

Synthesis of Findings from System  
Change Grant Programs

October 18, 2012

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## I. INTRODUCTION

The Disabled and Elderly Health Programs Group (DEHPG) within the Centers for Medicare & Medicaid Services (CMS) has funded a series of grant programs designed to promote change in the long-term care system so that states rely more on home and community-based services (HCBS) rather than institutional care. This report summarizes the findings and recommendations from those grant programs.

Chapter II of this report presents the cross-cutting findings that emerged from the review of grant reports. Because these findings appeared across multiple grant programs, they tend to highlight broader issues related to collaboration, planning, and federal policies and regulations. When possible, we identify policies and programmatic and legislative changes that have addressed, at least in part, particular findings. Chapter III includes detailed information on the key lessons learned and recommendations for each of eight attributes of a well-functioning long-term services and supports (LTSS) system.

## II. METHODS AND STUDY LIMITATIONS

### A. Methods

To identify the program-specific lessons learned and recommendations, Mathematica Policy Research reviewed the final report—or an interim report when a final report was not available—for each of 10 grant programs selected by CMS for inclusion in the report. Staff in DEHPG administered these programs. Although the final and interim reports for the 10 programs were our main data source, for some programs, we reviewed additional reports as well. The 10 grant programs including the following:

1. Real Choice Systems Change Grants (RCSC)
2. System Transformation Grants (STG)
3. Person-Centered Planning Grants (PCP)
4. Medicaid Infrastructure Grants (MIG) and Medicaid Buy-In Programs
5. State Profile Tool Grants (SPT)
6. Hospital Discharge Planning Grants (HDP)
7. Psychiatric Residential Treatment Facilities Grants (PRTF)
8. Aging and Disability Resource Centers Grants (ADRC)
9. Money Follows the Person Demonstration Grants (MFP)
10. Direct Service Workers Demonstration Grants (DSW)

The findings and recommendations are organized by eight attributes of a high-performing long-term care system. Appendix A links the reports consulted with each attribute. The development of these eight attributes was guided by work done by AARP, the Commonwealth Fund, and the SCAN Foundation to construct a state scorecard on LTSS (Reinhard et al. 2011). We chose this approach to organizing the findings and recommendations to provide a framework for highlighting how these grant programs have worked together to address several different aspects of the long-term care system. The eight attributes are:

1. Accessible HCBS
2. Systems that support transitions among settings and service systems
3. Comprehensive single-entry point/no wrong door systems for accessing community-based LTSS
4. Person-centered planning and service delivery
5. Employment supports for people with disabilities
6. Adequate supply of direct service workforce and adequate support for caregivers
7. Adequate supply of housing to support community-based living options
8. Quality assurance and quality improvement systems

To identify findings for each attribute, we reviewed the relevant reports and developed summaries of the key lessons learned and recommendations suggested by the report(s). We then identified findings and recommendations that appeared across programs and attributes; these are the findings described in Chapter III.

## **B. Limitations**

The programs included in this review are only a subset of those funded by DEHPG; the report is not meant to be comprehensive review of all programs funded over the past few years. It should be noted that, for some programs, the only reports available were interim reports, which generally do not include definitive findings or recommendations. Additionally, for two programs, no reports were publicly available. Finally, some reports were several years old and written before passage of the Patient Protection and Affordable Care Act of 2010, which changed the health care landscape significantly and introduced an array of new initiatives designed to strengthen the long-term care system. Whenever possible, we identified recent CMS policies and programmatic changes that may address, in part, some of the cross-cutting findings. Because we are not aware of every step CMS and staff within DEHPG have taken to address these particular findings, this part of our review should not be considered comprehensive.

### III. CROSS-CUTTING FINDINGS

The following findings frequently arose across the different grant programs. Most of these findings and recommendations were developed before the passage of the Affordable Care Act of 2010. As a result, several issues described here are being addressed to some extent through initiatives introduced by that legislation and other recent legislative and policymaking actions. We have noted when the authors were aware of steps taken to address a particular issue.

Collaboration on system change initiatives takes time; buy-in and involvement by key stakeholders should start at the planning stage and continue through program implementation. Developing the necessary buy-in for system change is time-consuming, particularly when the collaboration involves entities that typically do not work together, such as Medicaid and agencies that provide employment or housing supports. As a result, recommendations frequently included requests for more planning grants and more resources and time to design interventions and longer grant periods.

Current initiatives that may, in part, address this issue. CMS partly addresses this issue through state planning grants. As part of the MFP national demonstration, CMS has awarded planning grants to help states with the initial development phase of a new initiative that requires collaboration across several different state agencies (departments on aging, developmental disabilities, and mental illness) and between the Medicaid program and providers. In addition, the Balancing Incentive Payment (BIP) program introduced by the Affordable Care Act provides enhanced funding to help states build collaboration among a wide variety of stakeholders at the agency and provider levels to create single-point entry systems, conflict-free case management, and a uniform needs assessment tool.

States would like more flexibility in waiver and benefit design and covered services. Almost all grant programs echoed this finding. States frequently mentioned that they want more flexibility in the services they provide through waivers, particularly in the areas of mental health, youth transitioning to adult services, and assistive technology. For example, they want the Medicaid definition of assistive technologies to be more flexible because of the rapid pace with which new technologies are introduced. States want this flexibility because, in part, they have problems financing an array of services that promote aging in place, including provider training programs for new assistive technologies, and medication assistance services and onsite resident service coordinators for people in congregate, publicly financed housing settings.

Current initiatives that may, in part, address this issue. The MFP demonstration allows states more flexibility regarding transition services, including the provision of some waiver services before a Medicaid beneficiary transitions from institutional care to the community and formally enters a waiver program. In addition, the Affordable Care Act introduced several new options that provide states more flexibility in their provision of HCBS, particularly personal care assistance services, including the Community First Choice Option and the revision of the 1915(i) program.

Although states want model programs and information on best practices from which to build new system change initiatives that are standardized, equitable, and evidenced based, they also want to individualize models and practices to fit the needs of their state or a particular locality. The findings from several grant programs indicated that states would like more information on best practices and details on model programs to help them implement new evidenced-based initiatives. However, many findings also indicate that states want to tailor a program to the needs of the local community.

Modifying a standard model might provide a better fit for the local community or organization, but these modifications can increase the complexity of program implementation and lead to situations in which not all individuals receive the same program or services. Importantly, tailoring programs makes it more difficult to make strong conclusions about the effectiveness of a model or program, or to identify the keys to success.

Current initiatives that may, in part, address this issue. We are not aware of specific efforts to create an overall public-use catalogue or warehouse of best practices in LTSS, but several current programs administered by DEHPG include technical assistance contracts that collect and share information on best practices among grantees. Examples include the technical assistance contracts for the national MFP demonstration and the ADRCs and the National Quality Enterprise.

More and better data are needed to demonstrate the effectiveness of programs. The conclusion of most grant programs reviewed was that states needed ongoing support with their data to help them provide clear evidence for policymaking. Demonstrating program effectiveness is increasingly the key to the long-term sustainability of programs and initiatives. For example, the type and quality of data on personal assistance and mental health services is highly variable across states, making research on these services challenging and at times impossible. States would also like assistance with analyses of survey data and preliminary interpretation of information related to the quality of their community-based LTSS. The research support provided to the MIGs may be an effective strategy for other data and research issues because this support helped to strengthen state research abilities and provided them tools to advocate for the Medicaid Buy-In program with state legislators.

Current initiatives that may, in part, address this issue. CMS currently has a series of Medicaid learning collaboratives and one collaborative is focused on helping states strengthen their data and data analytics more generally. Specific to LTSS is the CMS effort to develop an HCBS taxonomy, which represents a key step to helping states use more uniform definitions for key services, such as personal assistance, residential care, and habilitation. Clearer definitions will improve the quality of the information available at both the state and national levels. CMS, along with the Agency on Healthcare Research and Quality (AHRQ), have been developing HCBS quality measures based on inpatient admissions. Uniform measures such as these address the desire for new tools that LTSS programs can use to provide clear evidence about their initiatives. However, these measures are relatively narrowly defined and states are likely to want an array of measures that capture the breadth of LTSS they provide.

Similarly, states need support for strengthening their data and information systems through data integration. The MIGs research work demonstrated that by promoting better data integration, CMS can (1) reduce state reporting burdens, while improving overall data quality; (2) create a supportive environment for states to improve their own monitoring efforts; and (3) demonstrate the benefit of cross-agency collaboration and integrated data at the federal level, which encourages data sharing and rigorous research and evaluation at the state level. To continue improving the information infrastructure serving people with disabilities, existing databases should be expanded by adding data about other populations—for example, individuals receiving benefits counseling—or other types of services (such as housing and training). To inform future LTSS policy at the state level, states need help using information that ADRCs collect on the supply and demand for HCBS. The HDP grants indicate that hospitals and other community-based providers often do not have the data systems to support improved transitions, such as data that identify individuals with disabilities and that track people after discharge.



The development of single-point entry/no wrong door systems have several information challenges including technical issues related to linking systems from different agencies.

Current initiatives that may, in part, address this issue. We are not aware of any CMS initiatives that specifically promote the integration of data across state agencies. A Medicaid learning collaborative on information technology infrastructure is bringing states together to identify ways of improving the design and efficiency of state data systems. More directly related to LTSS is the BIP program, which will help states strengthen their information systems primarily through the single-point entry systems that participating states will have to develop. Well-functioning single-point entry systems require a well-integrated, state-level information system. The development of uniform assessments might also help states integrate data if the assessment information collected is captured in one location and then integrated with eligibility information from all agencies that provide LTSS. In addition, some grant programs, such as the MFP demonstration, have provided states additional financing to strengthen their data systems for grant reporting and monitoring purposes. Lastly, CMS has been developing more data reporting requirements for newer programs, such as the Community First Choice Option, which requires states to report on a large number of program indicators. The Medicaid administrative data states are required to report on a quarterly basis are also under review and states will most likely be required to submit more detailed Medicaid eligibility and claims records in future years.

Grantees need clear guidance regarding federal financial participation, covered services, and the definition of various eligibility criteria. Grantees reported that ambiguous, overly complex, and/or changing regulations have led to confusion, misinformation, and uncertainty. Uncertainty about covered services and the effect of proposed regulations hindered progress in some instances because stakeholders were less willing to implement program changes when federal guidance was not clear. Examples of instances in which grantees thought federal guidance was not clear included benefits counseling services and when Medicaid would cover them, policies for the provision and payment for the implementation of PCP models, requirements related to self-direction programs, and policies related to savings mechanisms and asset building programs. The MIG and Buy-In initiatives also indicate states would like a clear definition of work that does not conflict with the work definition used by the federal disability benefit programs.

Current initiatives that may, in part, address this issue. We are not aware of any CMS initiatives designed to address this finding.

States continue to struggle with finding meaningful ways for consumer participation in program design and monitoring. Obtaining consumer input is important because the consumer perspective is frequently different from that of providers, particularly in the areas of quality (what constitutes quality and how it should be measured) and determining service needs (not all consumers and their families view community living as a goal). Some grantees have found consumer surveys to be a powerful tool for empowering people with disabilities and capturing the different perspectives of different populations.

Current initiatives that may, in part, address this issue. Other than the national MFP demonstration which encourages consumer involvement and requires the administration of participant quality of life surveys, we are not aware of any other CMS initiative designed to address this finding.

Several notable barriers to community living remain. These barriers include the lack of affordable, accessible, and safe housing; transportation services, particularly for people with disabilities who want

to work; and the ongoing shortage of LTSS providers, including behavioral health providers. The provider shortages include not only the general and ongoing shortage of direct service workers, but states frequently do not have adequate numbers of community-based providers capable of serving consumers with high needs or who need 24-hour care.

Current initiatives that may, in part, address this issue. CMS has been building a collaborative relationship with the Department of Housing and Urban Development (HUD) which has resulted in HUD's release of targeted housing vouchers to nonelderly people with disabilities who transition from institutional to community living. HUD's new 811 supportive housing demonstration also helps to improve housing options for people with disabilities, while providing states incentives to increase the collaboration between Medicaid and state housing authorities. DEHPG provided grant funding to six MFP states to help them enhance housing supports; most grantees used this funding to help them pursue the new 811 housing option. MFP grantees may also apply for additional 100 percent administrative funds to hire and train housing specialists. We are not aware of particular initiatives focused on transportation issues, but DEHPG continues to provide states assistance with the development of the direct service workforce to help alleviate the shortages most states face.

## IV. DETAILED FINDINGS AND RECOMMENDATIONS

### 1. Accessible Home and Community-Based Services

High-performing long-term care systems make community-based LTSS easily accessible and almost every state has received funding from CMS to improve the infrastructure for HCBS. The key CMS infrastructure grant programs in this area have been the Real Choice System Change (RCSC) Rebalancing and Comprehensive Systems Reform Grants (Abt 2011a; O’Keefe et al. 2009). Other key grant programs designed to help states improve the HCBS infrastructure have been the STG (Abt 2011a) and the MFP demonstration (Irvin et al. 2011). The following is a summary of the key lessons learned, findings, and recommendations from these grant programs related to system rebalancing, as well as related findings from the RCSC Family-to-Family Health Information Center (FHIC) grants (O’Keefe et al. 2009) and the Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities demonstration (Urdapilleta et al. 2011).

#### Lessons Learned/Key Findings

- Successful infrastructure building and systems change programs involve key stakeholders from the beginning and have a program champion within state government. It is important to involve stakeholders such as program administrators and managers, high-level state administrators, legislators, consumers, and service providers in grant and project planning. However, managing the stakeholder input process so that it does not become overly complex and hinder progress is challenging.
- Remaining barriers to community-based LTSS include (1) shortages of LTSS providers for specific types of services (such as around-the-clock support and personal care), non-medical transportation, and affordable and accessible housing; (2) insurance limits in the private market; and (3) Medicaid regulations that are ambiguous to states, which can lead to denials of services and are difficult to appeal.
- Factors that contribute to system transformation include (1) implementation of statewide systems for community-based LTSS and (2) triage systems that ensure those at risk are served in the community whenever it is appropriate to do so. These features, along with integrated care payment models and budget methodologies, promote the use of community-based LTSS.

#### Recommendations

- States would like CMS to advocate for (1) requiring the provision of HCBS under Medicaid, (2) requiring timely eligibility determinations, and (3) increasing the federal match for HCBS.
- New mechanisms are needed for making HCBS more accessible to more people. These new mechanism can include, but are not limited to: (1) expanding the Program of All-Inclusive Care for the Elderly (PACE) to cover dually eligible beneficiaries under age 55; (2) creating a federal program for wrap-around supplemental health care for children and adults with special health care needs; (3) raising the SSI income eligibility level; (4) lifting the moratorium on special needs plans; and (5) basing premiums for publicly subsidized health programs on a sliding scale.

- States would like to have more flexibility in how they design and implement their programs, particularly in the area of benefits. States would also like CMS to allow Medicare savings that result from managed long-term care programs to be used to fund LTSS in integrated programs.
- States would like the waiver approval process to be more streamlined and to have more time and resources to prepare program applications and to complete grant programs. When waiver amendments are considered, the states believe that the whole waiver should not be opened up for re-review. They would also like to have more funding for grant-planning activities (similar to the original systems change planning grants) and they believe grant programs should be for a period of at least five years, because it takes at least that long to make real change.
- States would like CMS to encourage the expansion of health care coverage for children and youth with special health care needs.<sup>1</sup> Many families of children with special health care needs have incomes too high to qualify for public programs, but too low to cover the cost of their children's medical expenses. Promoting Katie Becket waivers would be one approach and raising the income eligibility levels for the Children's Health Insurance Program (CHIP) would be another (for example, to more than 300 percent of poverty). At a minimum, states need to be encouraged to advertise the Early, Periodic Screening, Diagnosis, and Treatment (EPSDT) program because many families and health care providers are not aware of this program.

## 2. Systems that Support Transitions Among Settings and Service Systems

If not handled properly, transitions among care settings or systems can lead to discontinuity of care and declines in the health and functional status of individuals. High-performing long-term care systems have processes and procedures in place to facilitate coordinated transitions among various settings: from institutions to the community, from acute care hospitalizations to the community, and from the youth to the adult health care system. The key grant programs in this area have been the Real Choice Systems Change: EPSDT to Adult Supports grants (O'Keefe et al. 2009), the MFP grants (Irvin et al. 2011; Lipson et al. 2011), and the Person-Centered Hospital Discharge Model grants (HDM) (Ascellon 2009). The following is a summary of the key lessons learned, findings, and recommendations from these grant programs related to transitions among care settings, as well as related findings from the ADRC grants (Lewin Group 2006).

### Lessons Learned/Key Findings

- The EPSDT to Adult Supports grants found that new initiatives in this area are most successful when advisory councils that include the target population are involved at the beginning. In addition, the transitions in the mental health system, from the pediatric to the

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<sup>1</sup> This recommendation was from the RCSC EPSDT grants and may be addressed, in part, by provisions within the Affordable Care Act to expand Medicaid coverage to more people and helps states establish health insurance exchanges.

adult mental health care systems, are particularly difficult because of the shortage of providers and constrained funding for these services.

- Local providers often modify hospital discharge models because the full evidence-based model frequently does not fit the organization's needs. Nevertheless, when implementing a hospital transition program (1) project management experience is as important as subject matter expertise; (2) some organizations that want to implement person-centered discharge planning models do not always have the funding to train staff on the model, hindering progress; and (3) hospitals and community partners might have to improve existing data systems to better identify individuals with disabilities and to improve their ability to track individuals after they have left the hospital.
- People who might benefit from community-based LTSS have better access to these services when the ADRC is the entity responsible for conducting institutional level-of-care assessments, including those done at the time of discharge. Provider awareness of community-based LTSS options is also enhanced when nursing facility and hospital staff serve on the ADRC board.
- Transition programs that help people move from institutional to community-based care take time to establish. States need time to find qualified community organizations, train staff, and ensure they understand Medicaid and program rules as well as community resources. MFP programs that made the most progress early in the demonstration employ skilled, dedicated transition coordinators who have the passion, commitment, and creativity to do whatever is needed to help anyone who wishes to return to the community. These programs also hire separate housing coordinators who specialize in finding and securing appropriate housing for transitioning individuals; (2) give transition coordinators sufficient autonomy and the ability to provide extra HCBS when needed, and allow payment for one-time moving expenses and for services provided before an individual has left an institution; and (3) recruit potential MFP participants directly, regularly sending transition coordinators, outreach staff, and peer counselors to institutions to meet with residents. In addition, these states generally have project directors who have been in their role for many years, have considerable knowledge of Medicaid rules and systems, and spend a significant amount of time developing relationships with other agencies and stakeholders.
- Although current results suggest promising outcomes for MFP transition programs, states might have to pay close attention to what happens during the first few months after the transition because most re-institutionalizations occur during this initial period. In addition, states might have to work on integration issues for some time after the transition to the community because the MFP quality-of-life survey found that approximately one-third of MFP participants report low moods or barriers to community integration a year after the initial transition to the community.

## Recommendations

- Any type of transition program needs the collaboration of multiple agencies and/or providers. To obtain buy-in for systems change from both leadership and frontline staff, all collaborating agencies and providers need to be involved before an initiative starts and every entity needs a clear understanding of roles. Divergent business needs and inflexible operational guidelines of the various entities involved in youth transition, hospital discharge

initiatives, and facility-to-community transition programs can create challenges to collaboration. To stay on schedule, it is important when planning an intervention with multiple partners to schedule ample time in the work plan for dealing with barriers to collaboration.

- Lack of knowledge or misinformation among providers and other organizations regarding Medicaid and other funding sources can create barriers to care transitions. States and participating entities need clear and consistent guidance regarding federal financial participation for services that support care transitions. Uncertainty about covered services and the effect of proposed regulations can hinder progress.
- Programs need (1) knowledge of the evidence-based models being employed, (2) clear leadership and a project coordinator, (3) regularly scheduled check-in meetings with project staff, (4) good documentation of all processes to minimize disruption due to staff turnover or organizational changes, and (5) data that can convince other organizations to join the initiative. Promoting and discussing the care transition model with key staff from the originating provider can help increase visibility of the program, lead to more complete inclusion in planning meetings, and strengthen the initiative.
- Transition programs need ongoing contact with service coordinators to increase awareness of the services available to consumers and their families. Brochures and fact sheets can help raise awareness as well.
- It is important for health care providers to understand the consumer's and family's perspective. The concept of transitioning from the pediatric to the adult health care system is difficult for some families to grasp and might not be a priority when families have more immediate and pressing concerns. Therefore, significant family-based outreach and education is needed on an ongoing basis. Additionally, not all cultures or families view independent living as a goal.
- Peer counselors—individuals who have experienced the care transition—are frequently an important feature of care transition programs, particularly those focused on populations with mental illness. A peer counselor can assist with the transition and help with the adjustment to a new and different level of care.

### 3. Comprehensive Single-Entry Point/No Wrong Door Systems for Accessing Community-Based LTSS

A high-performing long-term care system allows people to obtain LTSS easily, no matter where or how they enter the long-term care system. CMS has had several funding opportunities designed to help states develop easily accessible LTSS through single-entry point (SEP) or no wrong door (NWD) systems. The key grant programs in this area have been funding for ADRCs (Lewin Group 2010; 2006) and the RCSC Family-to-Family Health Care Information and Education Center grants (FHIC) (O'Keefe et al. 2009). The following is a summary of the key lessons learned, findings, and recommendations from these grant programs, as well as related findings from the STG and a National Health Policy Forum report (Abt 2011b; O'Shaughnessy 2010).

## Lessons Learned/Key Findings

- Developing the information technology and management information systems (IT/MIS) that support SEP/NWD functions is a complex and time-consuming process. Specific challenges may include (1) technical issues linking systems from different agencies; (2) difficulty procuring IT/MIS vendors; (3) delays due to other agencies' activities, issues or concerns; and (4) consumer privacy issues that require the development of policies that protect privacy while facilitating data sharing among agencies. Due to the complexity of the issues that need to be addressed, establishing SEP/NWD functions usually requires more time and resources than anticipated by stakeholders, in some cases as much as three times the anticipated amount of time required for the task.
- Developing strong relationships between the ADRCs, Medicaid, and the agency that administers the state's income maintenance programs can help to facilitate the eligibility determination process which is often fragmented. In addition, physically or virtually co-locating staff involved in financial and functional eligibility determinations at the ADRC helps to streamline the eligibility determination process for people.
- Involving consumers in ADRC implementation in meaningful ways can be challenging. Strategies that facilitate involvement include (1) asking consumers to review and provide feedback on marketing messages, materials, and tools such as online resource directory systems; (2) establishing links with existing advisory committees; and (3) creating a separate consumer advisory board composed entirely of consumers. Internet-based tools, such as monthly e-newsletters, are another important means for communicating with stakeholders and consumers, particularly for those unable to attend meetings.
- The current level of federal funding for ADRCs might be insufficient to support their multifaceted agendas. At \$10 million, the federal appropriations for ADRCs in 2010 represented less than \$1 for each person receiving LTSS.

## Recommendations

- Staffing and leadership changes, insufficient staff capacity, and lags in hiring due to budget freezes and delays are common challenges when developing SEP/NWD systems. To address these challenges, states need to (1) develop relationships with new leadership as early as possible to secure program buy in, (2) appoint a dedicated project manager responsible for establishing and maintaining relationships with partner agencies and stakeholders, and (3) cross-train ADRC staff so they better understand the needs and values of the partner organizations.
- To increase the effectiveness of a SEP/NWD system, ADRCs need to be fully integrated into the state LTSS system. To achieve this integration, states must facilitate close coordination among ADRCs, centers for independent living, Medicaid, the agency that administers the state's income maintenance programs, and other partners. ADRCs need to be integrated into other Medicaid system reform initiatives and they must ensure that all LTSS users—including children and youth with special health care needs—have access to high quality information.



- Strong partnerships are the key to the success of a SEP/NWD initiative. These partnerships need to focus on data-sharing agreements and general protocols for working together. To increase the chance of success, partners need to be involved early in the planning process and each partner needs a project champion. States will benefit from setting clear and realistic expectations about the responsibilities of all partners. When starting a new initiative, selecting pilot sites that already have strong partnerships with key agencies has been found to be an effective approach.
- States need to include in their plans sufficient time for developing IT/MISs to support SEP/NWD functions. Specifically states should be encouraged to (1) provide adequate time and resources to determine IT/MIS needs and procure a vendor; (2) establish a systematic process for determining user specifications; and (3) create or utilize tools that facilitate re-engineering of processes, such as mobile input devices.
- Whenever possible, states should build on existing ADRC grants when attempting to create a one-stop shop for LTSS information; they should also network with other states implementing similar programs to build upon best practices.
- To inform state policy, states need additional support for using information that ADRCs collect about the supply of and demand for HCBS.

#### 4. Person-Centered Planning and Service Delivery

A well-functioning long-term care system supports person-centered planning (PCP). Although PCP is becoming more common across states, new programs under the Affordable Care Act—such as the Community First Choice Option program—require a person-centered approach to care planning. The following is a summary of key lessons learned and recommendations from the major CMS-funded grant program in this area, the Person-Centered Planning Implementation Grant program (Abt 2011b). Findings from the RCSC Living with Independence, Freedom, and Equality (LIFE) Accounts Feasibility and Demonstration Grants are also included (O’Keefe et al. 2009).

##### Lessons Learned/Key Findings

- Established PCP models that are easy for consumers, facilitators, and clinicians to implement and use are much more likely to be accepted by these stakeholders. In addition, train-the-trainer programs combined with easy-to-implement PCP models can lead to a large number of individuals being trained in PCP.
- Modifying existing PCP models to fit the unique needs of states and/or target populations has both benefits and drawbacks. Modifications that tailor a model can better meet the needs or preferences of consumers and families. However, modifications also increase the complexity of implementing, monitoring, and evaluating PCP models, and could lead to equity issues because of inconsistent implementation across a state.
- Factors that facilitate implementation of PCP include (1) cultivating supportive stakeholders, (2) conducting community roundtables when choosing a PCP model, (3) having a PCP process in place for at least one population before attempting to scale it to all populations, (4) utilizing skilled facilitators for PCP training, (5) having project champions at each location to



oversee implementation of the program at the local level, and (6) utilizing expert consultants to advise on grant activities.

- Barriers to PCP implementation include (1) confusion regarding CMS policies for the provision of, payment for, and monitoring of PCP services; (2) concern that PCP will add to administrative burden at the state level; and (3) concerns about regulatory requirements for documenting medical necessity.
- When done well, the PCP model takes more time to implement than the standard process, especially for grantees with little experience with PCP. States need a strong feedback loop, particularly when moving from the design to the implementation phase, to make sure that the model is considered on an ongoing basis and revised or updated appropriately and they need to realize that what works well for one target population might not work for another.
- LIFE accounts are one aspect of PCP that have not been widely adopted. The lack of extra income to invest in asset development has been a barrier to the success of LIFE accounts and similar initiatives. Strategies to address this barrier include (1) providing tax credits to third parties contributing to LIFE accounts, (2) providing a match for savings in individual development accounts for those who work, and (3) allowing Ticket to Work reimbursements to be used as a match for LIFE accounts.

## Recommendations

- Before selecting a PCP model for implementation, states and organizations need to research the well-known PCP models and understand whether a model was designed for a specific population.
- Agencies report that the expansion of self-direction has been slow because of additional administrative costs and Medicaid accountability requirements for the purchase of services and supplies. In some cases, these reasons are based on misinformation or a reluctance to change established policies and procedures. Further, not all consumers are aware of the option to self-direct their services and they need more consumer education.
- Opportunities exist to integrate, simplify, and build upon existing work incentive and asset-building programs (for example, linking and simplifying programs that serve people with disabilities), and to leverage existing resources and partners in this area such as individual development account partners, Volunteer Income Tax Assistance sites, AARP tax aid clinics, local asset-building coalitions, and Medicaid Buy-In programs. Strategies that help low-income people with disabilities build financial assets include (1) making asset building a key component of the MIGs and funding more grants on this topic; (2) increasing the time limit for savings accumulation under the Assets for Independence program; (3) allowing people to use their individual budgets to purchase items that increase independence; (4) permitting Medicaid Buy-In participants to have independence accounts; and (5) making LIFE accounts available to all Medicaid participants. In addition, the effectiveness of savings programs such as LIFE could be improved by policy changes allowing all individuals in subsidized housing (or on a waiting list for a Section 8 voucher) to utilize escrow accounts to save toward goods and services needed to become more financially self-sufficient.
- Concern about the effect of savings mechanisms, such as LIFE accounts, on eligibility for public benefits is a barrier to the development of these mechanisms. New legislation could

ensure resources acquired through such accounts do not affect eligibility for Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, or other federal assistance programs.

## 5. Employment Supports for People with Disabilities

Employment frequently factors into people's quality of life and sense of community integration. A high-performing long-term care system supports the employment aspirations of everyone who wants to work and ensures that the need for personal assistance services (PAS) and other LTSS does not pose a barrier to employment for those with disabling conditions. The key CMS grant program in this area has been the MIG program, which promoted the development of state Medicaid Buy-In programs (Kehn et al. 2010; Schimmel et al. 2010). State Medicaid Buy-In programs enable people with disabilities who are working to obtain Medicaid coverage when they are not eligible through other avenues. Other key grant programs include the Demonstration to Maintain Independence and Employment (DMIE) program (Whalen et al. 2012), which established wrap-around health benefits and employment supports aimed at postponing or preventing the loss of employment and the receipt of disability benefits, and the MFP demonstration (Irvin et al. 2012), which seeks to promote employment among MFP participants who have transitioned from institutional care to the community.

### Lessons Learned/Key Findings

- The Medicaid Buy-In program has been attractive to those in older age groups and those with psychiatric conditions. However, younger working-age individuals and those with a serious disabling condition who are not yet receiving federal disability benefits (SSDI or SSI) seem to have better employment and earnings outcomes while in the program than others. In addition, employment rates and earnings were higher among Medicaid Buy-In participants in states with more generous earned income limits, work verification requirements, and spousal earnings exclusions than for those who reside in states with more restrictive requirements.
- The DMIE interventions did not have significant positive impacts on earnings and effects on employment were mixed. The lack of effects on earnings and employment might reflect the requirement that all DMIE participants be employed at enrollment and changes were possible only through job loss.
- The national DMIE evaluation shows that early intervention can have a significant impact on reducing disability applications and on preventing or forestalling the receipt of federal disability benefits. As a result, early intervention services that build upon or wraparound existing programs to address the problem of underinsurance can be a cost-effective strategy to help participants maintain independence.
- Timing of participation in an early intervention program relative to one's disability status can be a critical factor in determining a program's impact, and the evaluation results of the DMIE suggest that early interventions might be more successful when focused on workers with relatively weak attachments to the labor force.
- Among MFP participants, about 31 percent reported either working or a desire to work. Life satisfaction was highest among those who worked and they had some of the highest levels of community integration.

- A number of MIG staff reported that lack of accessible, affordable, and reliable transportation continues to create barriers to employment and training in many areas of their states.
- It is partly because of the strong evidence MIG grantees provided to state legislatures that Medicaid Buy-In (as an optional Medicaid program) has been able to survive changing political and financial environments.
- MIGs operate within existing service structures for people with disabilities, which include multiple agencies with different missions operating within complex bureaucracies. These programs operate with federal, state, local, and private funding and are governed by an array of legislative committees and public and private bureaucracies. MIGs report that it takes time to obtain the knowledge and establish the personal networks required to make structural changes. Further, the 10-year MIG period has encompassed dramatically changing economic environments and state political systems. With each change in legislative and agency personnel, MIGs must begin again to educate key stakeholders about an employment-oriented agenda for people with disabilities.
- Support from the technical assistance providers, information exchanged between states, and the establishment of the Medicaid Infrastructure Grants Research and Technical Assistance Center (MIG-RATS) have been useful strategies for enhancing grantees' research capacity, at least during the funding period.
- The federal disability benefit programs require an inability to work, whereas the Medicaid Buy-In requires people to work. Medicaid Buy-In programs find this discrepancy challenging when participants experience job loss or are between jobs. The lack of a clear definition of work has led to employment in non-competitive settings such as sheltered workshops or informal arrangements with in-kind pay, employment situations that are not in the spirit of competitive employment envisioned by the Ticket Act. Being able to clearly define work becomes even more important in economic downturns, when unemployment is high among all workers.

## Recommendations

- Continued funding for MIG grants could be used to help states assess how to design benefits packages for a reformed health care system. States must now assess how the Medicaid Buy-In will operate after 2014 and who it will serve; identify whether benefits packages available through Medicaid or state exchanges can or should offer coverage tailored to the needs of those with disabilities while they move between jobs or other sources of coverage; and retool their existing data infrastructure to track Medicaid beneficiaries.
- MIGs have used their funds to provide benefits counseling, work incentives planning, youth transition services, and peer counseling because states view these activities as critical components to successful competitive employment. Future MIG funding could reflect what states have learned and include these types of practices. Some of the practices could foster increased collaboration and cross-agency involvement.
- MIG funding has brought state agencies, advocates, and employers together to promote integrated changes. Many grantees consider cross-agency collaboration as a key MIG accomplishment and Medicaid agencies have become recognized as key players in

employment and disability issues. Improving employment opportunities for people with disabilities will require the continued collaboration of CMS, other U.S. Department of Health and Human Services (DHHS) agencies, the Social Security Administration, the Department of Labor, and the Rehabilitation Services Administration. These agencies can share data, cross-train field staff, and provide information about the MIG program and its relationship to other federal employment programs.

#### 6. Adequate Supply of Direct Service Workforce and Adequate Support for Caregivers

Recruiting and retaining a sufficient number of direct service workers (DSWs) to provide LTSS remains a significant challenge, which must be addressed to meet the growing demand for long-term services and supports in the coming decades. The key CMS grant program in this area has been the Demonstration to Improve the Direct Service Community Workforce (Engberg et al. 2009). The following is a summary of the key lessons learned, findings, and recommendations from the DSW evaluation report, as well as interim reports on health coverage interventions (Paraprofessional Healthcare Institute 2006) and marketing, recruitment, and retention efforts (University of Minnesota and the Lewin Group 2006).

##### Lessons Learned/Key Findings

- In general, increasing job satisfaction is seen as a more attainable goal than improving recruitment or retention because of the barriers created by low pay relative to the challenges of the job.
- The most effective strategies to improve recruitment, retention, and job satisfaction focused on worker recognition and showing them that they were valued. Examples of these types of initiatives included marketing campaigns that promoted DSW occupations as a highly rewarding job, and initiatives providing recognition for high-performing and long-serving workers. In addition, community-building efforts such as conferences, trainings, and banquets for DSWs are seen as successful strategies. Many DSWs work in isolation from one another and these types of events provide workers a rare opportunity to congregate and share ideas and experiences, develop informal support networks and gain a fresh perspective on their jobs.
- Job previews that present a realistic view of the rewards and challenges of a position tend to attract the right workers. These initiatives were associated with a reduction in turn-over.

##### Recommendations

- It is important to tailor DSW programs to meet the needs of the audience and to include DSWs in the planning phase of the program. For example, programs seeking to attract DSWs by offering health insurance coverage need to consider that many DSWs work part time and are not eligible for many health plans created under these initiatives whereas others are covered by spouses or already are enrolled in public plans. In the case of training initiatives, topics have to be of sufficient interest to DSWs and fit their schedules. Providing transportation to trainings conducted outside of work hours, and compensation or other incentives for participation might increase participation in training programs and contribute to a culture in which workers feel appreciated.

- Implementing a package of initiatives will increase job satisfaction because this approach can have a stronger impact than any single intervention. Packages that include paid training, increased benefits, and employee recognition and career development opportunities, help to create a culture in which DSWs feel appreciated and experience increased job satisfaction, which in turn increases retention.
- When developing realistic job preview initiatives, the following approaches are recommended: (1) match the content to the actual job for which the person is applying; (2) conduct the preview before hiring to lower administrative costs; (3) follow-up the preview with post-hire activities, such as peer-to-peer job coaching, mentorship, or other supports; and (4) consider combining a video-based preview with job-shadowing or in-person question and answer opportunities with DSWs, consumers, or families.
- The local evaluations of DSW grants frequently had limited utility. To provide useful information that can facilitate mid-course corrections, local evaluations must be designed well and adequately funded, and the evaluator and grantee should be in frequent contact to facilitate real-time sharing of lessons learned. Ideally, local evaluators are involved in the grant design as well, so that the feasibility of a project and the necessary data can be determined before an initiative begins.
- Employers might want to consider recruiting DSWs who have alternate sources of income, and are therefore less concerned with the low pay and poor benefits common to DSW work. Some individuals receiving disability benefits could be good candidates for some DSW positions, but they would probably need benefits counseling and case management to assist them in transitioning to work.

## 7. Adequate Supply of Housing to Support Community-Based Living Options

Securing an adequate supply of accessible and affordable housing for those with disabilities remains a major challenge for most states. In addition to an inadequate supply of affordable and accessible housing, states cite other barriers that make solving the housing challenge difficult. These other barriers include a lack of coordination between housing agencies and service providers that coordinate HCBS for individuals and a lack of funding for the full range of services and supports required to live in the community successfully. The key CMS grant program in this area has been the RCSC Housing grants which helped eight states develop better supported housing strategies (O’Keefe et al. 2009). A second round of RCSC housing grants were awarded to four MFP grantees in 2011, but the full results from that initiative were not available at the time this report was written. However, it is the MFP demonstration that has highlighted and emphasized the challenges low-income individuals with disabilities face when trying to find affordable and accessible housing. The MFP grantees continue to report that the biggest barrier hindering the transition from institutional to community-based care is a lack of affordable and accessible housing in communities where people want to live (Williams et al. 2012).

## Lessons Learned/Findings

- Including all stakeholders early is the most effective long-term strategy for bringing about systems change. Housing and social service agencies have a long history of not working together and early inclusion means early buy-in to the goals and strategies of housing

initiatives for people with disabilities. Early buy-in also provides the time necessary to establish formal agreements to ensure long-term cooperation.

- Social services and housing are distinct and separate; personnel in each do not know the details of what the other provides and learning about each other's role can be difficult, particularly if there is no single agency that can represent all populations with disabilities. One state surveyed professional staff from both social services and housing before and after a housing initiative was launched, which helped to obtain buy-in and to sustain it after the grant ended. Another state thought sharing social services and housing staff who had time to devote to building relationships was a critical element of success.
- To affect system change in housing supports, states need leadership from the top and the bottom. Leadership at the policy/resource level is important both to set direction and support systems change activities, whereas grassroots support is needed to engage local stakeholders in the systems change process and to disseminate best practice information.
- Initiatives to develop housing with services can be enhanced if they build on existing state service infrastructure and housing programs. By working with existing service teams and housing programs, listening to what they need, and supporting them, a new initiative will find both the service providers and housing programs more willing to expand their portfolio of responsibilities.
- Using a broad definition of disability can be important for building broad support for a new housing program because it reduces competition among different groups with disabilities and eliminates any stigma that might be attached to a particular group that could energize opposition to the program in local communities. The local lead social service agency role can be designed to both protect client confidentiality and provide property management with a single point of contact for issues that arise.
- Strategies that facilitate the connection between housing and services include a housing coordinator who strengthens the relationships between affordable housing policymakers and providers responsible for long-term supports; bridge subsidy programs (that is, providing assistance with rent until the household could transition to a Section 8 voucher) that incentivizes the move to Section 8 housing by requiring higher rents under the subsidy program than under Section 8; and fostering more and better communication among housing developers, service providers, and consumers.
- Strategies that do not seem to foster more affordable and accessible housing include the conversion of residential care facilities to assisted living because the high costs of doing so discourages many facility owners. In addition, home purchase programs have not been fruitful because most people in institutions would rather move to a rental apartment than wait years to qualify for a home purchase.
- To support aging in place, a wide range of services must be available, including medication assistance and homemaker and personal care. However, finding financing to offer such supportive services in publicly financed, congregate housing is a challenge. It is difficult to provide medication assistance services in this type of housing because housing providers typically cannot afford to hire an on-site registered nurse to provide medication assistance or to supervise delegation of medication administration. Funding is also insufficient for resident



service coordinators who help people identify service needs and arrange for services in the home or in the community.

- The dually diagnosed, those with both mental illness and an intellectual disability, have been very hard to maintain in supportive housing, because these individuals frequently have aggressive behaviors. To help these people, the discharge team has to work closely with supportive service coordinators and provider agencies to ensure that appropriate services are in place at the time of discharge.
- Consumers, family members, public agency personnel, and providers are largely unaware of the new assistive technologies becoming available. When such awareness is achieved, it often influences housing design. Assistive technology offers ways of promoting self-determination and independence but raises issues about privacy and control. Although assistive technology can be a means to reducing the amount of direct care, it should be viewed as a means for focusing resources on the promotion of autonomy and community integration. Also, assistive technology is most effective when service providers have the training and knowledge to match the right people to the right technology.

## Recommendations

- To expand affordable assisted living options states need to (1) create new capital financing programs, including those that support pre-development activities, (2) increase Medicaid reimbursement rates for services provided in assisted living facilities, and (3) develop technical assistance programs for affordable assisted living. In comparison, the expansion of adult foster care homes requires the development of a proper regulatory framework.
- More collaborative efforts at the federal level are needed to promote affordable and accessible housing at the local level. Nationwide dissemination of models of affordable housing with services requires leadership. To be effective, new or redesigned programs must include operating assistance, new approaches to developing affordable rent payments, and flexible funding sources for health and behavioral health care and support services.
- Medicaid waiver programs need to be more flexible in the areas of supportive services and assistive technology. States need more flexibility to allow reimbursement for services designed to help someone live in the community successfully, including an initial fund for household set-up and support services that help someone develop budgeting, money management and life skills and become more knowledgeable about fair housing and landlord-tenant laws. Assistive technology is advancing rapidly and the line between home modifications, assistive technology, and durable medical equipment is increasingly blurred. The development of model waivers flexible enough to promote the use of the diverse and rapidly changing array of assistive technologies would be useful. In addition, approval processes for home modifications need to be streamlined and simplified because lags in these processes create barriers to accessible housing.
- Federal and state policy and regulations can impede the development of affordable, accessible housing. For example, federal housing regulations allow the reallocation of space in an existing floor plan to add an accessible bathroom on the ground floor, but they do not permit an addition for this purpose.

- Fragmentation in housing resources could be reduced by creating a housing trust fund that pools funding from multiple sources as a dedicated funding stream for providing affordable, accessible housing.
- To ensure that units are fully accessible and adaptable to the changing physical needs of different populations, publicly financed housing development for those with disabilities has to incorporate universal design principles. Policies that require a certain percentage of subsidized new construction contain a plug-in-ready Internet connection to facilitate remote monitoring technologies also help to promote accessible housing that is adaptable to the various needs of different populations.
- Funding is needed to ensure medication assistance services and onsite resident service coordinators are available to people in congregate, publicly financed housing settings. These types of services promote aging in place, but are frequently difficult to fund. In addition, it is important for states to find funding to train service providers on assistive technology.
- For medication assistance in supported housing the development of model standards would support those states that want to allow medication administration by individuals other than registered nurses. This approach could expand the availability of affordable medication assistance services in both private homes and congregate settings.

#### 8. Quality Assurance and Quality Improvement Systems

The quality of the HCBS provided will, in part, determine the effectiveness of the HCBS to ensure people remain in the community as long as possible. In addition, for the long-term care system to perform at a high level, the HCBS planning process must be person-centered. The key CMS grant program in this area has been the RCSC Grants for Quality Assurance/Quality Initiatives awarded to nine states (O’Keefe et al. 2009).

#### Lessons Learned/Key Findings

- For new quality improvement initiatives to succeed, they need strong leadership to counteract political and provider resistance. Programs frequently need a committed champion, someone whose time is allocated specifically to the initiative and who is respected and trusted by stakeholders, to energize others and build momentum toward goals. Also, to gain staff buy-in, they have to believe that the new initiative will make their jobs easier and/or provide them with new information and tools to help them work more efficiently.
- In many cases, change is best achieved by not recreating wheels but by building on existing protocols. Changes to a quality management system can be sustained when the planning and implementation process is built into the ongoing responsibilities of staff and the initiative’s goals are linked to goals already established by the state.
- For systems change efforts to succeed, the goals, policies, and procedures of state budget, IT, and program staff must be aligned as early as the application stage and share the same vision and buy-in to the culture change. For example, IT staff have to understand what data are needed, how those data will be used, and by whom; program staff need to understand the resources they will have and the state’s process for approving grant expenditures.



- To introduce IT to quality assurance/quality improvement processes requires (1) sufficient time to plan, particularly to work with stakeholders throughout the development process and to modify the system based on feedback; (2) the ability to determine what the state wants to accomplish and what the system will look like as a whole, rather than to simply identify each component part; and (3) the ability to envision where the state wants to be with the system three to four years in the future (such as the types of reports it should be able to generate, for whom, and on what schedule).
- Multi-state collaboratives require a higher level of trust among participants than single-state programs and the most effective cross-state collaborations start out small and focus on interaction among state leaders who already know one another and/or where projections suggest relative stability in organizational structures.
- States continue to struggle with obtaining meaningful ways for consumer participation in program design and monitoring. Barriers, such as a lack of transportation, create challenges to involving people with disabilities. Surveys conducted by peer interviewers can be a powerful tool for empowering people with disabilities and their family members to be active participants in the quality of their services. These surveys can identify the heterogeneous perspectives of consumers across the different populations who use HCBS. In addition, a consumer's perspective of quality might differ from a professional's perspective, which means the development of a person-centered services delivery system will require a lot of time and resources. States have to determine the appropriate balance between compliance-oriented and person-centered quality monitoring and quality management.
- Regularly reporting data on specific quality indicators to local quality steering committees and other key stakeholders provides a useful method for identifying potential quality issues and launching actions to address them. However, states would like quality measures that are applicable to all waiver populations. These measures might be based on core values on which all population groups agree.

## Recommendations

- The HCBS planning process would be more person-centered if the assessment and care planning processes included asking people what kind of life they wish to live and what they need to make that possible.
- Individual budgets that align segregated service models (such as sheltered living arrangements and sheltered workshops) would help all HCBS users achieve their desired outcomes.
- Quality management activities would be more effective if they included specific performance indicators that determine whether participants achieve their desired outcomes.
- States would like quality measures applicable to all waiver population; CMS, in conjunction with the AHRQ and other organizations, is the natural leader at the federal level to lead efforts to design common measures and establish common standards for measuring HCBS waiver and institutional performance across disability groups.

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APPENDIX A

REPORTS REVIEWED BY ATTRIBUTE

## REPORTS REVIEWED BY ATTRIBUTE

### 1. Accessible Home and Community-Based Services

- Abt Associates 2011a
- Irvin et al. 2011
- Lipson et al. 2011
- O’Keefe et al. 2009 (Comprehensive System Reform Grants, Family-to-Family Health Care Information and Education Center Technical Assistance grants, Rebalancing Initiative grants)
- Urdapiletta et al. 2011
- Williams et al. 2011

### 2. Systems that Support Transitions among Settings and Service Systems

- Ascellon 2009
- Irvin et al. 2011
- Lewin Group 2010
- Lewin Group 2006
- Lipson et al. 2011
- O’Keefe et al. 2009 (Portals from Early and Periodic Screening, Diagnosis, and Treatment to Adult Supports grants)
- O’Shaughnessy 2010
- Urdapiletta et al. 2011
- Williams et al. 2011

### 3. Comprehensive Single-Entry Point/No Wrong Door Systems for Accessing Community-Based LTSS

- Lewin Group 2010
- Lewin Group 2006
- O’Keefe et al. 2009 (Family-to-Family Health Care Information and Education Center Technical Assistance grants)
- O’Shaughnessy 2010
- Urdapiletta et al. 2011

#### 4. Person-Centered Planning and Service Delivery

- Abt Associates 2011b
- O’Keefe et al. 2009 (Living with Independence, Freedom, and Equality Accounts Feasibility and Demonstration grants)

#### 5. Employment Supports for People with Disabilities

- Kehn et al. 2012
- Schimmel et al. 2012
- Whalen et al. 2012

#### 6. Adequate Supply of Direct Service Workforce and Adequate Support for Caregivers

- Enberg et al. 2009
- University of Minnesota and the Lewin Group 2006

#### 7. Adequate Supply of Housing to Support Community-Based Living Options

- Irvin et al. 2011
- Lipson et al. 2011
- O’Keefe et al. 2009 (Integrating Long-Term Supports with Affordable Housing grants)
- Williams et al. 2011

#### 8. Quality Assurance and Quality Improvement Systems

- O’Keefe et al. 2009 (Quality Assurance and Quality Improvement in Home and Community-Based Services grants)

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