

To be identified through an RFP process.

Target Population(s)

Children with serious emotional disturbances (SED).

Goals

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.

Activities

- 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

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Subcontractor(s)

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Consultants to be hired.

Target Population(s)

Individuals with developmental disabilities.

Goals

- Design a model and corresponding plans to implement a Quality Services Network 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.

Activities

- Design the necessary structures and processes, and identify the needed resources and supports that will be required to implement a Quality Services Network 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 *Quality Services Network* 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 network 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 network operations. Focus areas of the implementation plans include (1) a system for providing training and technical assistance to providers to achieve higher levels of quality in their services and supports, (2) a process for expanding the available network of generic resources and service providers, (3) a network to support consumers' and family members' involvement in decision-making, and (4) identification of the resources and supports needed to support the operations of the *Quality Services Network*.

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-advocate and family advocacy groups.

Abstract

Colorado has a complex decentralilzed 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 multi-tiered, 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 information technology 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 information technology (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, web-based platform to receive it.

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 information technology. 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 Grantee	Connecticut Department of Mental Retardation		
Title of Grant	Connecticut 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

Contact Information

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Subcontractor(s)

Project consultants to be decided.

Target Population(s)

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

Goals

- Develop the capacity to input, store, analyze, and report quality indicators from the department's new quality review system.
- Assure 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.

Activities

- 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.
- 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 back-up staff arrangements.

Abstract

The Connecticut Department of Mental Retardation (DMR) is using Real Choices 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, training 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 fairly compare provider performance 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 Waiver services and self-directed 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

Contact Information

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Subcontractor(s)

Two primary project consultants to be decided.

Target Population(s)

Consumers with developmental disabilities.

Goals

- Assess current quality management functions for waiver and non-waiver home and community based services (HCBS), including strengths and weaknesses, desired outcomes, gaps across the HCBS Quality Framework, and consumer satisfaction and quality indicators.
- Develop a strategic plan based on assessment findings that outlines specific objectives to formulate the Division's QA/QI system program consistent with the 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.

Activities

- Assess status of policies, practices, and documentation/data by collecting data through the National Core Indicators Project (ongoing) and Consumer Experience Survey (MR/DD version).
- 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 Consumer Experience Survey and National Core Indicators Project Survey.
- Establish and/or revise QA/QI management monitoring functions for gathering real time information/data on outcomes and client satisfaction/outcomes areas.
- Develop QA/QI data management computer systems and interfacing databases to identify problems in risk management/indicator data plus service provider performance measures.
- 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 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 based services.

Abstract

Building on the Division of Developmental Disabilities Services (DDDS) participation in the National Core Indicators Project and in the Re-inventing Quality Conferences, a 3-year plan for developing a consumer-centered QA/QI system for home and community based services (HCBS) has been developed. A Consumer/Stakeholder Task Force will be formed to direct the project, which uses the HCBS Quality Framework (National Quality Inventory Project) and the Consumer Experiences Survey (MR/DD version) to structure the changes to the Division's QA/QI System.

The project has three phases: (1) assess quality management functions in the current QA/QI HCBS System; (2) develop a QA/QI HCBS "strategic plan" around the HCBS Quality Framework focus areas and desired outcomes; and (3) 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

Contact Information

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Subcontractor(s)

Connie Lyle O'Brien 770-987-9785 connielyleobrien@mac.com

A consultant who specializes in developmental disabilities (DD) performance measurement and quality improvement systems (to be named.)

A consultant to help create an interim system to collect, store, and disseminate DD performance, quality, and outcome information (to be named).

Target Population(s)

Persons with mental retardation and other developmental disabilities.

Goals

- Promote greater statewide understanding and provision of person-centered practices.
- Design enhanced consumer outcomes that are objective and person centered to complement the NCI survey.
- Establish an efficient and comprehensive, real-time data system that produces easily accessible information and reports.
- Bring meaningful consumer and family participation into the quality improvement (QI) program.

Activities

- Conduct two pilot programs (for 20 to 40 consumers) of active learning training and supports to create and implement a Person-Centered Plan (PCP) and provide follow-up support.
- Design enhanced consumer outcome measures that are objective and person centered.
- Link existing data systems to provide ease of data entry and accessibility of comprehensive provider and consumer information.
- Recruit and facilitate the participation of consumers and family advocates in QI committees and work groups.

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 waiver programs based in DMHDDAD currently serve persons with mental retardation and other developmental disabilities (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 test methods for implementing these principles and provide a provider guide.

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

The state currently uses the Schalock Quality of Life Questionnaire (QOL-Q) and an internally developed individual and family survey to measure the quality of services provided to persons with MR/DD. However, many stakeholders believe that the Schalock QOL-Q may not accurately reflect the degree to which programs promote quality of life for all the people served. This project will enable Georgia to move to a system that measures quality by the achievement of personal outcomes that are important to the individual.

Georgia has long garnered and appreciated the input and participation of individuals served by MHDAD and their families, but has not had a mechanism with which to involve them in the QI process. Through this project, Georgia will promote their ongoing participation, in quality committees and performance improvement teams.

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

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Individuals receiving services funded by the Aged and Disabled Waiver, the Medically Fragile Children's Waiver, the Traumatic Brain Injury Waiver, and the Assisted Living Waiver administered by the Bureau of Aging and In-Home Services.

Goals

- 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.

Activities

- 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 back-up 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, Aging and Rehabilitative Services (DDARS)/Bureau of Aging and In-Home Services (BAIHS) supports 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 quality assurance and quality improvement systems for all programs within the DDARS.

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 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)

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Dennis Tan, TANerprise, Inc.

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.

Goals

- Create and formalize interdepartmental 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 home and community based services 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.

Activities

- 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

The Maine Department of Human Services, as lead agency and applicant, the Maine Department of Labor, and the Maine Department of Behavioral and Developmental Services 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 Workgroup 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.[1] The Work Group for Community Based Living is Maine's Olmstead planning group comprised of consumers and state officials.

The project will move efforts to improve quality from a project or program level to a collaborative interagency commitment to assure the health and welfare of individuals who participate in HCBS waiver and related programs.

[1]Maine'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

Contact Information

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Subcontractor(s)

Four to be awarded.

Target Population(s)

Home and Community Based Services Waiver participants.

Goals

- Enhance participant safeguards and support in exercising rights and preferences.
- Support achievement of participant outcomes and participant-centered planning for, and satisfaction with, home and community based services (HCBS).

Activities

- 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 consumer's 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 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 HCBS 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 assure 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

Contact Information

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Project Director to be appointed.

Subcontractor(s)

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

Target Population(s)

Participants in all the state's home and community based services waiver programs.

Goals

- 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 home and community based services (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.

Activities

- Develop interagency protocols and a framework for reporting quality of services.
- Develop a formal client survey to assess the needs and concerns of in-home service participants.
- Evaluate current systems, including common and agency-specific issues.
- Develop training for providers and case managers specific to issues identified.
- Develop a web-based, interagency database 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 HCBS waiver services 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 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 project will also develop a formal client survey 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, the end result being to expedite complaints to ensure that client health and welfare are protected. The solicitation of input from program participants will be an integral part of the project.

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

Contact Information

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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.

Goals

- 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 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.

Activities

- 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 Long-Term Home Health Care Program (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 assure 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 Long-Term Home Health Care Program (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 system-wide 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 Long-Term Home Health Care Program. 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

Contact Information

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Subcontractor(s)

Yet to be awarded.

Target Population(s)

Individuals in psychiatric institutions, intermediate care facilities for 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, intermediate care facilities for people with mental retardation, 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 and/or enhance tools, protocols, and systems for collecting and managing data to identify problems and successes in structures, processes, and consumer outcomes for the transitioning populations.
- 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.
- Conduct follow-up interviews with members of the transitioning populations using trained consumers and family members to address problems in the process.
- 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, intermediate care facilities for people with mental retardation, 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):

1. 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 ICFs/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

Contact Information

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Subcontractor(s)

To be determined by an RFP process.

Target Population(s)

Individuals with mental retardation and other developmental disabilities.

Goals

- Promote increased efficiency and improved effectiveness of supports for individuals with mental retardation and other developmental disabilities (MR/DD) by identifying current available resources and targeted needs for improvements, and partnering with individuals and agencies to determine needed system improvements.
- 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 about the needs of individuals and support agencies.

Activities

- Evaluate Ohio's current quality assurance and quality improvement (QA/QI) system and determine the personal and systems outcome measures that must be reinforced to align with CMS' Quality Framework.
- Research and develop a new QA/QI framework and design a training curriculum to initiate the new framework in five demonstration counties and test to determine whether it should be replicated.
- Pilot a new Quality Assurance framework to individuals and families in five demonstration counties.
- Assess and update current business processes relative to services provided by the Ohio Department of Mental Retardation and Developmental Disabilities ODMR/DD to individuals and support agencies.
- Achieve a multidimensional system of reporting information and discoveries regarding individuals served that are ascertained through available data and compliance reviews to improve services from local service providers.
- Research and conduct a cost analysis of computer hardware and software capable of assimilating, organizing, and analyzing available information and purchase, install, and test hardware, software, and new and updated processes.
- Train staff and evaluate and update the effectiveness and relevancy of reporting information and discovery processes.

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 board's and private provider's compliance with federal/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 MR/DD. 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 analysis; 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

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Subcontractor(s)

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

Target Population(s)

Persons of all ages with disabilities.

Goals

- Develop a systemwide 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 assures continuity and ongoing improvement of the systems/practices initiated.

Activities

- Develop and support a process for consumers and stakeholders provide input to and oversight of the project.
- Develop critical tools and implementation procedures for assuring 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, Seniors and People with Disabilities (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 assure 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 assure 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 Grantee	Department of Public Welfare		
Title of Grant	Pennsylvania'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 HCBS waivers.

Goals

- 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.

Activities

- Develop an intake form for developing a personalized service plan across all disability groups, and train staff on how to use 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 quality management data system across Aging and Welfare Departments.
- Develop a back-up system for providing services.
- Phase in and pilot-test the QM systems developed and expand the system statewide.

Abstract

Pennsylvania is committed to assuring 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 assure 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 QA/QI Grant project, which will execute specific tasks to improve the quality management 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 back-up 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 assure 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 assure that grant goals are achieved.

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

Contact Information

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Project Director to be decided.

Subcontractor(s)

To be determined by an RFP process.

Target Population(s)

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

Goals

- 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.

Activities

- 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 assure 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, the South Carolina Department of Disabilities and Special Needs (SCDDSN) has developed a sophisticated, multi-tiered, coordinated quality assurance/quality improvement 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 peer review organization (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

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Subcontractor(s)

To be determined by an RFP process.

Target Population(s)

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

Goals

- Create a Quality Assurance/Quality Improvement (QA/QI) system that will result in timely remediation and system-wide 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 non-urgent 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.

Activities

- 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 non-urgent 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 quality assurance and quality improvement (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 quality assurance/quality improvement 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 system-wide 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 2316 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 non-urgent needs for remediation within the state's QA/QI system.
- The design and implementation of a sustainability plan.

TEXAS

Grant Information

Name of Grantee	Texas Department of Mental Health and Mental Retardation		
Title of Grant	Texas 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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Long Term Services and Supports
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Subcontractor(s)

Project consultant to be decided.

Target Population(s)

Persons with mental retardation served in the Texas Department of Mental Health and Mental Retardation Medicaid waiver programs.

Goals

- Develop cost-effective methods to measure individual participant experiences in the Texas Department of Mental Health and Mental Retardation (TDMHMR) waiver programs.
- Develop an automated, critical incident reporting process that will capture information identified by the QA/QI Task Force as needed to ensure the health and welfare of waiver participants.
- Develop a centralized, information-gathering system for compiling newly collected data and currently collected data, which will be accessible to stakeholders (e.g., waiver participants and family members of waiver participants, advocates), program providers, and TDMHMR staff.
- Conduct statewide training to implement the new system.

Activities

- Establish a task force to assist the Texas Department of Mental Health and Mental Retardation (TDMHMR) with the development and implementation of the QA/QI project.
- Research existing tools and processes to (1) determine the best process for gathering critical incident information currently not reported to TDMHMR on a consistent basis, and (2) help develop cost-effective methods to measure individual participant experiences in TDMHMR waiver programs.
- Hire a consultant to work with the Task Force on reporting formats and other design features.
- Develop training curriculum and materials, and conduct training in nine state regions.

Abstract

The project will redesign and improve the state's information-gathering system to integrate TDMHMR's existing waiver quality assurance and quality improvement reporting mechanisms into a comprehensive data collection system. This system will ensure that TDMHMR's methodology to measure the quality of services assures an accountable use of public resources and a balance between personal outcomes and flexible supports and regulatory requirements to improve the quality of the TDMHMR waiver programs.

The project will establish a Quality Assurance/Quality Improvement Task Force that will include waiver participants, participants' family members, advocacy groups, waiver program providers, local authorities, and other stakeholders. The project's goals are

- Develop cost-effective method(s) or tool(s) by which to measure individual participant experiences in TDMHMR waiver programs. Outcome measures will include achievement of participants' goals and aspirations.
- Develop an automated, critical incident reporting process to capture information that will include, but will not be limited to, restraint use, medication errors, and serious injuries.
- Develop a centralized information-gathering system for compiling newly collected data (e.g., participant experiences, critical incidents) and currently collected data (e.g., data collected through Survey & Certification reviews of waiver program providers conducted by TDMHMR). Make system reports accessible to stakeholders, program providers, and TDMHMR staff.
- Conduct statewide training to implement use of the new critical incident reporting process, the participant experience measurement tool, and the new information gathering system.

The integrated information-gathering system will give TDMHMR and stakeholders enhanced data and the tools needed to evaluate and improve individual components of the waiver system, and the waiver service system as a whole. The integrated information-gathering system will provide a foundation on which TDMHMR can continue to build a comprehensive quality assurance and quality improvement system into its waiver programs. The system will provide an opportunity for TDMHMR and stakeholders to build a data collection, analysis, and reporting mechanism that will enable TDMHMR to continually monitor and improve its Medicaid waiver services to the greatest extent possible.

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

Contact Information

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Subcontractor(s)

Marcus Canaday, Program Manager Center for Excellence in Disabilities West Virginia University	304-293-4692

Target Population(s)

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

Goals

- Develop, implement, and support a quality assurance process and improvement infrastructure in the design of home and community based services (HCBS).
- 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 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.

Activities

- 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 mental retardation and developmental disabilities (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 assure the health, welfare, and dignity of individuals participating in HCBS waiver services, 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 (BMS), 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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Quality and Research Manager
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Madison, WI 53707

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.

Goals

- Improve local HCB programs' QA/QI 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 HCB programs' care management.
- Review and revise the state's HCB programs' QA/QI systems to enable, support, and empower more effective local HCB QA/QI systems.

Activities

- Develop model standards for a basic local QA/QI 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 QA/QI systems for HCB programs.

Abstract

The primary objective of this project is to improve local waiver agencies' QA/QI programs, consistent with the CMS *HCBS Quality Framework*. The project will also improve the state's own HCBS QA/QI program and its ability to enable, support, and empower more effective local QA/QI programs. The Department wants to create sustainable improvements in state and local QA/QI 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 QA/QI standards, guidelines, and benchmarks, and more effective training and technical assistance materials that are consumer-outcome oriented. A consulting firm with expertise in quality issues 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 QA/QI 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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William West, Project Director	303-866-2735	william.west@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, a technology consultant, and consumer trainers.

Target Population(s)

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

Goals

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

Activities

- Identify the state's current capacity for statewide emergency back-up and critical incident management within community-based, long-term care programs.
- Develop and implement improved critical incident and emergency back-up systems for the state's consumer-directed programs.
- Develop and implement a training program for consumers and other stakeholders on the use of critical incident management and emergency back-up systems.

Abstract

The Colorado Department of 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 back-up 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 back-up 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 back-up 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 back-up 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

Contact Information

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Subcontractor(s)

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Interim Director
Braceland Center for Mental Health and Aging
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Hartford, CT 06106

Target Population(s)

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

Goals

- 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.

Activities

- Conduct meetings, informational sessions, and presentations for the grant's Steering Committee.
- Produce 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

Connecticut Department of Mental Retardation (DMR) is engaged in discussions with the Single State Medicaid Agency, Department of Social Services, to develop and submit a second HCBS MR waiver using the Independence Plus template.

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 MR waiver. Data gained from individuals using an Individual Support Agreement option are being gathered to prepare focus group meetings and 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 assure 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.

This grant project will support this effort. 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 (1) amend the existing waiver to clearly identify individuals in Connecticut who, if eligible, would be best supported under the current 1915(c) waiver and (2) delineate in the Independence Plus Initiative waiver a methodology to calculate individual budgets for waiver participants.

Grant products will include a database, an algorithm model, a training manual, an individual budget template, strategic plans and budget forecasts, policies and procedures, and a completed waiver application.

FLORIDA

Grant Information

Name of Grantee	Florida Department of Children and Families		
Title of Grant	Florida Freedom Initiative		
Type of Grant	Independence Plus Initiative		
Amount of Grant	$501,801	***Year Original Funding Received***	2003

Contact Information

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Subcontractor(s)

Center for Self-Determination

Target Population

Individuals with developmental disabilities who are enrolled in Florida's Consumer-Directed Care Plus (CDC+) Program, self-advocates, and their families.

Goals

- 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 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.

Activities

- Identify and convene stakeholders to assist in the development of the waiver application.
- Develop and submit waiver application.
- Educate developmental disability districts, support 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.
- Implement train the trainer sessions.
- Establish a working committee in each district that will be responsible for developing the district-wide plan to implement self-determination.
- Create/modify training and technical assistance to emphasize new aspects of broad waiver authority.
- Create training materials for a core group of support brokers to act as personal agents for individuals with developmental disabilities.

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 3,350 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 allow individuals with developmental disabilities to work and explore typical housing opportunities while maintaining their SSI/SSDI eligibility until resources increase over current allowable levels.

The grant will also be used to fund an initiative to train self-advocates to work with the 1115 waiver program. This training initiative will incorporate the principle of self-determination. If the SSI waiver is obtained, the training will be expanded to develop and implement a comprehensive training and technical assistance effort related to the new income and asset limits, including a train-the-trainer initiative for individuals with disabilities and family members.

This project is a cooperative effort of the Florida Department of Children and Families' Developmental Disabilities Program, 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 Grantee	Georgia Department of Human Resources		
Title of Grant	The Georgia Independence Plus Initiative		
Type of Grant	Independence Plus Initiative		
Amount of Grant	$432,108	***Year Original Funding Received***	2003

Contact Information

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Division of Mental Health, Developmental Disabilities and Addictive Disease
Office of Developmental Disabilities
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Subcontractor(s)

To be named later.

Target Population(s)

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

Goals

- Develop a uniform methodology for calculating all individual budgets in the state.
- Adapt the HCBS waiver program quality assurance/quality improvement (QA/QI) system to assure 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.

Activities

- 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 back-up 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 services. Current HCBS services, 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 back-up 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 Grant	Idaho Independence Plus		
Type of Grant	Independence Plus Initiative		
Amount of Grant	$499,643	***Year Original Funding Received***	2003

Contact Information

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Subcontractor(s)

Marilyn Sword, Executive Director Idaho Council on Developmental Disabilities 802 W Bannock, Suite 308 Boise, ID 83702	208-334-2178	msword@icdd.state.id.us

Target Population(s)

Individuals with developmental disabilities.

Goals

- 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.

Activities

- 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 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 supports 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 an emergency back-up system 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 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 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 services, isolation will be addressed with a team of family, friends, and others to assist and support the person in developing a plan that better 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 appropriate provider infrastructure to support self-directed care, (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

Contact Information

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Subcontractor(s)

Center for Outcome Analysis

Target Population(s)

All individuals with cognitive and physical disabilities.

Goals

- Create a long-term care waiver system based on the principles of self-direction.
- Create an individualized back-up system for three waiver programs: Independence Plus, Elderly and Disabled Adults, and Children's Choice.
- Expand opportunities for waiver participants to earn income, own businesses, and increase participation in their cost of care.
- Expand the current Independence Plus Waiver (NOW) evaluation process to include participants from the Children's Choice Waiver and the Elderly and Disabled Adult Waiver by annually interviewing 200 waiver participants during the 3-year grant period.

Activities

- Create an Independence Plus Advisory Committee (IPAC) whose primary responsibility will be to oversee the project and guide the systems change process.
- Analyze policies and procedures manuals and fiscal procedures for the three targeted waiver programs, and recommend revisions to language to incorporate the philosophy of self-determination.
- Train agency staff and stakeholders on principles of self-determination.
- Identify best practices regarding back-up systems and modify the state's back-up system for all targeted waivers. Conduct training on the use of the revised back-up support systems.
- Recruit providers willing to offer back-up support to waiver recipients who have chosen self-direction and/or are using a fiscal agent.
- 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 27 waiver participants from the three targeted waivers 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, 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 state will revise the system based on empirical data collected and analyzed under the supervision of the Center for Outcome Analysis. The BCSS intends to develop a back-up system, expand opportunities for any interested waiver recipient to earn income by owning a micro-enterprise business (thereby generating personal income), and make data-driven decisions based on objective analysis of data collected by the Center for Outcome Analysis.

The current Independence Plus waiver (NOW) will also be the catalyst for change in the Children's Choice and Elderly and Disabled Adult waivers. BCSS will create an Independence Plus Advisory Committee (IPAC) to oversee this initiative. At least 51 percent of the IPAC members will be HCBS waiver participants or family members.

MAINE

Grant Information

Name of Grantee	Department of Behavioral and Developmental Services (BDS)		
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

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.

Goals

- 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.

Activities

- 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 Behavioral and Developmental Services (BDS) 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.

MASSACHUSSETTS

Grant Information

Name of Grantee	University of Massachusetts Medical School		
Title of Grant	Massachusetts 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)

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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.

Goals

- Build upon the current self-directed program infrastructure to prepare for an Independence Plus waiver.
- 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 no later than the third year of the grant.

Activities

- 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.
- Ensure a peer-support component is available to program participants that is designed to meet the needs of different populations.
- 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.
- Increase the knowledge of housing and disability service providers, developers, and advocates regarding the housing needs of and opportunities for people with disabilities.
- 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 representatives if appropriate) 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, (4) peer mentoring, (5) participant protections with a participant-driven continuous quality improvement system, and (6) education on housing issues. 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

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Target Population(s)

Current or potential participants in state Community Mental Health Services Programs, including adults with mental illness, children with mental illness or emotional disturbance, and persons with developmental disability.

Goals

- To refine the implementation methods associated with Michigan's policy direction for self-determination in the Michigan prepaid specialty Medicaid mental health and developmental disabilities services system.
- Implement self-determination in the MI Choice home and community based services (HCSB) waiver system, including the capacity to apply individual budgets to person-centered planning (PCP).

- Implement a Section 1115 waiver to afford a limited number of beneficiaries the option of receiving a cash allotment in lieu of formal Medicaid support services.

Activities

- Determine best practices for self-determination activities used by Community Mental Health Services Programs (CMHSPs).
- Prepare and disseminate person-centered planning training materials for consumers and providers.
- Develop and implement protocols for the consumer and waiver agent to use with the PCP MI Choice HCBS waiver system.
- Develop a Section 1115 waiver to provide flexibility in PCP and self-determination for various personal assistance services and supports (PASS) 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 system-wide, 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, and consumer-controlled options to the MI Choice HCBS waiver system and building 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 Section 1115 Independence Plus Initiative waiver arrangement, 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 project 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 person-centered planning and consumer-directed care; (3) the development of options for emergency back-up 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

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.

Goals

- 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 the pilot of the Missouri consumer-directed support program.
- Assure a Missouri self-direction system through continuance of successful, fiscally neutral activities and obtaining additional funding.

Activities

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

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 gate-keeping 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 back-up 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 well 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, an Independence Plus Initiative waiver application will also be submitted.

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

Contact Information

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Grant Coordinator to be decided.

Subcontractor(s)

Mountain Pacific Quality Health Foundation
Summit Independent Living Center
Montana Center on Disabilities, Montana State University—Billings

Target Population(s)

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

Goals

- Develop a cash and counseling model.
- Implement and evaluate a cash and counseling pilot program.

Activities

- Research best practices of cash and counseling models.
- Conduct forums and focus groups, and administer consumer surveys to inform the research.
- Complete and submit an 1115 Waiver application and prepare a 1915(c) amendment to facilitate a cash and counseling program.
- Develop selection criteria for cash and counseling participants.
- Determine process 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 back-up system and an incident management protocol.
- Enhance the Job Service employer/employee job registry website. Develop a plan to facilitate caregiver background checks.
- Conduct and evaluate a pilot of the cash and counseling program at two sites, including an Indian Nation.

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 a cash and counseling option for self-directed personal assistance services through the state plan and the home and community based services waiver program for elderly and disabled persons. The third will be achieved through implementation of an emergency back-up 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 groups 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 the Native American Coordinator at the Montana Center on Disabilities, Montana State University, 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 back-up 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

Contact Information

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Subcontractor(s)

Evaluation consultant to be decided.

Target Population(s)

Individuals with Mental Retardation and other Developmental Disabilities (MR/DD).

Goals

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

Activities

- Identify barriers to implementing an Independence Plus Initiative 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 Self-Determination waiver application and submit it to CMS for approval as an Independence Plus Initiative 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 family's current information to help them maintain current skills and gain new skills needed for participation in the Self-Determination waiver.
- Produce routine reports of formative learning and develop tools and a strategy for obtaining baseline data of individuals prior to enrollment on the Self-Determination waiver.

Abstract

The overall goal of the grant is to obtain approval of an Independence Plus HCBS waiver, titled "Self-Determination," 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 Independence Plus Initiative template for the Self-Determination 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 position authority to eliminate barriers and establish the infrastructure needed to support implementation of the waiver.

Each demonstration county will use their experience from previous local and state self-determination efforts to identify, for each individual receiving Self-Determination waiver services, (1) barriers that must be reduced or eliminated and (2) 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 Self-Determination waiver in the demonstration counties, an independent evaluation will be conducted of: (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

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Subcontractor(s)

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

Target Population(s)

Adult Medicaid-eligible nursing facility residents.

Goals

- Develop standardized protocols and processes for transitioning nursing facility (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 based settings.

Activities

- 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? 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.

Goals

- 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.

Activities

- 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 (a) examine the political and fiscal feasibility of increasing living resources, and (b) 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 Behavioral and Developmental 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

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Target Population(s)

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

Goals

- 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 cross-system performance measures that enable Maine to comprehensively and coherently assess its success at achieving a balance of services across systems.

Activities

- Adapt a standardized individual assessment and budget tool to meet Maine's needs.
- Develop a published rate structure, rebalanced to enhance community integration goals.
- 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.
- Identify and define key terms related to rebalancing and community integration, and identify performance measures for evaluating the state's success at rebalancing.

Abstract

With this grant project, the Maine Department of Behavioral and Developmental Services (BDS), with the Maine Department of Human Services (DHS) as an active partner, 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, BDS 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. DHS will (1) analyze and test the feasibility of offering cost-effective community options that redirect funding for individuals with brain injury to more integrated settings and (2) develop strategies for stimulating new community service options to support such individuals.

The two departments will work with Maine's Work Group for Community-Based Living to identify cross-system 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

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Subcontractor(s)

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Target Population(s)

Individuals with disabilities and long-term illnesses.

Goals

- Give consumers and families a central role in defining and implementing the systems changes necessary to realize the principle that 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.
- Develop alternatives to traditional models for nursing home care.

Activities

- 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 development of community support.
- Establish and implement the model at three pilot sites.

Abstract

Michigan's LTC programs do not have a single point of entry or source of comprehensive information about LTC options, an integrated continuum of services, or integrated funding sources. Michigan's LTC programs also have different eligibility criteria, which interfere with movement between programs.

This project will develop and implement system 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 includes 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 three local pilot sites, the project will develop an integrated model for LTC services, including nursing facility and home and community services. The project will also establish integrated, capitated pilot sites 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 LTC Roundtable, modifications to waiver programs, policy changes at the state level, and 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

Contact Information

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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.

Goals

- 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.

Activities

- 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 assure 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	Department of Public Welfare		
Title of Grant	Money Follows the Person Rebalancing Initiative		
Type of Grant	Money Follows the Person Rebalancing Initiative		
Amount of Grant	$698,211	***Year Original Funding Received***	2003

Contact Information

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Subcontractor(s)

Project consultant to be decided.

Target Population(s)

Persons with disabilities currently in a nursing home, intermediate care facility for the mentally retarded (ICF/MR), 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.

Goals

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

Activities

- Create a statewide MFP Planning Group to develop a feasibility analysis and design the MFP demonstrations.
- 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 Money Follows the Person (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 multi-county.

Projects will begin at the beginning of the second 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 Human 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

Contact Information

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Community Care Provider Services
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Austin, TX 78714

Subcontractor(s)

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

Target Population(s)

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

Goals

- 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 workgroups to help individuals transition from nursing facilities to the community.

Activities

- 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 clients, Centers for Independent Living staff, consumer advocates, and other stakeholders about all community care options.
- Evaluate training efforts and determine the need for follow-up training.
- Establish workgroups and educate members about transition problems, community programs and services for people transitioning, service coordination, and other activities needed to enable successful transitions.
- Workgroups will develop transition plans for individuals using a client-centered approach to assure that client needs are addressed.
- Workgroups, which will include the client's individual case manager, will identify and secure resources needed for transitions and conduct a monthly client-directed assessment/ evaluation to ensure that progress is made toward addressing client needs and resolving client problems.

Abstract

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

The DHS San Antonio Region has established a voluntary workgroup 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 workgroup looks at individual needs, establishes transition plans based upon those needs, offers technical assistance to group members and clients, secures resources, and transitions individuals to the community.

A first step in replicating this model throughout the state is to educate DHS staff, consumers, advocates, and other stakeholders about the range of community care options available through DHS. 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 workgroups in the other 10 regions of the state.

Measurable outcomes include increased knowledge of community long-term care options available thorough DHS, community care coordination workgroups 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 Grant	Money Follows the Person Rebalancing Initiative		
Type of Grant	Money Follows the Person Rebalancing Initiative		
Amount of Grant	$608,008	***Year Original Funding Received***	2003

Contact Information

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Subcontractor(s)

Three project consultants to be identified.

Target Population(s)

Adults and children with developmental disabilities.

Goals

- 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.

Activities

- 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 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 the Comprehensive Assessment Reporting Evaluation (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 least restrictive 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 will 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.

WISCONSIN

Grant Information

Name of Grantee	Department of Health and Family Services		
Title of Grant	Wisconsin's Money Follows the Person Initiative		
Type of Grant	Money Follows the Person Rebalancing Initiative		
Amount of Grant	$743,813	***Year Original Funding Received***	2003

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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.

Goals

- 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.

Activities

- 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

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 Original Funding Received***	2003

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Subcontractor(s)

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Target Population(s)

Medicaid-eligible persons with physical and developmental disabilities.

Goals

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

Activities

- Plan and implement a Human Services Cooperative.
- Plan and implement a Human Services Cooperative targeted to the Spanish-speaking community.
- Plan and implement a Federated Cooperative Development and Support Center.
- Develop support materials for Human Services Cooperatives, state agencies, and providers.

Abstract

For 15 years, Arizona has been operating its Long-term Care Service and Support System, including its Home and Community Based Services (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 FCC 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 FCC, 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 Human Service Cooperative will operate after the grant ends, continuing to provide state-funded LTC self-directed services. Grant activities will transition to the FCC, 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, *C*onnecticut *H*as *O*pportunities for *I*ndependence, *C*hoice and *E*mpowerment		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$595,349	***Year Original Funding Received***	2003

Contact Information

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Subcontractor(s)

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University of Connecticut
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.

Goals

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

Activities

- Identify current recruitment efforts and registries, and conduct focus groups to inform the development of an interagency collaboration agreement and a website for matching personal assistants (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 three 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 personal assistants.

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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Subcontractor(s)

Project consultants to be decided.

Target Population(s)

Persons with serious and persistent mental illness (SPMI).

Goals

- Develop a common definition and service model of personal assistant services (PAS) for persons with serious and persistent mental illness 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 assure adequate consumer participation and sustainability of training effort following the grant period.
- Increase effectiveness of provider training and personal assistance services through evaluation.
- Develop and make available public education materials regarding consumer self-direction of PAS.

Activities

- Develop a common definition and service model of personal assistance services (PAS) for persons with severe and persistent mental Illness (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 personal assistant services (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 personal assistance services (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 in order for persons with mental illness to achieve and maintain community living status, the usefulness of personal assistance services 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 personal assistance services 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.

MASSACHUSSETS

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

Contact Information

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Grant coordinator yet to be identified.

Subcontractor(s)

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

Target Population(s)

Individuals of all ages with disabilities or long-term illnesses who are seeking personal assistance services.

Goals

- Develop and test quality assurance and safeguard procedures for assuring that the scope and quality of personal assistance services and supports (PASS) services 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.

Activities

- 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 back-up 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, 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 insure consumer choice and consumer direction of PASS. The grant manager will be the Department of Mental Retardation.

MASS C-PASS will build on work begun in two, successful federally funded CMS New Freedom projects designed to promote systems change in community-based long-term care.[2] 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 C-PASS Grant will fund three pilot projects that will produce new models of quality assurance, flexible supports, and consumer direction.

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.

This is a consumer-driven project. Consumers have contributed to the design of this proposal. Through their membership in the grant's Coordinating Council—a collaborative partnership of consumers, ILC's, 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.

[2]Real Choices Systems Change (10/01–9/30/04) & *Bridges to Community* NF 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

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Subcontractor(s)

University of Nebraska Medical Center (UNMC) Munroe-Meyer Institute (MMI)
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Washington, DC 20016

Target Population(s)

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

Goals

- Develop infrastructure for consumer-directed financial management and supports brokerage model services.
- Develop consumer awareness and training activities.
- Develop a quality assurance process to monitor quality of financial management and support brokerage services systems.
- Incorporate elements of consumer direction throughout grant activities.

Activities

- Design and implement financial management services and supports brokerage models for community-integrated personal assistance services and supports.
- Develop and implement consumer awareness and training activities, including a statewide peer advocacy training network to disseminate information and train consumers about financial management and supports brokerage services.
- Establish and implement quality assurance processes for consumer-directed personal assistance services (PAS), financial management services, and supports brokerage services.
- Incorporate consumer direction into grant activities through appropriate PAS policy changes and awareness training for providers.

Abstract

Under this grant, Nebraska will explore alternative mechanisms to enhance consumer control and choice in the delivery of PAS services. Specifically, the grant will establish the infrastructure for a financial management and support brokerage services system for a consumer-directed model of financing and delivering PAS. This system will offer support services to enable consumers to perform required employer tasks and ensure compliance with legal requirements related to employment of PAS workers.

In addition, the grant will develop a peer advocacy network that will support consumers through training and peer mentoring. A quality improvement process with consumer involvement will be developed to establish an ongoing mechanism for monitoring and improving the new model. This grant will have a wide scope, targeting consumers from the aging population and adults and children with developmental disabilities, behavioral health needs, physical disabilities, and complex medical needs. The Real Choice Consumer Task Force, which includes state, consumer, and provider representatives, will lead the design and implementation of grant activities.

The project will lead to substantial, ongoing system change in PAS services in Nebraska. The financial management services and supports brokerage services structure will be sustained by revising the Medicaid reimbursement process for PAS and through reduced costs from a decreased reliance on Medicaid Home Health services. The train-the-trainer technique provides an inexpensive and effective approach to train staff and consumers as part of a peer network, allowing for an ongoing system of education and supports to increase consumer capacity to manage their own services. Finally, the financial management services structure has the potential to promote increased wages and possibly the provision of benefits for personal assistants, which could attract more qualified individuals to the field, upgrade their status, and increase worker retention.

OREGON

Grant Information

Name of Grantee	Oregon Health & Science University		
Title of Grant	Oregon CPASS Project		
Type of Grant	Community-Integrated Personal Assistance Services and Supports		
Amount of Grant	$585,007	***Year Original Funding Received***	2003

Contact Information

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OHSU Center on Self-Determination
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Subcontractor(s)

None.

Target Population(s)

Persons with psychiatric disabilities.

Goals

- 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 consumer self-direction of their services.
- Promote the awareness and use of effective practices in consumer-directed personal assistance services.

Activities

- Identify barriers to using the PCS Program and strategies for successful use.
- Implement a comprehensive plan for marketing the PCS Program, including mini-grants 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, a CPASS planning tool for consumers, and e-mentoring.
- Conduct a CPASS Best Practices Conference.
- Collect and analyze information related to the level of consumer-direction demonstrated by PCS participants, their institutionalization and hospitalization rates, their quality of life, and the cost of services.

Abstract

In Oregon, only about 300 persons currently 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 will improve community-integrated services by promoting mental health consumer access to and successful utilization of the PCS Program. The project will be implemented collaboratively by the Office of Consumer/ Survivor Technical Assistance (OCTA) at the Oregon Health & Science University Center on Self-Determination, in partnership with the State Office of Mental Health and Addiction 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 Human Services		
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

Contact Information

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Subcontractor(s)

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

Target Population(s)

Adults and children who are eligible for Medicaid state plan personal care services. To be eligible, individuals must have health problems that cause functional limitations in activities of daily living.

Goal

Implement a service responsibility model in the Primary Home Care Program, which is funded under the Medicaid state plan through the personal care option.

Activities

- Develop materials for statewide use to train consumers, providers, and Department of Human Services (DHS) staff.
- Educate consumers about the service responsibility model, and train them to perform activities under this model, such as recruiting, hiring, supervising, and conflict resolution.
- Train consumers to carry out the responsibilities of the budget and service responsibility model (also known as the consumer-directed services model).
- Train providers and DHS case managers and regional staff to implement and oversee all service delivery models: agency, consumer direction, and service responsibility.
- Pilot the service delivery model in one region of Texas that includes rural and urban areas.
- Calculate provider rates under the service responsibility model.
- Add the service responsibility model to the state's automated service authorization and billing system, and to its automated eligibility and referral system.
- Analyze the differences between the three models of personal assistant care (agency model, service responsibility model, and budget and service responsibility model).
- Assess the effectiveness of the service responsibility model and recommend improvements based on the assessment.
- Expand the service responsibility model statewide.

Abstract

The primary goal of the grant is to implement a service responsibility model in the state's Primary Home Care Program, which is funded under the Medicaid state plan through the personal care option. The model will be piloted in a region of the state that includes both rural and urban areas.

The project includes training components and consumer surveys to assess the effectiveness of the training. Consumer surveys will also be conducted to develop an understanding of why consumers choose particular models of service delivery, and their satisfaction with those models.

The effectiveness of the service responsibility model will be assessed and improvements made as needed prior to expansion of the model statewide.

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

Contact Information

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Subcontractor(s)

None at this time.

Target Population(s)

Recipients of services under three waiver programs: the Consumer-Directed Personal Attendant Waiver, the Mental Retardation Waiver, and the Individual and Family Developmental Disability Support Waiver.

Goals

- 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.

Activities

- 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 are often hesitant to adopt this option due to a lack of awareness about consumer-directed options or concerns about worker shortages. Case managers and providers often do not provide adequate information about consumer-directed personal assistance services, and individuals, family members, and other representatives are only now beginning to receive needed information, tools, and supports. The current process is also cumbersome and not user-friendly.

Through this grant, the Partnership for People with Disabilities will seek active involvement from recipients of personal assistance services, family members, case managers, and service facilitators to determine ways to increase individual choice, control, and responsibility over 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 service recipients 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

Contact Information

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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.

Goals

- 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.

Activities

- 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

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/advocate groups.

Goals

- 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.

Activities

- 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 and health care providers to measure increases in the effectiveness and utility of information materials.
- 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 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, websites, 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 ongoing evaluations to determine its success.

INDIANA

Grant Information

Name of Grantee	The Indiana Parent Information Network, Inc. (IPIN)		
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

Contact Information

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Subcontractor(s)

None.

Target Population(s)

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

Goals

- Improve the ability of no less than 100 families in each of two Indiana regions (to be determined) to care for their CSHCN in the community.
- Improve the ability of no less than 20 health care professionals to provide a medical home for no less than 50 families of children with special health care needs.

Activities

- 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 CSHCNs to provide information to families on childcare, community resources, health care financing, genetics, and education law.
- Modify existing the training curriculum for professionals.
- 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 waiver programs. To address the information needs of families of CSHCN, the Indiana Parent Information Network (IPIN) established The Indiana Family-to-Family Health Information and Education Center to (1) make information and materials available online; (2) to 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, IPIN will expand and improve its current website 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 IPIN 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, assure 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

Contact Information

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Subcontractor(s)

None.

Target Population(s)

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

Goals

The goal of this project is to develop and implement statewide strategies to assure 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.

Activities

- 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 Parent's 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 children with special health care needs 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 Grantee	Parents, Let's Unite for Kids (PLUK)		
Title of Grant	Family-to-Family (F2F) Center Project		
Type of Grant	Family-to-Family Health Care Education and Information Centers		
Amount of Grant	$150,000	***Year Original Funding Received***	2003

Contact Information

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Subcontractor(s)

Spotlight Productions

Target Population(s)

Adults and adolescents with disabilities, and parents of children with disabilities.

Goals

- Increase the capacity of Parents, Let's Unite for Kids' (PLUK) existing infrastructure to enable family-to-family assistance regarding health care information and education to further the ability of children with special health care needs (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 children with special health care needs by increasing the presence of family advocates within the health care system.

Activities

- Develop a statewide inventory of children's health-related programs and add to an existing website.
- 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.
- Conduct a conference for families of CSHCN by families with CSHCN.
- Develop a self-advocacy training track at the CSHCN conference and a plan to provide this training in other venues.
- 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

Parent's Lets Unite for Kids (PLUK) is a nonprofit organization dedicated to helping children with special health care needs (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

Contact Information

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Subcontractor(s)

None.

Target Population(s)

Children and youth with special health care needs and their families.

Goals

- Increase the understanding of and utilization of appropriate health care resources for children and youth with special health care needs (CYSHCN).
- Promote family-centered and consumer-directed health care services and support.

Activities

- 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 children and youth with special health care needs.
- 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 children and youth with special health care needs (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.

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

Contact Information

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Subcontractor(s)

None.

Target Population(s)

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

Goals

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.

Activities

- 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 website 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 children with special health care needs and their families; and promote the philosophy of individual and family-directed supports.

Project activities and collaboration will increase the percent 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

Contact Information

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Subcontractor(s)

None.

Target Population(s)

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

Goals

- 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 Spanish-speaking 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.

Activities

- 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 websites.
- 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 children with special health care needs.
- Establish a statewide Advisory Council that includes families and parents of children with special health care needs, 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 children with special health care needs 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 children with special health care needs. 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		
Title of Grant	Family Voices of Wisconsin Health Information Project		
Type of Grant	Family-to-Family Health Care Information and Education Centers		
Amount of Grant	$142,959	***Year Original Funding Received***	2003

Contact Information

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Subcontractor(s)

ABC for Health
Parent consultants

Target Population(s)

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

Goals

- Increase coordination between existing, state-funded information and assistance activities, and increase the availability of health and community resources to CDSHCN.
- Increase the availability of highly-trained health benefits specialists with expertise in CDSHCN.
- Assure 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.

Activities

- 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.