



Summary of 2004 Real Choice Systems Change Grants

In fiscal year 2004, Congress appropriated approximately \$40 million in funding for a new round of Real Choice Systems Change Grants. The 2004 grants are divided into nine categories; state DD agencies will participate in projects in seven of these categories:

1. Quality Assurance and Quality Improvement in Home and Community-Based Services (HCBS)
2. Integrating Long-Term Supports with Affordable Housing
3. Portals from Early Periodic Screening, Diagnosis, and Treatment (EPSDT) to Adult Supports
4. Comprehensive Systems Reform Effort
5. Rebalancing Initiative
6. Living with Independence, Freedom, and Equality (LIFE) Account Feasibility and Demonstration
7. Family-to-Family Health Care Information and Education Centers

Of the 52 grants awarded across all ten categories, 32 will have a direct impact on persons with developmental disabilities and the state systems that serve them.

Since 2001, the Real Choice Systems Change Grants for Community Living have provided states with the

opportunity to explore projects that would allow their long-term care service systems to better serve consumers in community settings. Grants are awarded to projects designed to enable individuals who have a disability or long-term illness to live in the most integrated community setting appropriate to their individual support requirements and preferences; exercise meaningful choices about their living environment, the providers of services they receive, the types of supports they use, and the manner by which services are provided; and obtain quality services in a manner as consistent as possible with their community living preference and priorities. State developmental disabilities agencies have, for the past three years, used the grants to fund key projects aimed at developing the infrastructure and methodology necessary to improve community-based services for the individuals they serve.

Quality Assurance and Quality Improvement in Home and Community-Based Services (HCBS)

The Quality Assurance & Quality Improvement in Home and Community-Based Services (HCBS) grants exist to assist States to fulfill their commitment to ensure the health and welfare of individuals who participate in the State's home and community-based waivers, develop effective methods to meet statutory requirements and CMS expectations by the use of ongoing quality management strategies, and develop methods to involve program participants and community members in active roles in

state quality management activities. CMS invited proposals from states to develop, improve, or expand a comprehensive strategy for Quality Management (QM) in HCBS services. CMS expected that the QM Strategy Document would evidence consideration of the roles and responsibilities of various individuals and entities including the Medicaid agency, sub-State managing entities, participants and families, advocacy groups, providers, and external independent entities; and describe existing and/or proposed information technology systems used to support program and quality management activities, mechanisms for immediate intervention in cases of immediate jeopardy, methods of determining improvement projects, and the scope of the QM Strategy. All projects funded under this grant opportunity must utilize the CMS HCBS Quality Framework. Grant funds may be used for design, implementation, and evaluation activities. A maximum of ten percent of grant funds may be used for direct services that support the involvement of participants and family members in grant activities.

ALASKA

Department of Health and Social Services

In response to a largely positive 2003 CMS management review of Alaska’s four currently approved HCBS waiver programs (for Persons with Mental Retardation and Developmental Disabilities, Older Alaskans, Adults with Physical Disabilities, and Children with Complex Medical Conditions), the Department of Health and Social Services (DHSS) and the Division of Senior and Disability Services (DSDS) are instituting a cohesive state-level quality system, implementing standards for case reviews, annual comprehensive assessments, and data collection, as well as tracking and responding to complaints, incident reports, and emergencies. Alaska’s \$417,849 grant project will expand the ability of DSDS to more comprehensively provide quality management by building in more “front end” strategies—to make the system increasingly proactive. In the first year, partner organizations that include representation of persons with disabilities and family members, rural residents, and Alaska Natives will examine instruments and methodologies for assessing quality of life on an ongoing basis, and make recommendations to the DSDS Quality Improvement Steering Committee. An assessment will be implemented with a small random sample of waiver recipients within

the largest service sector of the state. After an informed review of this effort and its results by the partner organizations, any identified problems will be addressed. In years two and three, this assessment will be implemented with larger samples and expanded to other regions of the state, becoming an ongoing part of Alaska’s Quality Management System. In addition, the state’s Medicaid system already generates automatic, brief, quarterly satisfaction surveys asking only for complaints. Under this project, the automatic assessments will be modified to solicit general feedback that is person-centered and focused on quality of life. Simultaneously, in collaboration with the Alaska Mental Health Trust Authority, the project will assist in the implementation of an already existing data management system that can integrate quality of life data with other data, such as eligibility assessments, case management, service delivery, program provider performance, complaints, and incident reports. This will make it possible for Alaska’s Quality Management System to become much more data-driven in ongoing monitoring and improvement activities and allowing DSDS to provide data-supported information accessible to consumers and families as a tool for making informed choices and to providers as a tool for making their own QA decisions, as well as to other stakeholders.

ARIZONA

Department of Economic Security

Arizona plans to develop and test a consumer-to-consumer strategy for gathering quality assurance (QA) data and identifying quality improvement (QI) needs. To accomplish this, Arizona’s Department of Economic Security (DES) will develop a compendium of quality characteristics, under the direction of a consumer-led steering committee, based on a literature review and consumer focus groups. The agency will then develop a training curriculum for peer quality reviewers and data gathering procedures and tools, as well as a database for storing and analyzing information.

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

assure that the model is sustainable, and implement model components as appropriate in their quality management systems.

Measurable outcomes and products of this project include (a) a consumer-run steering committee with a direct connection to the quality management system, (b) a set of consumer-identified characteristics of quality services, (c) a training curriculum for consumer-to-consumer assessment, (d) a cadre of peer quality reviewers, (e) pilot study and demonstration reports, and (f) a consumer-to-consumer model plan. Ultimately, the project will help to improve services provided to people with disabilities in Arizona by offering a consumer perspective on the quality of services provided to individuals and families in their own homes. This new source of information will aid continuous quality improvement efforts for the target population.

ARKANSAS
Department of Human Services

In its grant proposal, Arkansas Department of Human Services (DHS) commits to move HCBS quality assurance and improvement activities from the project or program level to a collaborative, interdepartmental initiative to ensure the health and welfare of all Arkansas waiver participants. DHS, with the Division of Aging and Adult Services (DAAS) as lead agency, will update and standardize quality assurance procedures across programs with the \$500,000 grant.

The goals of Arkansas’s QA/QI project are to:

- Establish a Quality Assurance/Quality Improvement Task Force that will include waiver participants and their family members, representatives of advocacy groups, waiver program providers, local authorities and other stakeholders.
- Create an interdepartmental Quality Management System Committee to oversee operation of the Quality Management plan.
- Develop a system-wide Quality Management Strategy for all HCBS waivers that will fulfill the State’s commitment to implement CMS Quality Framework design features and quality functions.

- Develop a single integrated data collection system to evaluate the effectiveness of waiver programs.
- Design and implement participant feedback mechanisms to assess satisfaction with waiver services and assist the State in designing quality assurance and quality improvement strategies.
- Disseminate educational materials to support participants in directing their services.
- Implement a peer-counseling program for HCBS waiver participants.

The project will result in a sustainable Quality Management Plan that meets all CMS requirements, a single functional data collection and reporting system that generates reliable and timely reports to allow for informed program decisions, participant-defined measures of quality in both services and service delivery, and shortening of the response time between identification of problems and issues and their remediation.

FLORIDA
Department of Children and Families

Florida’s \$475,000 grant will fund a partnership effort between The Agency for Persons with Disabilities (APD) (formerly the Developmental Disabilities Program), The Council on Quality and Leadership (CQL), Delmarva Foundation and the Agency for Health Care Administration (AHCA). The focus of Florida’s initiative will be to enhance the use of data from their quality assurance activities and realign district functions to build quality improvement and management capacities throughout the service system. The project will specifically target QI and ongoing Quality Management for organizational change that supports self-determination and meeting customer expectations through the following outcomes and products for the project:

- ♦ Establishing statewide leadership capacity (organizational consultants in each district) to assist with organizational change by establishing and training district steering committees made up of key stakeholders to oversight and advise local QI initiatives, providing technical assistance to districts in Quality Improvement and Quality Management, providing consultation and technical assistance to providers in revising

organizational practices that best promote achievement of customer outcome expectations, and providing education, consultation and assistance to consumers, their families and other local stakeholders related to self-determination and customer satisfaction;

- ◆ Expanding current quality assurance activities and capacity by training reviewers to use a consultation model for organizational change as part of their review exit strategy;
- ◆ Creating district staff capacities for technical assistance and follow up on provider’s organizational practices and overall quality management roles; and
- ◆ Collaborating with the existing DD Program structure in the use of Personal Outcome Measure (POM) Core Trainers and strengthening oversight.

MASSACHUSETTS

University of Massachusetts Medical School

Massachusetts’ QA/QI grant will be used for a collaborative effort between six New England States. The Commonwealth of Massachusetts, through the University of Massachusetts Medical School’s Center for Developmental Disabilities Evaluation and Research, has received \$499,266 in Real Choices grant funding to develop a unique quality improvement collaboration between the New England mental retardation/developmental disabilities state systems. Grant funding will be used by the Commonwealth of Massachusetts to establish an integrated infrastructure to promote the use of objective and analytic methods of measuring the quality of services and supports by developing a set of regional standards, quality indicators, and objective measures of quality that will include regional benchmarks. In addition, grant funds will be utilized to establish methods to facilitate the sharing of resources regarding quality and quality improvement across the participating states, and training of stakeholders in the use of quantitative information and methods for consumer use of objective quality information, including prototype provider profiles.

The project will build upon the National Core Indicators (NCI) by incorporating more objective data, with a focus on developing prototype health indicators. It will also strengthen the actual utilization of NCI data by allowing

more focused analysis of findings within northeast U.S. through the use of targeted New England NCI benchmarks. Consumers, families, service providers, and CMS regional personnel will be invited to participate with state personnel in the initial identification of standards and indicators, to ensure the design reflects what is important to HCBS participants, providers, and federal monitors. While the grant application was submitted by Massachusetts, the state MR/DD systems in the other five New England states – Connecticut, Maine, New Hampshire, Rhode Island and Vermont, will actively participate in grant related activities.

NEBRASKA

Department of Health and Human Services

Nebraska will use its \$470,000 grant to develop an integrated and comprehensive Quality Management System at state and local levels based on the Quality Framework and incorporating expanded consumer involvement. The state plans to implement a tool mirroring the CMS Participant Experience Survey to assess children’s families’ satisfaction with services, as well as a risk assessment process to assure consumer health and welfare while allowing self-direction and consumer decision-making. The Department of Health and Human Services (HHS) also plans to establish Quality Councils that include consumers to serve as advisory groups: one for in-home consumers and one for assisted living consumers, create data collection protocols for quality monitoring, develop written protocols for consumer participation in Participant Experience Survey, establish a Web-based feedback and incident reporting system, with accompanying reports and protocols for linking information with the regulation and licensure system, and develop and implement a medication risk process including an assessment instrument and instructions, a pharmacist referral protocol, and corrective action process.

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

Aged and Disabled Home and Community-Based Waiver, which covers populations across the lifespan.

NEW HAMPSHIRE

Department of Health and Human Services

Much of New Hampshire's \$498,988 grant project will focus on the states elderly and chronically ill waiver, and apply findings to other HCBS recipients, although some initiatives will affect all HCBS waivers. New Hampshire seeks to design and implement a participant-centered and participant-directed interdepartmental quality assurance and quality management infrastructure for all waiver programs and other Medicaid and state-funded services under the LTC system. The state will adopt a structured waiver operations business plan to streamline processes, expand clinical expertise in community-based support programs, and increase the level of quality services provided to waiver participants and develop an automated system that will perform multiple clinical management tasks and interface with the State's Medicaid reimbursement system.

The Department of Health and Human Services (DHHS) will engage HCBS participants and include their perspectives in active development, evaluation and monitoring of the home and community-based services and system, and design and implement standardized quality management for all HCBS waivers and throughout DHHS that includes vision and mission statements; principles, goals, and objectives; operating and system performance standards; a training curriculum and evaluation; and a DHHS quality Web site. Grant funding will also be used to improve internal processes and response to consumer eligibility, assessment, and service provision, and develop a formal risk management protocol and training module and develop a critical incident tracking and review system.

NEW JERSEY

Department of Human Services

New Jersey's grant project involves implementing a system wide person-centered planning system, creating an integrated quality management (QM) system, consistent with the state's IT strategy, based on the CMS HCBS quality framework, and expanding the Department of Developmental Disabilities (DDD) Web site to involve

the entire DD community in using timely and accurate information for QM. The \$475,000 in grant funds will be used to design and implement training in scoring and evaluation of plans of care for staff and for family members and participants to support a system wide person-centered planning system; restructure the Quality Improvement Steering Committee system to enhance family and participant involvement in program planning; create a Web-based system of data collection through browser-based interfaces with a single integrated database to support an integrated QM system; and develop new business processes to assure that providers and DDD staff are accountable for timely and accurate QA/QI data collection and entry, including a revised and more meaningful data reporting format. DDD will also implement a new model for involving stakeholders in the quality review process for providers, and expand the DDD Web site to provide enhanced support for New Jersey's Quality Improvement Regional and Central Steering Committees and for browser-based surveys to facilitate consumer input.

VERMONT

Agency of Human Services

Department of Aging and Independent Living

The state of Vermont has received a \$499,709 grant to develop a comprehensive quality management system across the state's four HCBS waivers within the Department of Aging and Independent Living, including the Division of Developmental Services' (DDS') waiver for individuals with developmental disabilities. The goals of the project are to effect enduring systems change to ensure the health and well-being of individuals receiving HCBS waiver services within Vermont's community-based, long-term care system and to provide a comprehensive quality assurance and quality improvement management system in all four HCBS waivers utilizing the CMS Quality Framework.

Grant funds will be used to develop a Quality Management Plan addressing all four waiver programs; include consumers, their families and community members as active participants in Vermont's quality management activities; develop and implement quality management activities to improve supports and services to Vermont's elder citizens and those with disabilities; develop a technology-based system to manage and analyze critical

incidents; and develop an ongoing system of technical assistance to all providers of services across age and disability and provide training to service recipients and relevant staff.

Vermont will develop multiple discovery and data collection activities that include direct participant experience within each HCBS waiver. The funds will also be used to develop a technical assistance manual to instruct staff, volunteers, or participants in the implementation of creative methods of information gathering activities and a system of technical assistance that includes problem solving, training and consultation in the delivery of quality services to service providers within each HCBS waiver program. Vermont also plans to institute a technology based critical incident management system to assist quality assurance staff in assessing the quality of services in HCBS waivers, and implement a pilot project to hire consumers to participate in the evaluation of services.

Integrating Long-Term Supports with Affordable Housing

The purpose of this grant is to assist States in creating the infrastructure to increase the access to and the capacity of affordable and accessible housing for Medicaid-eligible individuals with disabilities, and to coordinate housing funding with supports funded through State Plan services, waiver services, or other service agencies. The grant requires partnerships among the State Medicaid agency, State service organizations, and housing agencies. Five of the eight grants awarded will directly impact the DD population.

The housing involved may be integrated or “single-purpose” and may be a rental unit or a privately owned home. Improving access to affordable housing with long-term supports can be achieved either within a State’s existing housing capacity or in conjunction with expanding housing capacity through increased set-aside vouchers for individuals with disabilities of any age and new or retrofitted construction of affordable and accessible housing.

In addition to improving capacity and access to housing that is coordinated with long-term supports,

applicants were strongly encouraged to incorporate one of the following three components:

1. The development of a model for public housing with services that permits elderly residents to age-in-place and avoid or delay institutionalization.
2. Encouraging the development of a new or amended §1915(c) waiver or §1115 demonstration program that provides the long-term supports necessary to enable persons to live in the community, including accessing services that assist in the home ownership process.
3. Developing the State’s infrastructure to transition individuals from institutional settings to affordable housing in the community.

Grant funds may be used for design, implementation, and evaluation. The “Housing Support Coordinators” or other similarly titled positions are considered an administrative expense. A maximum of ten percent of the grant funds may be used for direct services.

DISTRICT OF COLUMBIA Department of Mental Health

The District of Columbia (D.C.), awarded \$812,004, will focus its grant efforts on individuals who have been “dually diagnosed” as persons with both mental illness and mental retardation/developmental disabilities. The grant will assist two agencies, the Department of Mental Health (DMH) and the Mental Retardation and Developmental Disabilities Administration (MRDDA) (housed in the Department of Human Services (DHS)) to expand and solidify a comprehensive and extensive partnership base to address needs pertaining to long-term supports integrated with housing, and a system of interdependent processes targeted to this specific population.

The District Government agencies in charge of providing services for individuals with mental illness and/or mental retardation and developmental disabilities will partner with housing and service provider organizations such as the D.C. Housing Authority, D.C. Housing Finance Agency, Department of Housing and Community Development, Fannie Mae and Freddie Mac. A working group

comprised of the State Mental Health Planning Council and the DD Council in collaboration with District Government, service providers and other key stakeholders will also participate in this endeavor. The grant effort will concentrate developing an integrated and streamlined process for applying for Medicaid funded long-term supports and housing choice options as well as creating a mechanism to pay for transition needs (e.g., rental deposits, furniture, bedding, etc.) of individuals moving out of an Intermediate Care Facility for Mental Retardation (ICF/MR) to community housing. The participating agencies will also develop a process that provides individuals with disabilities access to housing of their choice, to include both individual and collaborative relationship housing options and create a Section 1115 Research and Demonstration Project Medicaid waiver to eliminate barriers that prevent individuals sharing a home from pooling long-term supports.

MISSISSIPPI

University of Southern Mississippi

The Institute for Disability Studies (IDS) at the University of Southern Mississippi has received a \$720,000 grant to work with the Division of Medicaid and other key stakeholders to develop the state's infrastructure to meet the needs of Medicaid-eligible individuals with disabilities requiring long-term supports who want to live in the housing arrangement of their choice. Mississippi's Project BRIDGE, as the grant project is known, will create a statewide BRIDGE Action Council, comprised of agency professionals, housing providers, long-term support providers, and Medicaid-eligible individuals with disabilities, to develop a comprehensive plan for systems change that results in integrated and coordinated long-term supports and housing services. The Council will receive ongoing technical assistance from IDS, hold community forums across the state, review the performance of Mississippi's current system, and develop a statewide Action Plan to develop an infrastructure to meet the needs of individuals requiring long-term supports who want to live in their community. IDS will then pilot the Action Plan by supporting two community-based demonstration projects that stress innovative community partnerships between housing providers and long-term support providers.

NORTH CAROLINA

Department of Health and Human Services

North Carolina was awarded \$775,000 over three years for a partnership between the NC Department of Health and Human Services (DHHS) and the North Carolina Housing Finance Agency (HFA) to assure access to the array of available community services and long term supports, both Medicaid and non-Medicaid funded, individuals may need to live successfully in the community. The grantees will also work to develop processes, procedures and monitoring mechanisms to operationalize the DHHS and HFA partnership in the Low Income Housing Tax Credit (LIHTC) program, including implementation of a state funded rental assistance program demonstration.

The LIHTC initiative will serve as the basis for bringing local partners together around the issue of housing in their communities. Subsequent activities will use this opportunity to provide education and training on other components of the affordable housing system, local, state, and federal resources, and Fair Housing protections and Landlord-Tenant Law. The grant will support local communities in quantifying the unmet housing needs of persons with disabilities and developing strategies to expand the supply of integrated community housing with access to long-term supports available to persons with disabilities.

OREGON

Department of Human Services

Oregon's \$828,233 grant will develop the state's infrastructure to remove barriers that prevent people with physical, developmental, and psychiatric disabilities from residing in the community housing of their choice. The Expanding Housing and Supports for Oregonians proposal will accomplish this through a dual focus: promoting use of assistive technology that will enable people with physical and developmental disabilities to achieve greater independence in community housing, and reforming outdated service financing infrastructure to better facilitate integration of supports with housing for people with psychiatric disabilities.

About \$550,000 of the grant funds will go towards the assistive technology component. The outcomes and

products to be achieved by this part of the grant include a report on available assistive technology, systemic barriers and blueprint for system change, and the establishment of a resource clearinghouse on assistive technology. Other grant activities include completing analyses of existing and proposed resources and strategies, planning and implementing identified infrastructure changes, developing resource materials to support changes, providing training and technical assistance, and transitioning the grant accomplishments to insure sustainability. Meaningful involvement by consumers and other key stakeholders will be insured through a Stakeholders' Coordinating Council.

PENNSYLVANIA Office of the Budget

Pennsylvania, through the Governor's Office of Health Care Reform (OHCR), will use its \$893,340 grant to create state and local infrastructures to increase access to and the amount of affordable accessible housing and systems to help link persons with long-term supports to affordable, accessible housing options, including public housing, scattered-site rental units, and PHFA financed units. Additional goals of the grant include addressing such barriers as the reluctance of property owners to rent to individuals needing long-term supports, bad credit issues, and fragmented and inadequate home modification programs. OHCR will work with the Pennsylvania Housing Finance Authority and public housing authority partners to expand the supply of affordable and accessible housing available to persons needing long-term care services and supports and help provide a feeder system for those units from nursing home transition and diversion projects; develop an inventory of Pennsylvania's publicly funded accessible housing; develop a real time listing of vacant, affordable, accessible housing available to housing coordinators and nursing home transition teams; do a needs assessment of present and future accessible and affordable housing stock needed for persons with long-term care supports to live in the community; and develop a strategic plan for the state of Pennsylvania for the development of affordable, accessible housing and linking mechanisms with persons with long-term care needs for the next decade. OHCR will test these reforms at two regional demonstration sites.

Portals from Early Periodic Screening, Diagnosis, and Treatment (EPSDT) to Adult Supports

The Portals from EPSDT to Adult Supports grants will assist states in addressing the needs of children with disabilities who receive community health services through Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) and who are redetermined to be eligible for Medicaid at age 21 (or younger at the discretion of the state). The grant was offered for use in (a) developing and implementing a State Plan amendment, (b) developing a waiver or demonstration application to provide new supports to this population and implement enrollment into the waiver or demonstration, or (c) developing a waiver amendment application to expand either services or slots in the state's existing targeted disability waiver(s). No grant funds may be used for direct services or to finance current activities. One of the two grants given in this category focuses on individuals with DD.

NEBRASKA Department of Health and Human Services

This \$500,000 three-year project will develop a transition project for young adults with disabilities, the ultimate goal of which is to improve access to adult-focused tertiary and specialized medical care for SSI-eligible youth transitioning from EPSDT to adulthood. The Nebraska Department of Health and Human Services will develop an amendment to Nebraska's Home and Community-Based Aged and Disabled Waiver to modify the assessment process used for persons transferring from children's services to adult services, to include a medical transition component; coordinate training for general practitioners so they are ready to serve young adults on the Waiver, and cultivate relationships between them and pediatric specialists who have been serving these persons in their youth; implement a pilot project with a rural school district that will integrate medical transition assessment and planning into required transition plans for employment preparation; and create a transition clinic as part of the Medically Handicapped Children Program's specialty clinics, specifically for SSI-eligible youth as they age out of children's services. The grant will create an infrastructure of training, clinics, and assessment.

Comprehensive Systems Reform Effort

One of two grants given in this category will significantly impact individuals with developmental disabilities. The purpose of this initiative is to support a comprehensive planning, designing, and implementation effort by states to reform their long-term care systems in order to decrease their reliance on institutional services and increase the level of supports that are controlled by the individuals that receive them. This grant opportunity, open to any state, is distinguished from the Rebalancing Initiative grant opportunity in that it is intended to assist States in developing a comprehensive reform plan rather than a targeted rebalancing plan.

Grantees are expected to explore improvements in how individuals access long-term supports, including interventions that target pathways to institutional supports to ensure that those pathways may also lead to community-based supports, speed up the eligibility determination process, and facilitate the ability to make informed choices. The grants are also meant to fund efforts to remove barriers within State budgets that prevent funds earmarked for institutional supports from moving to home and community-based supports, and the building of quality management systems that reflect the desire of individuals to direct their own services. No grant funds may be used for direct services under this grant program. Grant funds may not be used to finance current activities.

WISCONSIN

Department of Health and Family Services

The Wisconsin Department of Health and Family Services (DHFS) received \$5.5 million to develop and implement a comprehensive plan for statewide expansion of long-term care (LTC) reform by applying managed care strategies in new and expanded programs for older adults and persons with disabilities who are Medicaid eligible. The programs will be facilitated by public/private partnerships to be implemented in at least one-half of the State by 2007. The project will also seek to improve management of access to the LTC system and develop systems and

processes that will enhance the availability of service options.

The Department of Health and Family Services plans to support local partnerships to undertake a one-year planning process for local reform, create Web-based content for consumer links to information and other service systems, and design an effective multimedia campaign around LTC services. The grant funds will also be used to improve the functional eligibility screen and develop related tools and supports for local use. The state will also develop strategies to retain people in the direct care workforce and a training curriculum for options counseling workers, as well as a comprehensive consumer-centered curriculum that can be utilized by nurses and social workers. Additional activities include implementing an outcome tool in all waiver programs, compiling and analyzing results across programs; and piloting the encounter reporting tool currently used in Wisconsin's Family Care program in participating counties and conducting pilot post implementation analysis.

Rebalancing Initiative

The purpose of this initiative is to enable states to develop and implement strategies to reform the financing and service designs of state long-term support systems in order to decrease reliance on institutional forms of care and increase the utilization of community-based long-term supports. This grant is distinguished from the Comprehensive Systems Reform Effort grant in that it is intended to assist states in developing a targeted rebalancing plan rather than a comprehensive reform plan. Applicants were directed to select a targeted issue (such as waiting lists for community-based services, services for a particular population to reduce reliance on institutional care, or mechanisms to enable money to follow the person to the optimal setting) to address with a rebalancing plan. Proposals were required to address all of the following components:

- Access to community-based long-term supports;
- Financing of programs and services;
- Services that are self-directed and include supports for transition from an institutional to community-based locus of support; and

- Quality management mechanisms.

Applicants were strongly encouraged to consider utilizing, as part of the implementation plan, the Medicaid Statistical Information System (MSIS) to capture enrollment data and to track service utilization. Grant funds were available for design and implementation activities only. Three of the seven grants awarded in this category directly impact individuals with developmental disabilities.

LOUISIANA
Department of Health and Hospitals

Louisiana will use its grant to develop a comprehensive plan that will address the pattern of needs of people with developmental disabilities to move from large Intermediate Care Facilities for the Mentally Retarded (ICF/MRs), thereby increasing the choices for community-based living options. The state ultimately seeks to create a viable plan for transitioning over the thirty-six month course of the project 10 percent of the number of people with developmental disabilities living in large institutional settings to community-based living options. DHH, under the auspices of the Office for Citizens with Developmental Disabilities (OCDD), will use their \$300,000 grant to establish an Advisory Board comprised of people with developmental disabilities and their families, case managers, advocates, agency personnel, local government employees, profit and nonprofit organizations, housing authority representatives and others to look at congregate needs in the transition from 16 plus bed ICF/MRs to the community. This Advisory Board will seek the services of a consultant who will serve as advisor for the development of a viable plan for increasing the percentage of those people who transition from institutional settings to community-based supports and services. Additionally, this Advisory Board will establish action plans to offer technical assistance to group members and people receiving supports and services, assess and develop community supports for individuals and families of individuals transitioning to the community, and make recommendations on increasing the transition of individuals to the community.

OCDD will establish workgroups in all regions of the state, using grant funds to employ a trained consultant and expert to educate regional workgroup members and the service

provider network. Further, the grant will fund the development and implementation of training modules to adequately equip consumers and multiple levels of providers with the skills necessary to assure that consumer directed and controlled support services are delivered to people with developmental disabilities in a manner that enhances their participation, choice, and autonomy in community living.

NORTH CAROLINA
Department of Health and Human Services

The North Carolina Department of Health and Human Services (DHHS) \$249,500 Rebalancing Project will develop a comprehensive plan to prevent and correct inappropriate placements among adults with disabilities or long-term illnesses. The Project will target Medicaid eligible adults who have applied for admission, are waiting to enter, or reside in institutions. DHHS will develop Rebalancing and 5-year Implementation Plans to describe the target populations, the nature of the diversion/institutionalization services, the role of key stakeholders, the policies and procedures governing service priorities, and the schedule of events. The project will be managed by a broadly based Rebalancing Team consisting of staff, representatives from all involved state agencies, professional organizations, consumers, and service providers, professional organization representing consumers, and technical persons.

VIRGINIA
Partnership for People with Disabilities

Virginia's Rebalancing Initiative targets the issue of individuals planning, selecting, and managing their own services. The \$300,000 project will focus its work strategies in two areas: the design, development, and piloting of materials and processes to increase the use of person-centered thinking, planning, and services for individuals who are targeted to receive new waiver slots, including the development of resources that explore multiple options for support; and mechanisms and strategies for determining how additional services can become consumer-directed.

The outcomes of the rebalancing initiative will include:

- Individuals with disabilities, family members, case managers, providers, and other supporters gaining knowledge, tools, and resources to design person-centered plans and have information and processes to maximize informed choice in the selection of services and service providers.
- Individuals currently in state training centers and individuals currently on the statewide urgent waiting list for MR Waiver receiving maximum opportunities to choose, design, and manage needed community support and services.
- Additional services becoming consumer-directed as a result of analysis of information from other states and existing barriers.

Products include:

- Materials that organize person-centered thinking, planning, and services in formats useful for individuals, family members, case managers, providers, and other supporters;
- Resource documents that explain informed and meaningful choices and provide an array of options for community support and service possibilities;
- A report that describes the pilot demonstration, including methods, findings, and results;
- A report listing the findings of research from other states and outlining additional prospective CD services and definitions for services;
- A rebalancing plan to be submitted to key state agencies and leaders; and
- An implementation plan to that addresses how Virginia can integrate and continue the work of this initiative, including how these efforts eventually become a part of a greater reform effort.

Living with Independence, Freedom, and Equality (LIFE) Account Feasibility and Demonstration

The purpose of the Living with Independence, Freedom, and Equality (LIFE) Account Feasibility & Demonstration

grant is to enable States to examine the feasibility of establishing and maintaining a program of individual savings accounts within which eligible Medicaid participants can build savings without affecting their eligibility or benefit levels for the State’s Medicaid, Supplemental Security Income (SSI), Social Security Disability Income (SSDI), or any other Federal assistance program. The LIFE Account savings program is intended to enable people with a disability or chronic condition to become more independent by allowing eligible participants the opportunity to save for needed supports without losing their health coverage. Both grants given in this category will involve individuals with developmental disabilities.

The President has proposed a LIFE Account savings program in his FY 2005 budget. The LIFE Account program is intended to reflect promising practices in self-direction and to remove barriers to saving for equipment and supports while allowing participants to maintain their health coverage and standard of living. The President’s proposal would make changes to programs at the Federal level that would then enable States to design and implement LIFE Account savings programs. Some design elements that are under consideration for the LIFE Account savings program are:

1. Only individuals who are Medicaid-eligible, meet the Social Security definition of disability, reside in the community, and self-direct (or for children, have a family member direct) all of their Medicaid, community-based, long-term supports will be eligible to establish a LIFE Account.
2. LIFE Account holders will be able to (a) retain a portion of savings from their self-directed Medicaid, community-based, long-term supports budget at year-end, (b) save earnings from employment, and (c) accept limited contributions from others.
3. Neither resources in or income from the LIFE Accounts will be counted in determining eligibility for SSI, SSDI, or any Federal assistance program, nor will such resources in or income from the LIFE Accounts be considered in establishing benefit levels under those programs for either the Account holder or for any members of the Account holder’s immediate family.
4. LIFE Accounts, once established, will belong to the individual. However, limitations on the eligible sources

of deposit established by the program remain in effect for as long as the individual's LIFE Account is open. Should an individual need to re-enroll in Medicaid, SSI, SSDI, or any Federal assistance program, funds in a LIFE Account will not be counted in determining eligibility or benefit levels.

Grant funds are to be used to complete feasibility studies and development activities that may be useful for future provision of a LIFE Account savings program. As part of these efforts, grant funds may be used to hire staff and/or contractors to assist in research, planning activities, and the creation of documents. No grant funds may be used for direct services.

NEW HAMPSHIRE
University of New Hampshire

The Institute on Disability (IOD) at the University of New Hampshire has received \$99,999 to study the feasibility of implementing LIFE Accounts in the state. IOD will assess the various factors that could influence the success of a LIFE Accounts savings program, including potential demand, potential and actual ability to save, and barriers to saving for individuals and families who self-direct Medicaid-funded services and supports. The Institute will also sample and survey individuals who self-direct to obtain information about the characteristics of those interested in participating in the LIFE Accounts savings program and produce a report of the findings, and use the findings to inform a feasibility study and implementation plan and host a conference to elicit feedback on the plan.

WISCONSIN
Department of Health and Family Services

Wisconsin has received \$100,000 to identify an eligible population to participate in the LIFE Accounts savings program, develop, and implement a survey to determine interest in program participation and identify barriers to employment, increasing savings, and financial independence. The state plans to establish linkages and coordinate with a stakeholder advisory committee to provide guidance on the development of the feasibility study and implementation plan for establishing the LIFE Accounts savings program. The grant will also be used to study systems and policy issues that may impact the

implementation of a LIFE Accounts program and to develop guidelines regarding allowable purchases and required documentation.

Family-to-Family Health Care
Information and Education Centers

In 2004 CMS awarded approximately \$1.5 million to private, not-for-profit entities in 10 states to develop and implement an information and referral network for parents of children with special health care needs. The purpose of this grant opportunity is to support the development of statewide family-run centers to provide education and training opportunities for families with children with special health care needs, and develop and disseminate needed health care and HCBS information to families and providers. Each grant totals \$150,000 over three years. Grant funds may be used for design, implementation, and evaluation activities. No grant funds may be used for direct services under this grant opportunity.

ARIZONA
Raising Special Kids

This program is directed by Raising Special Kids, Arizona's Family Voices Chapter. The three-year project will create new initiatives for increased capacity in Family to Family health care information and education through partnership activities with Arizona's Department of Health Services, Office of Children with Special Health Care Needs (OCSHCN). The goal of the program is to create a coordinated system of Family to Family health information that provides the broadest coverage for parents and families in Arizona, with effective and enduring improvements in community resources, supports, and systems. Through the grant, Raising Special Kids will create health care education and training initiatives to provide parents of children and youth with special health care needs with information to understand systems of care and state Medicaid requirements, and the knowledge to obtain appropriate and needed services. Youth with special health needs, and their parents, will receive information, training and support for the development of self-advocacy skills, for understanding legislation and public policy issues, and

opportunities to participate at all levels of decision-making. The agency will also develop and/or strengthen new and existing community partnerships to promote family-centered practice within a statewide system of health care information and education.

To accomplish the goals and objectives of the project, Raising Special Kids will work with a host of community, state, and national partners. Technology, in the form of distance learning, telephone conferencing, Web site, and other methods will support the training and information needs of families. A statewide parent volunteer network will be engaged in outreach efforts by disseminating information, providing family to family training, and support for specific health care advocacy initiatives in communities around the state. Parents and medical professionals will receive information and training on the benefits of a Medical Home for children with special health care needs. Outreach initiatives and opportunities will promote the importance of coordinated systems of care that support the needs of families, children, and the professionals who serve them. The project will address the competence of health professionals in accessing culturally appropriate sources of family support, education, and information. An exploration of issues surrounding community resources available for designing an expanded continuum of care in respite services for families of children with life-limiting illness will be supported by the project.

KENTUCKY
Arc of Kentucky, Inc.

The Arc of Kentucky will use their grant to establish a new center that, in addition to providing education and training opportunities for families with children with special health care needs, will develop and disseminate information on health care and Home and Community-Based Services (HCBS) to families and providers, collaborate with existing Family-to-Family Centers, and promote the philosophy of individual and family-directed supports. Most of the staff of the center will be individuals with disabilities or family members, and will attend parent group meetings to provide information and education. The Center will also provide information and referrals to other programs that can help children remain in the community, and will help families assess their potential eligibility for long-term care programs and benefits.

LOUISIANA
Family Voices of Louisiana

Family Voices of Louisiana seeks to strengthen collaboration between families, health care and other service providers to enhance the care of all children with special health care needs by providing information, education, and training about a range of relevant topics and issues and increasing parental involvement in program development and service delivery. The organization will engage families and key stakeholders in discussions to identify ways to improve and coordinate public and private health systems and ensure that these systems are responsive to the needs of the families and children they serve, develop a standard data collection method to identify service gaps, and develop a user-friendly information collection, storage, and retrieval database for working with and providing services to partners, providers, and families.

MASSACHUSETTS
Massachusetts Family Voices

Massachusetts Family Voices, housed at the Federation for Children with Special Needs, will offer health care information and support to families of children with special needs, and others, as they negotiate various systems to enable their children to live in the community and be active participants in the decision making process, through their Family-to-Family Center. The Center will provide training opportunities to parents and parent groups on advocacy strategies for achieving quality care for their children with special health care needs, and technical assistance and education to families as they navigate health care service systems and advocate for their children with special health care needs. The Center will also act as a clearinghouse for specialized information and support related to eligibility, enrollment, benefits, and services available under Massachusetts and federal public benefits program, and will collaborate with existing and other new Family-to-Family Centers to provide input and feedback to CMS and the state of Massachusetts on training and technical assistance activities.

The Center will unite parent and agency initiatives in Massachusetts so families and others will have one-stop shopping for information and support around health care services, HCBS waivers, referrals, and other services and

supports available to families of children with special health care needs. The Center will collaborate with state agencies and programs to develop family-friendly training materials so families will have information on Massachusetts and Federal public benefits programs. The outcomes from this project will include materials development, increased numbers of families with children with special health care needs connecting to services, parent leadership and training opportunities, the provision of peer support opportunities, underserved/underrepresented families connecting to services, and information sharing and gathering.

NEW MEXICO

Parents Reaching Out to Help, Inc.

Parents Reaching Out to Help, Inc., (PRO) will call their Center a Family Health Information Center, and will provide parent-to-parent support. Parents of children with special health care needs who have learned to navigate and access the health care system will share their knowledge and experience with families who are facing similar challenges. The PRO parent-to-parent network is community-based, family-centered, and culturally competent. By providing additional training throughout the state, PRO will support families to become informed decision-makers, relating to the health and well-being of their own children and in turn, be better positioned to serve as partners in policy making for improved service systems.

NEW YORK

Parent to Parent of New York State, Inc.

Parent to Parent of New York State, Inc., founded in December of 1999 by parents of individuals with special needs seeking to establish a parent support network, will create a Center to develop a parent network of Health Information Resource Parents, training an average of 2 parents of children with special health care needs as volunteer Health Resource Parents in each county, per year, during the three years of the grant. The goal of this network of parents will be for each to provide support to three other families per year, for a total of 372 Resource parents over three years. The Center will also work to increase understanding of and utilization of appropriate health care resources for Children with Special Health

Care Needs (CSHCN) by assisting 3,000 families of children with special health care needs through training and technical assistance to secure health coverage, ensure that medically necessary services for their children are received and by all means possible covered by health insurance, develop effective partnerships with health care and other service providers, keep their children at home and in their communities by ensuring access to needed support services in childcare, schools, community settings, and their homes, and receive the emotional, parent-to-parent support they need to strengthen their parenting and advocacy skills. The Center will also seek to build the leadership skills of families of children with special health needs and their capacity to improve health policies and practices. Parents involved in the network of the Health Information Centers will participate on advisory committees and boards of organizations in New York that support individuals with special needs.

NORTH CAROLINA

Exceptional Children's Assistance Center

The Exceptional Children's Assistance Center (ECAC) will collaborate with the Children and Youth Branch of the North Carolina Division of Public Health to develop a Family-to-Family Center that will identify existing sources of information and education for families of children with special health care needs in North Carolina, provide training to organizations already serving such families, and develop and disseminate health care and HCBS information while promoting the philosophy of individual and family-directed supports. The project is designed to identify the needs for infrastructure development at both the state and local level while providing the training and coordination necessary to develop into a full service Family to Family Center as future funding is identified. After identifying existing sources of information, the ECAC will develop or adapt training materials and conduct trainer to trainer workshops targeted to organizations serving families of children with significant health care needs.

NORTH DAKOTA

Family Voices of North Dakota, Inc.

The North Dakota Family to Family Health Information and Education Center will be organized to identify the core components of a community-based system, identify

gaps in systems to inform and assist consumers in accessing services, and provide coordination to address unmet needs. An interprofessional/consumer leadership working group will advise the project in developing timely information that supports families in becoming informed decision makers and accessing services.

The goal of the Center is to develop the capacity of provider and consumer knowledge to coordinate and integrate systems as described by six core outcomes for children and youth with special health care needs in the President’s New Freedom Initiative (NFI), building on existing efforts and increasing coordination between families, communities, and other agencies and organizations. The Center will assist North Dakota to strengthen family-professional partnerships, creating new partners to develop a network of true allies to ensure that families have access to information and services responsive to their immediate and long-term needs. The Center will also collect and analyze data related to project activities, systems change and impact on families.

**UTAH
Utah Parent Center**

The activities of Utah’s Family-to-Family Center are designed to create a clearinghouse of information and a family-to-family system that will:

- Provide information and education on health care to families with children with special health care needs, parent groups, providers and other stakeholders;
- Provide training and education on home and community-based services and supports;
- Provide information and referral to other programs and benefits that can help children remain in the community;
- Collaborate with existing Family to Family Health Care Information and Education Centers and Family Voices throughout the country to benefit children with special health care needs;
- Provide a forum for peer group discussion and interaction;
- Help families assess their potential eligibility for public long-term care programs and benefits; and

- Promote the philosophy of individual and family-directed care and supports.

The Utah Family Voices Health Information Project will collaborate closely with and build upon initiatives occurring in the State of Utah. A family-to-family section will be added to the nationally recognized Utah Collaborative Medical Home Web site and a statewide, toll-free, family-run telephone number will be established. Families will have leadership positions in all aspects of project design, implementation and evaluation and be compensated for their efforts; strategies for supporting and training a network of family health partners will be defined and implemented; extensive linkages will be fostered with parent groups, advocacy organizations and disability related agencies concerned with the system of care for children/youth with special health care needs and materials and training will be offered to the existing information and referral organizations.

**WEST VIRGINIA
WVPTI, Inc.**

The People’s Advocacy Information and Resource Services (PAIRS) project will empower and educate families and challenge the State to carry out a system of long term health care that is centered on the individual and their family, provides support in the most integrated setting, treats people with dignity and respect, and provides real, informed choices in quality health care across the State. This grant will establish new capacity within West Virginia to provide information and education to families who have children with special health care needs.

The goals of the PAIRS project are to:

- Establish a recognized and utilized FamilyToFamily Health Care Information and Education Center in WV.
- Educate individuals and their families about effective health care options in the community.
- Maximize community-based options for health care for children with special health care needs.
- Promote the philosophy of individual and family directed supports.

- Provide education and training opportunities for families and match families together.
- Collaborate with other individuals and organizations that promote community health options.

Through the grant a coordinated resource center will be developed to support an estimated 3,000 families. Products will be available from multiple sources to meet individual family needs. Fact sheets and Web-based

educational materials will be available upon request. Products of the Project include:

- A PAIRS Center Web Site.
- A Toll free information and referral line.
- A PAIRS Advisory Committee composed of key individual and organizational stakeholders.
- At least 15 public Forums statewide.

FMI: More information on the Real Choice Systems Change Grants for Community Living program and the 2004 grantees, including a full list of grant recipients with state contacts and grant summaries, can be found online at <http://www.cms.hhs.gov/systemschange/compedium04.pdf>.

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