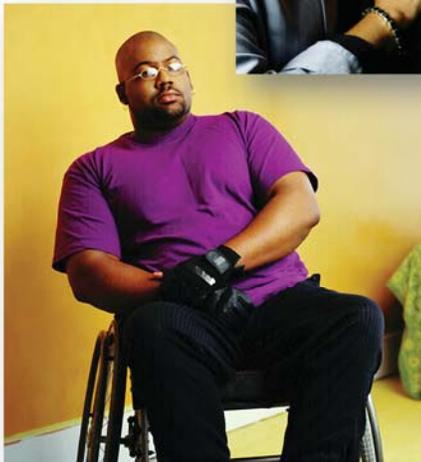# Real Choice Systems Change Grant Program

*FY 2003 Grantees:
Final Report*

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FY 2003 Grantees: Final Report

Janet O'Keeffe, Dr.P.H., R.N.
Christine O'Keeffe, B.A.
Wayne Anderson, Ph.D.
Angela Greene, M.B.A., M.S.

Prepared for

Submitted by

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

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Report Overview

In fiscal year (FY) 2001, Congress began funding the Real Choice Systems Change Grants for Community Living program (hereafter Systems Change grants) to help states make enduring improvements in their long-term services and supports system infrastructure. The grants' purpose, as stated in the invitation to apply, was "to enable children and adults of any age who have a disability or long-term illness to (1) live in the most integrated community setting appropriate to their individual support requirements and preferences; (2) exercise meaningful choices about their living environment, the providers of services they receive, the types of supports they use, and the manner in which services are provided; and (3) obtain quality services in a manner as consistent as possible with their community-living preferences and priorities."

The Centers for Medicare & Medicaid Services (CMS) awarded the third round of 3-year grants on September 30, 2003. Three categories of grants were awarded: Research and Demonstration grants (48), Feasibility Study and Development grants (16), and Technical Assistance grants (9).

The number and type of Research and Demonstration grants awarded were as follows:

- 8 Community-Integrated Personal Assistance Services and Supports (CPASS) grants

- 9 Money Follows the Person Rebalancing Initiative (MFP) grants

- 12 Independence Plus (IP) grants

- 19 Quality Assurance and Quality Improvement in Home and Community-Based Services (QA/QI) grants

The number and type of Feasibility Study and Development grants awarded were as follows:

- 6 Community-Based Treatment Alternatives for Children (CTAC) grants

- 4 Respite for Adults (RFA) grants

- 6 Respite for Children (RFC) grants

Nine states were awarded Family-to-Family Health Care Information and Education Center (FTF) Technical Assistance grants. The total number of grants awarded was 73.

Virtually all of the FY 2003 Grantees received 1-year or longer no-cost extensions to complete their grants, and they submitted their final reports 90 days after the grants ended, most by December 31, 2007. RTI is preparing a series of final reports to document the

outcomes of the Systems Change grants. This report documents the outcomes of the FY 2003 Grantees.

Methods

The principal sources of data for this report were (1) Grantees' semi-annual, annual, and final reports; (2) Grantee-prepared project reports; (3) topic papers prepared by RTI on activities and accomplishments of the FTF Grantees, increasing options for self-direction under the IP Grantees, improving quality management systems under the QA/QI Grantees, and initiatives of the MFP Grantees; and (4) materials developed under the grants. RTI used these reports and materials to prepare final report summaries for each grant, which were then reviewed by key grant staff. The RTI Project Director conducted in-depth interviews to obtain additional information and to clarify information with each Grantee; the revised summary was sent to grant staff for their final review and approval.

Organization of This Report

This report is divided into six parts. The first four parts each provide an overview of the enduring improvements, continuing challenges, lessons learned, and recommendations of the 48 Research and Demonstration Grantees, organized by the four types of grants: CPASS, MFP, IP, and QA/QI. Following the overview in each part is a section containing a detailed summary of each Grantee's initiative.

Part 5 provides an overview of the FTF Grants, followed by brief summaries of each grant initiative. Part 6 contains an overview, followed by brief summaries of the Respite for Adults and Children, and Community-Based Treatment Alternatives for Children grants.

The individual grant summaries describe the Grantees' major accomplishments resulting from numerous activities to address key long-term services and supports issues. In most cases, these accomplishments were essential preliminary steps in the systems change process. In addition to their many accomplishments, virtually all Grantees reported a wide range of enduring improvements that directly or indirectly helped to create a better and/or more balanced service delivery system. In some states, grant activities have acted as a catalyst for additional systems change activities since the grants ended.

Enduring Systems Improvements

Grantees made enduring systems improvements in several areas—many states in more than one area:

Personal Assistance Services and Supports (PASS)

- New policies to enable and support PASS and self-directed PASS

- Increased options for self-directed PASS

- Increased access to self-directed PASS

- Improved quality of PASS for persons with serious and persistent mental illness

- New methods to recruit and retain workers

Money Follows the Person Policies (MFP)

- New assessment and budgeting process for individualized portable budgets

- New MFP funding mechanism

- New infrastructure/funding to support transition services and MFP policy

- Increased access to and funding for home and community-based services (HCBS)

- Increased access to and funding for supported housing

- New process to involve consumers in policy development

Self-Directed Services

- New infrastructure for self-direction program

- New Independence Plus self-direction option in waiver or State Plan program(s)

Quality Assurance and Improvement

- New provider standards or monitoring tools

- New or improved system to collect, analyze, and report quality data

- New or improved methods to measure participant satisfaction and other participant outcomes, and new processes to involve participants in policy development

- New/improved critical incident reporting and/or remediation process or system

- New methods to involve participants in QA/QI processes and policy development

Lessons Learned and Recommendations

In the course of implementing their initiatives, Grantees gained expertise in developing and implementing policies and programs to achieve their goal to establish a more balanced long-term services and supports system and to ensure that improvements would be sustained. They reported numerous lessons learned that can guide other states that are pursuing similar systems change efforts.

Involving Participants and Stakeholders

Virtually all of the FY 2003 Grantees agreed that it is essential to involve consumers and other stakeholders in systems change initiatives to obtain stakeholder buy-in and commitment. Stakeholders include individuals or entities that will have authority over or be affected by planned changes: most importantly, the individuals who use services, their families and advocates; community and institutional service providers; Medicaid and other state agency staff; policy makers; and housing authorities.

Involving stakeholders in the development of new policies and programs can help to reduce the apprehension of some stakeholder groups and to ensure that new programs and policies are designed to meet participants' needs within federal parameters.

The involvement of service users, in particular, provides a valuable reality check for program and policy initiatives and can help drive systems change in ways that state staff cannot. It is also essential to ensure broad, strategic participation of stakeholders with the authority and responsibility to bring about change. Enlisting the support of top administrators and securing the commitment of relevant leaders can help to ensure that resources will be committed to a new initiative and that information about systems changes will be communicated to those whose work will be affected.

Both time and resources are needed to achieve buy-in from key stakeholders and to convince them to adopt new ideas and approaches. Stakeholders need to be involved in many activities: from advisory groups to work groups to focus groups. It is also beneficial to provide a forum in which service users and providers can hear about one another's concerns and gain an understanding of the limitations of the long-term services and supports system. Project staff need to clarify what is expected of stakeholders, and, if their input is solicited, be prepared to respond to it.

Sufficient time must be allocated to promote and sustain teamwork and stakeholder collaboration and networking to create the momentum needed to reach consensus on priorities and strategies. Additionally, comprehensive systems change efforts need an effective strategy for communicating with all stakeholders on an ongoing basis. Successful

strategies generally require multiple communication methods, such as meetings, e-mail, postings on state department websites, and teleconferences.

Internal communication among state decision makers is crucial to obtain buy-in by management and to ensure ongoing success. State agencies should report progress transparently, encourage stakeholders to review and provide comments on early product drafts, and celebrate milestones achieved. Having a full-time project manager can help states to develop a comprehensive and coordinated communication strategy, and executing Memoranda of Understanding can help to ensure that key stakeholders provide promised support, such as collecting data.

The state staff who develop and will operate new programs are also stakeholders. One Grantee emphasized the importance of a collaborative approach when developing self-direction policies and procedures that will cross systems serving different populations. Doing so will result in a comprehensive design that minimizes duplication while allowing for differences as needed. Another noted that states seeking to implement a single Quality Management System for multiple service delivery systems serving different populations are well advised to spend the time needed to engage all stakeholders in establishing priorities for the project *prior* to submitting a request for funding. When representatives of different service populations could not agree about design and implementation features, grant staff in one state found it helpful to get them back on track by reminding them of their initial agreement about priorities.

Other recommendations include the following:

- Contract with a knowledgeable outside entity to facilitate stakeholder meetings, and convey a national perspective on self-direction. Because stakeholders may disagree, this is a highly effective approach for reaching consensus.

- Use an independent research group to inform the discussion when stakeholders cannot agree on a particular approach to designing new program components, such as methods for assessing need and determining the amount of an individual budget. This approach can be very effective, but if the research group is unfamiliar with developmental disabilities (DD) services, for example, they may have difficulty understanding the complexities of the DD system.

- Use consumer surveys to identify individuals who are interested in serving on a committee, thus providing a pool of service users who can be contacted as needed, because it can be difficult to recruit service users to work for an extended period on an advisory committee.

- Provide supports such as transportation, stipends, and information in accessible formats to ensure ongoing participation. Focus groups and key informant interviews

are excellent ways to obtain input from diverse service users and families, not just those able to serve on advisory committees and work groups.

- When developing a quality management system, states should base their analysis of the system's performance on what program participants consider to be most relevant to them. Focus groups can be useful in identifying what is important to participants, and obtaining their input validates and provides credibility for the performance measures.

Specific Recommendations

Grantees also had lessons learned and made recommendations specific to the focus of their grants. For example, Wisconsin MFP grant staff conducted transition training for county staff, judges, guardians, and guardians ad litem and advised that states not underestimate the time and resources needed to successfully educate these stakeholders. They further noted that talent and commitment are also critical components; without them, transitions will be compliance driven and could have a negative impact on the quality of supports, as well as the health, safety, and personal growth of individuals being transitioned. Guardians and guardians ad litem need to be informed and involved, and mediation occasionally is needed when a lack of trust at any point in the process or among any of the parties jeopardizes transitions that are critical to an individual's best interest.

Other MFP Grantees stressed that each transition is unique; many factors determine whether a transition will occur, and nursing facility transition programs cannot anticipate every possible transition barrier. Thus, nursing facility transition programs and policies should have maximum flexibility to cover transition-related services and expenses, which is particularly important when transitioning individuals with extensive and/or complex needs. Another MFP Grantee noted that nursing facility transition program staff should not limit their efforts to individuals who are easy to transition, thus putting those who face challenges at the bottom of the transition list. With additional time and effort, even individuals who face many transition challenges can move to the community. States also should provide the flexibility to allow the development of customized transition teams to accommodate time, travel, and resource constraints in rural areas.

Many CPASS and IP Grantees made recommendations specific to implementing self-direction programs, including the need for states to conduct ongoing outreach, education, and training to help stakeholders—particularly long-term services and supports professionals such as case managers—make the paradigm shift from a traditional service delivery model to a self-direction model. Traditional service providers may be unfamiliar with the self-direction model or may have long-held negative views regarding the ability of people with disabilities to direct their services.

To assist case managers in making the shift from working in the traditional service delivery system to one that allows individuals to direct their services, states first need to understand case managers' fears and concerns and then address them systematically by using research findings and lessons learned from other states' experiences. To reduce the potential for provider resistance to a new self-direction option, it is important that the state frame the new option as one service delivery model in a continuum of options for managing services, including the traditional agency service option. This approach can help to defuse provider opposition as well as to promote informed choice by service users. In addition, to increase professional staff's knowledge of self-direction options, states should provide continuing education or licensing credits for completing training about self-direction.

One program initially had a "cumbersome and complicated person-centered planning process" that limited support brokers' effectiveness in working with participants and hindered program enrollment. Grant staff simplified the process and recommend that other states not "person-center the process to death like we did." Instead, they recommend that states staff the service planning and development process prior to implementation, with the goal of simplifying it to the extent possible.

Finally, successful outreach efforts for a new service delivery option, such as self-direction, require that individuals and families be informed about the full range of service options available to them early in the referral process. Additionally, participants and their families need education to understand the new program, and many may need training to succeed in directing their services and supports. Participant education and training materials should be developed with participant input to ensure that materials are effective and meet participants' needs.

QA/QI Grantees made numerous recommendations for implementing new QA/QI initiatives, including the following:

- States should determine where additional funding might be needed to finish work begun under a grant, and/or to supplement grant funds, because technology development often costs more and takes longer than anticipated, especially when integrating new systems with existing ones. This is particularly true when information about the existing system is unavailable and must be researched during the project.

- Whenever possible, states should combine any data system development projects in the quality area with other data systems and projects related to financial systems or other mandated reporting systems. Doing so will help to ensure ongoing financial and technical support for the quality data systems.

- Before designing new data management systems, it is essential to carefully consider how the data will be used and who is the target audience for particular data (e.g.,

CMS or the state legislature). Doing so will help to ensure that the new system provides the needed data. Systems should be designed to provide sound information when needed and to have the capability to quickly and easily identify trends, key issues, and patterns, to enable rapid resolution of program participants' problems.

- States may need to educate the audience for quality data about how to interpret such data. If the data are misinterpreted and used against providers, the providers will be reluctant to provide data in the future.

- States should find ways to identify high performers and provide incentives for high performance, which will help to embed a new quality management system into professional practice in a way that simple compliance systems can never achieve. This goal will most likely require some creative work with providers, advocates, participants, and families to identify ways to recognize excellence.

Approaches to Bringing about Systems Change

Several Grantees reported lessons learned and made recommendations for bringing about systems change generally, including the need to be realistic about what can be accomplished when attempting to implement change within a specified time period. Because progress is often incremental, it may be necessary to focus initially on one or two small changes, particularly when seeking to make major changes to a state's system for ensuring the quality of HCBS. Instead of trying to introduce changes in multiple agencies at the local, regional, and state level in a short time period, it is better to pilot new programs and policies in a limited area.

To ensure the success and sustainability of systems changes initiatives, Grantees noted the importance of several factors, most importantly, planning for sustainability from the beginning and incorporating grant goals and objectives into a state's long-term system reform plan to ensure that grant-related accomplishments will be sustained beyond the life of the grant. For example, a QA/QI Grantee noted that prior to committing resources to QA/QI initiatives, states need to conduct an assessment to determine which activities have priority and ensure that all activities are aligned with existing or planned quality management initiatives.

Others cited the importance of building on former or current systems change efforts or linking them to ongoing, high-profile initiatives such as an expansion of Medicaid managed care, a new quality assurance and quality improvement initiative, the development of an Aging and Disability Resource Center, or other major grant initiatives.

Recommendations for Changes in State and Federal Policy

Given that the Systems Change grants were intended to be catalysts for incremental improvements in states' long-term services and supports systems, most Grantees reported continuing challenges and made many recommendations for changes in state and federal

policy to address them. Although Grantees made many recommendations for policy changes that were state specific, many of their recommendations apply generally to all states, including the following:

Money Follows the Person and Transition Policy

- To facilitate transitions, certain waiver operational policies need to be changed, such as those requiring that residents be discharged from a nursing facility before waiver-funded home modifications such as a ramp installation can be made.

- States with waiver waiting lists need to allocate additional funding for more waiver slots.

- State agencies need to address the liability concerns of home health care staff regarding the health and safety needs of persons with complex needs who are transitioning to the community, so that these concerns do not become barriers to community living.

- To support community living, states should fund development of housing, transportation, and health care in rural areas, which often have far fewer services and supports for people with disabilities than do urban areas.

- Housing authorities should consider giving priority on their waiting list to transitioning nursing facility residents, although this may be difficult given the number of homeless people, particularly women with young children, on the waiting list.

- Because lack of affordable, accessible housing is a major transition barrier, states should implement policies that will permit waiver participants to retain sufficient income to pay for community housing (e.g., through Medicaid rules governing post-eligibility treatment of income). States should also extend the cost-sharing exemption for nursing facility residents from 1 month to 6 months.

- HUD should establish an accessible and easy-to-use process for institutional residents to apply for publicly subsidized housing. Currently, individuals must apply in person, which is difficult if not impossible for nursing facility residents who must arrange for accessible transportation to make multiple trips for multiple applications to multiple HUD housing sites.

Self-Direction

- States should increase efforts to serve individuals with a primary diagnosis of serious mental illness in traditional PASS programs and should develop self-directed support services that can help to prevent institutionalization among this population. For example, self-directed PASS could be used to assist individuals with deficits in instrumental activities of daily living as part of their recovery plan.

- Participants' views are essential for informing self-direction policy and practice, and help to inform planning to expand these services. States should offer participants multiple opportunities to report their experiences, particularly when changes are being implemented in the service system. Although the process can be expensive and difficult logistically, participants should be surveyed about their experiences and satisfaction with services and supports.

- The state should allow more flexibility in Medicaid HCBS programs to enable participants to purchase goods and services that can help ensure more favorable health and functional outcomes.

- The Deficit Reduction Act, which created the §1915(j) authority, requires that financial management services (FMS) be paid as an administrative expense, with a federal match of 50 percent. For states with higher service match rates (e.g., 70 percent in Montana), a 50 percent rate for FMS limits the state's ability to expand the IP model to State Plan services. A statutory change is needed to allow FMS to be reimbursed at the service rate.

Quality Assurance and Improvement

- Quality management for HCBS needs ongoing state and federal financial support. Because investments in information technology are essential to improve QA/QI systems, CMS should provide a 90 percent federal match for states to develop data systems that enable them to meet the waiver assurances, even if they are not directly part of the Medicaid Management Information System. CMS should also consider funding continuing costs for IT systems as well as the initial costs for IT development.

- CMS should amend the Participant Experience Survey to add an option for field notes, which would facilitate the survey process. The PES provides ample aggregate-level outcome data that identify programmatic challenges in many service areas. However, the tool does not provide insight into a program's micro-level dynamics. Adding an option for field notes would compensate for the tool's limitation.

- CMS should shift its primary quality management focus from emphasizing regulatory compliance to measuring outcomes—or at least achieve a better balance between the two.

- CMS needs to provide consistent reinforcement of—and help states to better understand and implement—a systems approach to quality management. Also, CMS regional staff who review and approve waiver applications and those who conduct periodic reviews of waiver programs need to better understand the concepts and requirements of a systems approach to QA/QI. Continuing education for CMS staff in this area would be helpful.

- To help states ensure that the data they collect are in accord with the CMS Quality Framework and the waiver assurances, CMS should clarify that the waiver

assurances differ from the domains in the Quality Framework, even though some appear to be the same (e.g., service planning). The Framework needs to be clarified to ensure that states' data meet waiver requirements.

▪ CMS wants states to automate data collection and reporting, but most states have old hardware and software, and the cost to upgrade is very expensive. To obtain the federal 90 percent match for new hardware, states need to fill out a complicated Advance Planning Document (APD), which is extremely time consuming. One Grantee noted that it would take one employee a full year's work to develop an APD. CMS needs to streamline the process for obtaining the 90 percent match to enable states to update their data systems.

▪ States should consider contracting with Quality Improvement Organizations (QIOs) to conduct quality management activities, because it can help to assure the public that the reviews will be objective. Another advantage is that CMS provides a 75 percent federal match for approved QIOs.

▪ CMS should establish uniform requirements for unlicensed Medicaid providers.

Increasing Access to HCBS and Supporting Community Living

▪ States should consider using one of the new HCBS options under the Deficit Reduction Act of 2005 to develop programs that will serve a broader target group of individuals with a wide range of needs.

▪ The state should lessen the stringency of its level-of-care criteria for nursing facilities.

▪ All states without a Medicaid Buy-in policy should adopt one to reduce work disincentives for persons with disabilities.

▪ Asset rules for Medicaid eligibility should be liberalized for individuals with permanent and significant disabilities who want to work and become independent. Florida needs to obtain a waiver from CMS that will permit participants with Individual Development Accounts (IDAs) who transition to Disabled Adult Child/Title II eligibility to have IDA assets disregarded when determining eligibility for Medicaid. Such an approach is used for accounts established under the federal Assets for Independence Act (AIA). Eligibility for public benefits is not affected by AIA accounts and should not be affected by IDAs. (More information about AIA accounts can be found at the following site: http://www.acf.hhs.gov/programs/ocs/afi/assets.html.)

▪ HUD should increase funding for housing models that promote independent living and self-direction. To ensure accessibility, HUD should also fund pre-development costs, property acquisitions, and home modifications. Ensuring accessible housing is a HUD responsibility, but because of a lack of funding, it is passed to the Medicaid program, which pays for home modifications.

- CMS and HUD should coordinate housing and services policy to enable individuals with disabilities to live in the community. HUD should increase funding for rental assistance and the development of affordable, accessible housing.

- CMS should provide resources to states to purchase local technical assistance (TA) to help improve the HCBS system. National TA providers often lack knowledge of individual state programs, policies, and politics—knowledge that is crucial for devising strategies to bring about systems change.

- CMS should have a process to ensure that changes in HCBS policy—as communicated in Olmstead Updates to State Medicaid Directors—are integrated into the §1915(c) HCBS waiver application template and instructions.

- CMS should continue investing resources in state infrastructure development to help improve the HCBS system for people of all ages with disabilities. The Systems Change grants have been invaluable for this purpose: allowing states to tailor the funds to meet unique needs. The grants provided resources that would not otherwise have been available. The flexibility afforded by the grant enabled the states to think "outside the box" and to adapt to changes resulting from frequent staff turnover without "jumping through a lot of hoops."

  However, much more infrastructure development is needed, along with additional funding to continue it. Systems change initiatives require a considerable amount of time to implement and need funding for more than 3 years. Access to grant funding is and will continue to be critical to help states fully implement the systems and technological innovations necessary to meet CMS requirements for §1915(c) evidence-based reporting.

Conclusion

Bringing about enduring change in any state's long-term services and supports system is a difficult and complex undertaking that requires the involvement of many public and private entities. As Congress and CMS intended, most states used the grants as catalysts for new initiatives or to expand existing initiatives; many used them to leverage funding for existing state efforts to develop and improve home and community-based services.

Despite their many accomplishments and enduring systems improvements, most Grantees described continuing barriers to community living for people of all ages with disabilities. These barriers include insufficient funding for home and community-based services and for infrastructure changes; lack of affordable, accessible housing and transportation; continuing difficulty in recruiting and retaining direct care workers because of low wages and lack of benefits; and outdated or inflexible administrative, statutory, and regulatory provisions.

This report provides an overview of 73 Grantees' initiatives to improve their long-term services and supports systems and the enduring systems improvements they achieved. It

includes lessons learned and recommendations that can guide states that are undertaking similar initiatives. As the population ages, increasing the demands on the service system, these Grantees' efforts will prove invaluable, helping states to provide a greater choice of high-quality participant-directed home and community-based services. These services will enable people of all ages with disabilities or chronic illnesses to live in the most integrated setting consistent with their needs and preferences.