The Hilltop Institute

analysis to advance the health of vulnerable populations

Home and Community-Based Services:

Examining the Evidence Base for State Policymakers

The Hilltop Symposium, June 11, 2009

Proceedings Summary

Introduction

The Hilltop Institute at the University of Maryland, Baltimore County (UMBC) is a nationally recognized research center that is dedicated to improving the health and social outcomes of vulnerable populations. Hilltop conducts research, analysis, and evaluation on behalf of government agencies, foundations, and other nonprofit organizations at the national, state, and local levels.

To further this mission, Hilltop hosts The Hilltop Symposium, an annual event that contributes to the national dialogue on timely and salient health policy issues that affect vulnerable populations. Hilltop is pleased to present the proceedings of its sixth symposium, *Home and Community-Based Services: Examining the Evidence Base for State Policymakers*, convened on June 11, 2009.

The symposium brought together more than 130 policymakers, program administrators, and health services researchers, including some of the nation's leading experts, to address the effectiveness of home and community-based services (HCBS), including the quality of care, person-centered service planning and consumer-directed initiatives, targeting HCBS candidates, and cost-effectiveness. The symposium was divided into four sessions, highlighted by a keynote address, a luncheon address, and concluding reflections.

In the following pages:

Symposium materials, including the symposium agenda, speaker biographies, and PowerPoint presentations, may be accessed at: http://www.hilltopinstitute.org/Symposium/2009Symposium.cfm.

Summary of the Proceedings

The Hilltop Symposium began with an introduction and overview by **Charles J. Milligan Jr**., JD, MPH, Executive Director of The Hilltop Institute. Mr. Milligan welcomed the group to UMBC and explained that the Hilltop Symposium is part of UMBC's mission to provide actionable information at the intersection of health research and health policy. He said that a traditional conference on HCBS would address how to expand services, promote re-balancing services away from institutional settings toward HCBS, and present new information on consumer choice and self-direction. He also said that he has never met a policymaker who opposes HCBS or prefers institutional care over HCBS. All policy leaders want to honor people's choices to live in the community.

Yet, throughout the country, funding for HCBS continues to comprise less than one-half of the total long-term care dollars, and Medicaid continues to provide more money for institutional services than HCBS, despite the widespread rhetorical support for HCBS. Although most people believe HCBS is "the right thing to do," there remains a skepticism among policymakers that is preventing states from further appropriating funding to expand HCBS.

The purpose of this Hilltop Symposium, then, was to address the sources of this skepticism by policymakers and explore whether the research and evidence base exists to address the concerns that are sometime raised by government officials. Some of these policymakers are skeptical that government can adequately monitor safety and quality in informal, unlicensed, and geographically spread-out low-occupancy, community-based settings such as group homes, individual homes, and apartments, and they fear expansions for this reason. Others believe that states lack effective methods of targeting individuals who are truly at-risk of institutionalization and, as a result, are concerned that expanded HCBS programs would cast their nets too wide and ultimately serve many individuals who might never require institutional care. This could add a large pool of new eligibles, without targeting the people most at-risk of institutionalization or reducing institutional care populations and costs. Some policymakers fear a net increase in state expenditures, because there would be no reduction in existing institutional costs as HCBS costs rise when systems are rebalanced; expansions in HCBS could monetize informal caregiving, thus substituting state funds for informal care without a net increase in actual services. Others fear that Cash & Counseling models might result in exploitation, as family members could take advantage of their frail and vulnerable charges, and receive payments without providing services, as a form of fraud.

Mr. Milligan stated the goal that, at the Hilltop Symposium, where policy and research intersect, the speakers and participants would analyze, with clear eyes, whether the evidence exists to address these concerns. Because further significant expansions in HCBS might depend on advancing the research and evidence base, rather than merely reciting the fact that expansions in HCBS ought to be pursued because it is "the right thing to do." Where the evidence might not yet exist, the day might illuminate areas for a new research agenda, in order to marshal the evidence to address the legitimate concerns that are barriers to the expansion of HCBS.

Keynote Address: Creating the Analytic Framework to Understand and Evaluate Home and Community-Based Services (HCBS)

In her keynote address, ***Creating the Analytic Framework for Home and Community-Based Services***, **Susan C. Reinhard**, Ph.D., M.S.N, senior vice president for Public Policy at AARP, constructed a framework for exploring both the current state of the evidence regarding rebalancing initiatives and the development of a new analytic framework to advance an evidence-based research agenda. Dr. Reinhard began her presentation by challenging the audience to reexamine the definitions for "HCBS" and "home." She also stated that the term "rebalancing" is not appropriate, because something must first be balanced in order to be rebalanced. Therefore, she would use the term "balancing" when referring to the long-term care system.

Dr. Reinhard followed these remarks with her contention that long-term supports and social services need interventions based on evidence. To aid in the examination of the role of evidence in policymaking and balancing initiatives, she presented two models: Kingdon's Policy Stream Model and Lewin's Force Field Analysis, an analytical model and a social psychology model, respectively.

Kingdon's model is comprised of three streams: the problem stream, the policy stream, and the political stream. Research studies are used to examine the magnitude and direction of a solvable problem, and it is in the policy stream where research is applied to a problem. The political stream reflects the public mood and prevailing value choices, as well as the need for technical and financial feasibility. According to Dr. Reinhard, the intersection of any two streams creates a window of opportunity for social change.

In Lewin's Force Field Analysis, opposing driving and restraining forces create equilibrium devoid of social change. Dr. Reinhard put forth the question, "Where is the data in the model? Can evidence reduce restraining forces?" Addressing these restraining forces can be a daunting task, as the issues are exceedingly complex and there is an overall lack of infrastructure and consistent, knowledgeable leadership at the state level to manage the process. Furthermore, Dr. Reinhard cited resistance from institutional providers in the name of "HCBS quality" and state budget officers who are concerned about increasing long-term care expenditures and the effective targeting of vulnerable populations. She also pointed out the Medicare/Medicaid disconnect beyond traditional long-term supports and services.

Dr. Reinhard presented data from a variety of sources to demonstrate that the percentage of Medicaid long-term care spending going to HCBS from 1995 to 2007 increased 1 percent to 2 percent per year, with 39 percent of long-term care dollars going toward HCBS for all Medicaid beneficiaries. The percentage of Medicaid long-term care spending going to HCBS for the Mentally Retarded/Developmentally Disabled (MR/DD) population increased 33 percentage points over the 12-year span, whereas HCBS spending for older adults and adults with physical disabilities increased by 15 percentage points over the same time span. Dr. Reinhard pointed out that current trends in balancing mean that we will achieve a 50/50 spending balance in 2019.

Dr. Reinhard presented data on balancing efforts in various states. The national average for the percentage of Medicaid long-term care spending for older people and adults with physical disabilities going to HCBS in 2007 was 27 percent, not taking into account state-funded HCBS programs. Comparatively, New Mexico spent 61 percent, Oregon spent 56 percent, Washington spent 55 percent, Rhode Island spent 11 percent, Utah spent 5 percent, and Tennessee spent only 1 percent of its Medicaid long-term care dollars on HCBS. Dr. Reinhard cited that, in 2007, nearly one-half of all states spent less than one in five Medicaid long-term care dollars for older people and adults with physical disabilities on HCBS, with only eight states spending more than two in five Medicaid dollars.

The data and analysis suggest that a richer dialogue is needed in examining the role of evidence in supporting HCBS and balancing. Dr. Reinhard maintained the need for stakeholders to present evidence and create dialogue.

> ***If such efforts result in***
> ***a decrease in the Medicaid nursing home growth trend line,***
> ***a broad array of HCBS programs must be in existence***
> ***to meet the needs of the vulnerable populations they serve.***
> --Susan Reinhard

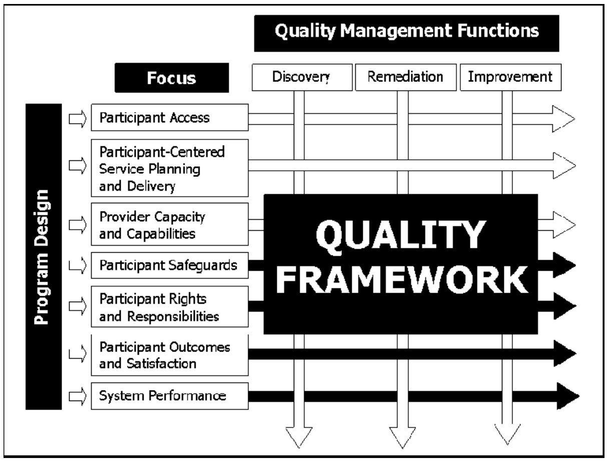
Following the keynote address**, Martha A. Roherty**, M.P.P., director of the National Association of State Units on Aging (NASUA), provided comments on Dr. Reinhard's address from the perspective of state policymakers and stakeholders. Ms. Roherty emphasized that, in order to make fundamental changes in the long-term care system, states need to support one another and share ideas about the multitude of programs that support home and community living. In addition, Ms. Roherty identified the need for states to increase housing and transportation options, information and referral services, and respite and meal services.

From the political side, many states are frightened of changes yet to come under the new federal administration. The financing of any federal mandate on HCBS expansion rests on the back of the Medicaid programs. In FY 2010, 70 percent of states are facing a 10 percent budget reduction, and another 14 percent of states are anticipating a 20 percent cut in their budgets. A cut in funding translates into a cut in services. Ms. Roherty concluded that we must first address economic issues in order to effect change on the state and federal levels.

Session 1: Effectively Assessing Quality in HCBS

This session focused on the complex process of establishing, maintaining, and improving quality measures for HCBS programs. The promotion of quality care in the community first requires defining quality outcomes. **Cynthia H. Woodcock**, M.B.A., director of the long-term supports and services unit at The Hilltop Institute, moderated this session.

Gale P. Arden, M.B.A., director of Public Programs, Research and Planning Federal Programs at BlueCross BlueShield of Tennessee and former director of the Disabled and Elderly Health Program Group in the Center for Medicaid and State Operations at the Centers for Medicare and Medicaid Services (CMS), began her presentation, ***The Evolution in Measuring whether State HCBS Waivers Deliver Quality***, with a brief overview on the history of HCBS. HCBS began in 1981 with the enactment of Section 1915(c) of the Social Security Act. In *Olmstead* v. L.C. (1999), the U.S. Supreme Court ruled that Title II of the Americans with Disabilities Act prohibits the unnecessary institutionalization of persons with disabilities. On February 1, 2001, President George W. Bush announced the New Freedom Initiative (NFI), a nationwide effort to remove barriers to community living for individuals of all ages with disabilities and chronic conditions, and to ensure that all Americans have the ability to choose where to live and participate in community life. Later that year, CMS sponsored the National Quality Inventory Project (NQIP) to address HCBS quality management and improvement. The project was conducted on behalf of CMS/Center for Medicaid and State Operations (CMSO) Disabled and Elderly Health Program Group (DEHPG) in collaboration with NASUA, the National Association of State Directors of Developmental Disability Services (NASDDDS), and the National Association of State Medicaid Directors (NASMD). The NQIP resulted in a widely distributed, participant-centered quality framework, as well as a national inventory of state HCBS waiver quality management and improvement strategies (see figure).



Following this introduction, Ms. Arden described the core features of the quality framework: design, discovery, remedy, and continuous improvement. She suggested that HCBS programs need to design quality assurance and improvement strategies at the initiation of the program and engage participants at the implementation and assessment phases.

Ms. Arden pointed out that an important aspect of quality assurance is oversight.

In addition to statutory assurances, such as level of care determinations and the development of individualized service plans, CMS has some oversight through the analysis of state systems in meeting assurances and site audits. Despite these oversight functions, Ms. Arden believes that a deficient reporting system, deficient practices, and the lack of consensus among states on what defines quality in HCBS settings make the current system inadequate.

Ms. Arden concluded her presentation by outlining the following future CMS initiatives related to quality: (1) establish a core set of HCBS quality measures, (2) build a national campaign on Consumer Quality Initiatives (CQI), (3) improve the quality of the direct care workforce, and (4) improve the utility of institutional assessment and data collection instruments.

Walter N. Leutz, Ph.D., M.S.W., associate professor in the Heller School for Social Policy and Management at Brandeis University, began his presentation, ***Quality in Integrated Systems***, with an introductory discussion of the topics of fairness, integration, and the disablement process (John Capitman, 2003). Dr. Leutz claims that it is "unfair" to provide universal Medicare for medical care but a means-tested, state-optional Medicaid program for supportive community services (SCS). Functional status is "entangled" with disease, but the effects of disease can be controlled by medical care, and deficits in functional status can be offset by SCS. The responsibility for lack of integration lies on both sides, as consideration of SCS is beyond typical medical practice and systems, and typical SCS programs do not expect care coordinators or direct care providers to coordinate with medical care. Dr. Leutz noted that, for a medical system that is already very complex, integration for some could mean fragmentation for others.

Following this introduction, Dr. Leutz presented the three levels of integration—linkage, coordination, and full integration. At the linkage level, service users would receive accurate information about how to access benefits and services in the system. At the coordination level, service users with moderately complex needs would receive assistance with navigating the system and coordinating care. For service users with complex needs, full integration would involve coordinated sectors where acute and long-term care providers and managers work in teams. High-quality coordination will address the unmet needs related to being both chronically ill and functionally disabled.

Dr. Leutz addressed quality concerns, quality measures, and potential solutions in the following key areas of need: linkages across systems, communication, information, relationships, and transitions. Dr. Leutz described how the creation of linkages across systems could be achieved through the establishment of single points of contact (SPOCs), pro-active consents, and information-sharing agreements. Poor communication leads to a disconnect between service providers and users. Effective communication with health professionals may allow service users to build self-effectiveness, e.g., through chronic disease self-management programs, and make judgments about what information they need and how to use the information to make care decisions. Unsuccessful hospital discharges and transitions may stem from a problem with SCS providers being out of the loop with regard to discharge planning and available community resources. Dr. Leutz cited the notion of SPOCs for SCS for discharge planners, service users, and their families as a potential solution.

To conclude, Dr. Leutz stated that linkage and care coordination should be available to everyone needing it. Both service providers and services users have some responsibility to "ask" and "tell," but there should not be a "no man's land" within the system.

> ***We should be encouraging service users to talk to health care providers about what is going on in their SCS services. And on the other hand, health care providers shouldn't feel like this is something they can't talk about because they'll have some real solutions.***
>
> --Walter Leutz

Session 2: Assessing the Performance of Consumer-Directed and Tailored Service Initiatives within HCBS

There is a growing interest in and support for individualized planning and consumer-directed initiatives. This session explored the challenge of balancing consumer control and preference with the most efficient use of limited HCBS resources. Although consumer control is the latest trend in HCBS, consumer-directed initiatives are fraught with concerns about cost-effectiveness, consumer safety, and fraud and abuse. **Stephanie Cannon-Jones**, M.P.P., senior research analyst at The Hilltop Institute, moderated this session.

In a co-presentation**,** ***Assessing the Performance of Consumer-Directed and Tailored Services within Home & Community-Based Services***, **William A.B. Ditto**, M.S.W., director of the Division of Disability Services for the State of New Jersey, and **Randall S. Brown**, Ph.D., vice president and director of health research at Mathematica Policy Research, Inc., examined the Cash & Counseling model of service delivery.

In the first presentation, ***The Evolving State Role in Managing Consumer-Directed Care, Part I: Consumer-Directed Care and the Cash & Counseling Model***, Mr. Ditto stated that services are "a philosophy and orientation to the delivery of service whereby informed consumers assess their needs, determine how their needs should be met, determine who can best meet them, and monitor the quality of services received. Consumer[s] exercise substantial control over the resources available to meet their needs." Mr. Ditto continued his introductory remarks by giving an overview of the basic model for Cash & Counseling.

Pioneered in the 1990s, the Cash & Counseling demonstration affords consumers control of an individual budget, availability of counseling and support services, ongoing quality oversight and monitoring, and fiscal management services. Cash & Counseling also holds the participant responsible for outcomes, which is a departure from traditional case management models. The basic Cash & Counseling model, as described by Mr. Ditto, has five steps:

- **Step 1:** Participants receive traditional assessments and individualized care plans
- **Step 2:** A dollar value is assigned to that individual's care plan
- **Step 3:** Participants receive enough information to make an unbiased personal choice between managing an individualized budget and receiving traditional agency-delivered services
- **Step 4:** Participants and counselors develop a spending plan to meet the participant's personal assistance needs
- **Step 5:** Participants are provided with financial management and counseling services and can make use of a representative or surrogate decision maker, if desired

In the second part of his presentation, ***The Evolving State Role in Managing Consumer-Directed Care, Part II: Lessons for Policy and Practice***, Mr. Ditto shared the reasons why New Jersey implemented the Personal Preference Program, which is New Jersey's Cash & Counseling program, and why this approach to HCBS makes sense in the current economic times. In addition to empowering consumers and family caregivers and increasing personal responsibility, the Cash & Counseling model offers employment opportunities for non-traditional and displaced workers and helps to maximize the use of limited public dollars. By not using home health agencies, states are able to reduce the amount of administrative overhead costs, leaving more money available for services.

Mr. Ditto listed several potential "landmines and bombs." He stated that fraud and abuse are inevitable and that the program affords limited consumer protection. Although the "woodwork effect" was not seen in New Jersey, it is a very real concern for some states that worry about skyrocketing costs. There is the possibility of traditional provider agency resistance and sabotage and an unfavorable public image, yet in New Jersey, this doesn't seem to be the case, as the growth of the state's personal care attendant program has exceeded that of the Personal Preference Program, the state's Cash & Counseling program.

To conclude, Mr. Ditto also shared some policy and practice implications. He has found that family caregivers benefit and feel rewarded, community integration is enhanced, participants are prudent purchasers, and the program helps to prevent or delay institutional care. Cash & Counseling is a personal, "value-driven" model that provides the ability to serve linguistically and culturally diverse populations in a responsive way. The program creates a climate of partnership between individuals who need care and the systems that are charged with helping secure that care. Within the aging population, there is a subset of individuals who are at high risk of institutionalization; for this subset of vulnerable individuals, Cash & Counseling may not be the best alternative. Frail, elderly individuals without community supports may be better served by a home health agency. The individuals who are most successful in a consumer-directed model are those who have natural supports in the community.

In the second presentation, ***The Relative Cost Effectiveness of Consumer Directed Care: Evidence from the Cash & Counseling Demonstration***, **Randall S. Brown**, Ph.D., vice president and director of health research at Mathematica Policy Research, Inc., began by providing further background information on the Cash & Counseling program. Implemented in Arkansas, Florida, and New Jersey between October 1998 and July 2002, the Cash & Counseling program enrolled Medicaid Personal Care Services (PCS)/HCBS waiver eligibles. In this model, participants could hire legally liable relatives and friends with no Medicaid contracting requirements. Dr. Brown highlighted state-to-state differences in target populations: Florida targeted children and adults under the age of 60 with developmental disabilities whereas Arkansas and New Jersey targeted mainly adults. In addition, the per member per month (PMPM) allowance in Arkansas was $300 whereas it was approximately $900 in New Jersey and Florida.

Dr. Brown then described the Mathematica study that investigated the effects of Cash & Counseling participation on paid and unpaid hours of care, consumer and caregiver well-being and satisfaction, and Medicaid expenditures. In the study, applicants were randomly assigned to a treatment or control group. The study included approximately 1,700 to 2,000 adults per state and 1,000 children in Florida. Mathematica performed separate analyses by state and age (< 18, 18-64, and 65+). Medicaid expenditures were calculated using claims files, and all other data were collected via surveys.

With respect to the hours of care received, the study found a large increase in the percentage of participants receiving any paid care (94 percent versus 65 percent to 80 percent). Those individuals in the treatment group also received more hours of paid care (17 percent to 25 percent more) and fewer unpaid hours (7 percent to 24 percent less). Participants in the treatment group received slightly fewer total hours of care, except for the 18-64 year old cohort in Arkansas and the over 65 year old cohort in Florida. The study found little measureable effect on the use of other allowances; an increase in paid care did not offset an increase in unpaid care. Additional study results found that there were large reductions in unmet needs, with large increases in consumer satisfaction with life and care. Care-related health problems/injuries were the same or lower. As for unpaid caregivers, the total hours of care provided decreased, and they experienced less emotional/physical/financial strain. Unpaid caregivers expressed a much greater overall satisfaction with life and increased satisfaction with consumers' care. When examining cost-effectiveness, Mathematica researchers found that Medicaid PCS/HCBS expenditures and total Medicaid costs increased for all states and age groups.

To conclude, Dr. Brown shared some lessons on controlling costs in consumer-directed service programs within HCBS, such as using a standardized assessment tool, having independent staff establish allowance amounts, and setting a clear and fair recoupment policy for unspent allowances. Although consumer-directed programs can increase access to care and vastly improve quality of life, given the current economic climate, states are very concerned about controlling costs. Waiver expenditure calculations showed cost neutrality and, in Arkansas, the PMPM rate was set at 55 percent of the agency service rate. Although the study results should allay fears about consumer-directed care, Dr. Brown suggested that costs may deter some states from implementing programs, and agencies/unions may oppose the states advocating for consumer-directed models as an alternative to institutional or home agency care.

Luncheon Address: Policy and Care Issues in Evolving HCBS Systems

The luncheon address reflected on the challenges facing HCBS providers. In her presentation, ***The Evolving HCBS Landscape: Challenges, Solutions and Recommendations,*** **Carol Raphael**, M.P.A., president and chief executive officer of the Visiting Nurse Service of New York (VNSNY), provided an overview of the issues facing HCBS providers on the frontlines. Ms. Raphael began her presentation with a brief history of VNSNY, a not-for-profit organization that is committed to serving the uninsured and under-insured through community benefit initiatives. VNSNY serves all five boroughs of New York City, plus Nassau and Westchester Counties, and provides a range of services to an average daily census of 30,000 patients. The HCBS workforce, which includes MDs, RNs, social workers, direct care workers (DCW), and family caregivers, faces many challenges, including ensuring quality care, financing, caring for populations with complex needs, and providing charity care.

Due to a shortage in all disciplines, the HCBS workforce is unprepared to meet the demand and need to care for older adults with complex needs. Although personal care aides and home health aides will be the second and third fastest growing occupations between 2006 and 2016, the roles of workers are changing. Workers whose jobs were traditionally task- and procedure-oriented are now managing care and patient outcomes without being fully integrated into the clinical team. DCWs receive low wages, no or minimal benefits, and no initial and continuing training. This current workforce structure leads to instability and a high turnover rate. As a result, the number of family caregivers is likely to increase. Like DCWs, family caregivers receive inadequate training in care management. Ms. Raphael urged that the family caregiver role be recognized, supported, and integrated into the formal care system to minimize burnout from day-to-day responsibilities, potential loss of work time and income, and potential deterioration of caregiver health.

Ms. Raphael addressed quality measures and assessment in post-acute care, end-of-life care, and long-term care. For post-acute care, Medicare-certified home health agencies are required to collect quality measures via the Outcome and Assessment Information Set (OASIS). End-of-life care quality is assessed against Perforum benchmarks, which incorporate indicators of patient and family experience. There is little consensus among providers and payers on appropriate quality measures for long-term care. Ms. Raphael argued, what she considers to be a minority view, that we should move away from outcomes and move toward process and patient experience in dealing with long-term care. In the past, when looking at quality, great emphasis was placed on regulatory compliance in nursing homes. According to Ms. Raphael, this presents an opportunity to lay a foundation for future payment incentives and to incorporate more of the consumer's perspective in shaping the long-term care system.

With respect to financial constraints, Ms. Raphael stated that HCBS providers face significant reductions in payments, and it is often difficult to restructure costs. As a result of the inadequate financing for long-term care, individuals are forced to pay out-of-pocket. There is little integration of financing for short-term and long-term care across settings. For frail older adults who have both acute and long-term needs, the lack of coordination between two payers results in expensive and inefficient duplication of services. Furthermore, this lack of integration drives poorer health outcomes, especially for dual-eligibles. In examining models of care for populations with a mix of complex short- and long-term needs, it is apparent that no one care model or program will fit all. Patients with the most complex needs consume the lion's share of a provider's resources and may require long-term medical and supportive services.

To conclude, Ms. Raphael shared some solutions that are currently in place at VNSNY to address the evolving landscape of the HCBS workforce and the health care needs of patients. VNYSY is striving to improve workforce development and retention rates by focusing on hiring high-quality workers, upgrading the paraprofessional workforce, providing training for various providers, and fostering teamwork. In addition, there is a quality infrastructure in place and a performance measurement system. Through innovative models in caring for complex populations, VNSNY hopes to prevent disability, support healthy aging, and help seniors remain in their communities. VNSNY also hopes to better manage transitions from institutions to the community and avoid preventable re-hospitalizations. For patients who require end-of-life care, VNSNY is expanding the reach of hospice care by increasing awareness, availability, and utilization. Efforts are underway to integrate family caregivers into the care team. Given the bleak financial forecast, Ms. Raphael believes that HCBS providers should work in the short-term to restructure costs, reduce administrative overhead expenses, and use technology as the platform for integration and care management. In the long term, payment policy must support the development of sustainable, scalable home and community-based care models.

Session 3: Effectively Targeting Candidates for HCBS

Effectiveness of HCBS is dependent on appropriately identifying candidates for program enrollment, either from among nursing home residents or from within the community. This session explored methods for effectively targeting older adult populations and individuals with physical disabilities for HCBS programs. **Anthony M. Tucker**, Ph.D., director of special projects at The Hilltop Institute, moderated this session.

In the first presentation of the session, ***Targeting Nursing Home Residents: What We Need to Know***, **Leslie C. Hendrickson**, Ph.D., owner and principal of Hendrickson Development, highlighted several data sources on nursing home residents, such as the CMS Annual Statistics Report, the 1999 and 2004 National Nursing Home Surveys, the Minimum Data Set (MDS), and the Thomson Reuters data on CMS-64 Expenditures (formerly HCFA-2082).

From 1997 to 2006, there was a 30 percent increase in the rate of patients discharged from hospitals to nursing homes or rehabilitation facilities. In addition, according to the CMS Annual Nursing Home Compendia, nursing home residents presented with more Activities of Daily Living (ADL) impairments at admission. Dr. Hendrickson also presented data from a Pennsylvania Department of Aging study showing that the average length of stay for persons discharged from nursing homes was less than three months for approximately 70 percent of the study population. In that same study, the largest percentage of nursing home residents who became Medicaid eligible did so within 30 days.

Dr. Hendrickson noted that identification of appropriate candidates for HCBS could be enhanced by a reorganization of state agencies, maximum use of local agency and nursing home staff, preadmission counseling, and an increase in adequate community housing. With regard to identification methods, Dr. Hendrickson described systematic or casual trolling, state assessment tools, and the use of other state data. Although some states visit nursing homes and perform educational outreach, other states rely on marketing, referrals from the long-term care ombudsman, and transition coordinators. He found that most states do not use systematic methods to select residents for transition. New Jersey does not use a formal method to identify specific nursing homes or groups; however, according to the Assistant Secretary for Planning and Evaluation (ASPE) MEDSTAT study in 2003, a significant number of individuals still transitioned, the nursing home population declined, and the initial focus on newly admitted individuals shifted to long-term residents.

To target specific nursing homes and specific groups, some states use MDS, Resource Utilization Groups (RUG) scores, and MDS Section Q lists. Section Q contains questions about consumer preferences for transitioning from a nursing home to a community setting. The current version of Section Q is generally considered to be of minimal use due to the 15-45 day time delay. The perception is that all residents respond "Yes!" when asked if they want to leave the nursing home. States are using Section Q in various ways. The lists of individuals to target that is generated from Section Q lists has been found to be helpful during pre-admission counseling and for states that are in the beginning stages of targeting efforts. MDS allows agencies to track several transition indicators, such as the number of individuals who received counseling, the number referred for transition, and the number transitioned. Oregon currently uses both MDS and state assessment to identify nursing homes with younger individuals who have minimal ADL deficiencies. Washington, D.C. is looking at younger persons, low RUG scores, and persons with behavioral health needs. Louisiana uses its nursing facility assessment tool, LOCET, to identify persons who qualify based on low ADL needs and projected short term rehabilitation stays. The California Pathways project focused on preference (see Acosta & Hendrickson paper, available on HCBS.org). Illinois currently uses low RUG scores to target individuals who have been in nursing homes for more than 6 months, whereas Pennsylvania is focusing on persons who have been in nursing homes for at least 90 days.

To conclude, Dr. Hendrickson stated that states need to know how to find persons with the desire and will to move in order for HCBS expansion to be successful. States need to increase transition efforts that will serve the most people and integrate culture change with transition. States need to work with nursing home staff, such as discharge planners, and develop training on the new MDS Section Q. As a national policy, Dr. Hendrickson believes that states need to learn from the success of other states and that the issue of HCBS programs being cost-effective should be addressed once and for all so that we as a country can move forward.

In the session's second presentation, ***Comprehensive Assessment and Service Planning***, **Kathy Leitch**, M.S.W., assistant secretary of the Aging and Disability Services Administration (ADSA) in the Washington State Department of Social and Health Services, Aging & Disability Administration, discussed how Washington State targets candidates for transition.

Since 2003, Washington has used a single comprehensive assessment tool, CARE, to maximize efficient eligibility determination for a variety of programs and consumers. Ms. Leitch noted that a single assessment tool can be used to inform consumers of various benefit options across settings and allow states to be more responsive to a consumer's desires or change in needs. An algorithm determines program eligibility for all programs that a consumer may consider and then generates either in-home monthly hours or residential daily rates, depending on the setting selected. Ms. Leitch stated that care management requires a uniform, comprehensive assessment that captures the following: ADLs and Instrumental Activities of Daily Living (IADLs), treatment and therapies, medication management, seizures, skin care, risk of falls, pain management, cognitive capacity, depression, behavioral issues, suicide risk, substance abuse, communication, family supports, and consumer goals.

Effective assessments require qualified social workers with nursing expertise to be available for assessment and discharge planning. In Washington, all recipients of HCBS are assigned a case manager. Case managers are assigned to nursing homes and hospitals to actively work toward diversion or discharge and prevent situations that would lead to a decrease in health status. Certain elements in the assessment act as "triggers," requiring action by the case managers and/or on-staff RNs related to medical issues that affect care planning. Other assessment items trigger required protocols for appropriate referrals to community resources for depression, pain, suicide prevention, and alcohol/substance abuse.

To leverage system improvement toward more effective chronic care, Washington has used acute health-care utilization data and risk criteria in CARE to identify the highest risk/cost Medicaid clients. These clients were randomly enrolled in either a pilot program to receive Intensive Chronic Care Management (ICCM) or a comparison group. Compared with the control group, clients enrolled in the pilot program reported improved health outcomes in all five areas examined: overall health, patient activation, self-sufficiency, pain impact, and quality of life. Additional ICCM findings showed a statistically significant lower risk of death among participating clients. For every dollar invested in the ICCM intervention, three dollars were returned in acute care cost savings.

To conclude, Ms. Leitch discussed the use of the CARE assessment tool as a database for system improvement. Washington's assessment is automated and used for each HCBS applicant and recipient. Virtually all data fields can be queried and compared with payment data, allowing for aggregation of data and comparison of multiple acuity scores across settings and time periods. CARE data can also be linked with MDS data for nursing home residents, and it can inform program improvement and validate evidence-based outcomes. Client-level data are useful to inform staff of consumer concerns and for client goal setting.

Session 4: Determining whether HCBS is Cost-Effective

The purpose of this session was to address cost-effectiveness from multiple perspectives and examine evidence from various program evaluations. Presenters sought to address the following questions: Does the expansion of non-institutional long-term care services reduce nursing home utilization, Medicaid spending, or public spending in general? To what extent does the expansion of HCBS result in unintended costs by monetizing informal care? **Stacey Mazer**, M.P.A., senior staff associate at the National Association of State Budget Officers (NASBO), moderated this session. Ms. Mazer opened the session by noting that resources are and will continue to be limited at all levels of government and that budget actions are often guided by cost-effectiveness. Relating back to the theme of the symposium, Ms. Mazer suggested that the role of the evidence is to attempt to reconcile the demand for services with expenditures.

H. Stephen Kaye, Ph.D., associate adjunct professor in the Institute for Health and Aging and co-director of the Disability Statistics Center at the University of California, San Francisco, began his presentation, ***Can States Reduce Long-Term Care Spending Through HCBS?***, by showing data on national per capita Medicaid long-term care expenditures, by type, adjusted for inflation in medical costs between 1988 and 2005. His interpretation was that HCBS expenditures are increasing in parallel with total long-term care spending. Kaye cautioned policymakers who argue that HCBS expenditures are the source of runaway costs, explaining that correlation is not causation.

A 2006 study by the Center for Personal Assistance Services (PAS) on HCBS costs relative to all public expenditures concluded that HCBS saved $44,000 per participant in 2002. In a 2007 study, Kaye and colleagues estimated the cost of mandatory personal assistance services under Medicaid and found that the proposed Community Choice Act (formerly known as MiCASSA) would cost between $1.4 billion and $3.7 billion per year, not the $13 billion to $25 billion that the Congressional Budget Office (CBO) estimated in 1997.

Although the aforementioned studies suggest that HCBS can be cost-effective, individual cost savings do not necessarily result in aggregate savings. States are concerned about the "woodwork effect" and the ability to demonstrate cost neutrality or actual cost savings. Kaye examined the experience of states with expanding or established HCBS programs in controlling cost. The major research question was: *Have states with thriving HCBS programs controlled total long-term care costs better than other expanding or non-established states?* The study approach was to examine annual state Medicaid expenditures for nursing homes, intermediate care facilities for the mentally retarded (ICFs/MR), home health, personal care, and HCBS waivers. The study design separated out costs for people with intellectual and developmental disabilities (MR/DD) from other types of disabilities, and combined states with similar spending patterns to examine trends in expenditures over one decade. MR/DD HCBS expenditures accounted for 30 percent of HCBS expenditures in 1995 and increased steadily after 1997, accounting for 60 percent of HCBS expenditures in 2005. In contrast, non-MR/DD HCBS expenditures did not begin increasing until 2001. Kaye noted that this makes sense, because the deinstitutionalization movements for the two populations are on different timelines, with MR/DD deinstitutionalization preceding non-MR/DD deinstitutionalization.

To better understand the difference between state expenditures between 1995 and 2005, the states were divided into low HCBS states and high HCBS states. Low HCBS states are those with per capita HCBS expenditures less than the median for all states in 2005. High HCBS states consisted of expanding states—those whose per capita HCBS spending more than doubled from 1995 to 2005—and established states—those with well established HCBS programs.

Kaye and colleagues compared non-MR/DD nursing home expenditures and found that low HCBS states' per capita inflation-adjusted nursing home expenditures increased gradually throughout the 1990s until 2002. In contrast, high HCBS states experienced a gradual decline in per capita nursing home expenditures.

For non-MR/DD HCBS expenditures, low HCBS states' per capita inflation-adjusted expenditures remained relatively low. Established states had high per capita HCBS expenditures to start, with per capita expenditures increasing slightly and then leveling off in later years, as might be expected. Expanding states had low per capita HCBS expenditures in the beginning years and sharply higher per capita expenditures in later years, eventually overtaking the per capita expenditures for established states. Established states are more successful with cost containment from year to year because they are further along on the HCBS development curve. Per capita inflation-adjusted total long-term care spending has exhibited a relatively slow rate of growth in all states, bringing Kaye to conclude that HCBS is not responsible for breaking states' budgets.

Kaye noted that state spending patterns for MR/DD are very different. Kaye and colleagues calculated per capita inflation-adjusted total long-term care expenditures for the MR/DD population and compared the high HCBS with the low HCBS states. They found little difference in expenditure trends and concluded that HCBS is not responsible for increasing expenditures.

Kaye and colleagues then looked at per capita inflation-adjusted total long-term care expenditures for MR/DD among low, established, and expanding states. Spending in established states remained relatively flat during the study period. Both low HCBS states and expanding states experienced expenditure growth over the study period. Again, established states more effectively contained costs. For expanding states, Kaye believes that there is an initial period of increasing costs and then expenditures eventually even out.

Kaye concluded that HCBS programs do not break states' budgets. The near identical per capita total long-term care spending for low versus high HCBS states confirms the cost neutrality of HCBS. Kaye noted that a particularly interesting research finding is that established HCBS states contained costs better than low HCBS states. HCBS expansion increases short-term per capita spending, but spending eventually levels off, which is consistent with the goal to serve more people at equal or possibly lower cost per person.

In his presentation, ***The Cost-Effectiveness of Home and Community-Based Long-Term Care Services***, **David C. Grabowski**, Ph.D., associate professor in the Department of Health Care Policy at Harvard Medical School, provided a background on the rebalancing of long-term care. Long-term care has historically been dominated by nursing homes. In recent years, there has been tremendous growth in the delivery of long-term care in non-institutional settings. Dr. Grabowski suggested that there are legal, economic, and preference-based reasons for the expansion of HCBS. Home and community-based services expenditures as a share of overall Medicaid long-term care expenditures rose from 12 percent in 1992 to 45 percent in 2007. In general, the majority of states have expanded long-term care spending under Medicaid. Given the budget neutrality restrictions imposed by CMS on HCBS waivers, there has been much interest in whether HCBS programs result in cost savings. Dr. Grabowski contended that the emphasis on cost savings is a bit misplaced.

Dr. Grabowski discussed four types of HCBS evaluations: (1) randomized, controlled experiments (e.g., Channeling), (2) Medicaid waiver spending studies, (3) capitated programs (e.g., PACE), and (4) consumer-directed care (e.g., Cash & Counseling).

In the largely federally funded, randomized, controlled studies, community dwellers were compared with community dwellers with greater access to HCBS. Researchers found slightly decreased nursing home use, but an increase in overall long-term care costs for the group with access to HCBS due to the "woodwork effect." There was, however, little improvement in survival, physical/mental functioning, client/caregiver welfare, or unmet need.

***Higher costs. Better effectiveness.
As an economist, I don't see
any problem with that …
Asking for lower costs and better
effectiveness is really hard to do.***
--David Grabowski

Medicaid waiver spending studies by the Governmental Accountability Office (GAO) and Lewin/AARP examined states that were early adopters of HCBS. In the absence of a comparison group, researchers created a counterfactual group. Studies compared actual versus projected spending in the absence of HCBS growth. Both studies found that greater HCBS waiver spending equated to lower overall state long-term care spending. Established HCBS states spent 10.7 percent more per capita in 2005 relative to low HCBS states, but had lower spending growth from 1995 to 2005. Dr. Grabowski's explanation for the lower spending growth is that inflation has been highest for institutional services.

Capitated programs integrate acute and long-term services through managed care and the use of capitation payments. Capitated programs are traditionally not pure HCBS, yet all emphasize greater use of HCBS and more efficient allocation of resources. The evaluations of capitated programs have produced mixed evidence regarding whether these programs increase or decrease costs.

An evaluation of consumer-directed care used a natural experiment in California and found greater client satisfaction without any decrease in safety or unmet needs. In addition, the randomized, three-state Cash & Counseling demonstration evaluation discussed in Session 2 generally indicates better consumer outcomes, but with higher Medicaid costs.

To conclude, Dr. Grabowski offered a summary of the HCBS cost-effectiveness literature to date. Sources indicate that achieving cost savings with HCBS has proven difficult and, relative to nursing home care, research has found that HCBS is associated with higher costs, similar outcomes, higher quality of life, and increased satisfaction. Dr. Grabowski suggested that, rather than asking, “Does HCBS save money?” we should ask, “What are we getting in return for increased spending?” The latter is the more difficult question to answer, although many believe that HCBS adds sufficient value to warrant further expansion and an increase in aggregate costs. The future of Medicaid HCBS in a recession is unclear, but the case for improved effectiveness needs to be made now.

Peter S. Arno, Ph.D., professor in the School of Public Health at New York Medical College, sought to go beyond HCBS to explore the continuum of care in his presentation, ***The Caregiving Continuum: Costs & Benefits Reconsidered***. Dr. Arno suggested that there are demographic and economic changes affecting the continuum of care. The socioeconomic consequences that affect caregivers and care recipients include income, education, race and/or ethnicity, gender, age, marital status, and socialization.

Dr. Arno asked, given the aging of baby boomers and the fact that the largest population growth rate is for age groups 70-84 and 85+, what will be the caregiving needs over the next few decades, and where will the caregivers come from? Many older persons will have chronic conditions that require complex care and appropriate housing options. Currently, approximately 20 percent of elderly persons who require assistance are not able to obtain any type of care.

Dr. Arno cited a great imbalance between supply and projected demand for direct care workers, which is at an all-time high. The projected increase in demand for direct care workers between 2006 and 2016 suggests that the demand for personal and home health aides will increase by 50.6 percent, home health aides by 48.7 percent, nursing aides by 18.2 percent, and all direct care workers by 34 percent. Wages for home health aides are barely above minimum wage and have not kept up with inflation. As a result, 30 percent of direct care workers are living at the poverty level, and 40 percent to 50 percent rely on government benefits. CMS projections for 2009 estimate that home care expenditures will total $70 billion and that the economic value of informal caregiving will be $354 billion. Dr. Arno suggested that, in order to create a better care economy, we must make the caregiving professions an attractive career choice, providing adequate wages and benefits and a career ladders. We must support informal caregivers and compensate the direct and indirect costs of informal caregiving, perhaps through tax credits. Finally, we must consider the continuum of care as a mix of informal, formal, and long-term care, all of which contribute to a better care economy.

Reflections

Henry Claypool, the newly appointed director of the U.S. Department of Health and Human Services' (HHS) Office on Disability and former policy director at Independence Care System, was introduced by Chuck Milligan. Mr. Milligan stated that Mr. Claypool has played a leading role in driving disability policy at the state and national levels for more than 25 years.

Mr. Claypool began his remarks by noting the 10th anniversary of the Olmstead decision on Monday, June 22, 2009. He urged that the dialogue and movement that began with the Olmstead decision continue to encompass critical issues for people who are underserved, yet not necessarily institutionalized. In addition, there needs to be a universal assessment instrument that is applicable across all populations. Mr. Claypool noted that the system for persons with developmental disabilities (DD system) has made good progress with assessment, access, and services, but we need to have more equitable distribution of resources across all populations. Mr. Claypool suggested that the current system look more uniformly at people, personal experiences, and the allocation of resources based on need instead of diagnosis.

When examining system infrastructure, Mr. Claypool maintained that the DD system has a highly developed case management system, yet there is a tremendous amount of unmet need in other populations. Mr. Claypool suggested that a modification of current infrastructure would allow for better care for non-DD populations. If we turn to the system for caring for the aging population, the challenge lies in modifying an infrastructure for people who rely heavily on Medicaid, namely poor people of color who live in depressed urban areas and do not receive services.

A new, developing practice is that of the Community Living Specialist. Mr. Claypool believes we should examine and elevate this practice, because these specialists are very knowledgeable about community resources and access to services (e.g., durable medical equipment [DME] repair, transportation, housing, etc.). Mr. Claypool suggested that the independent living community move away from advocating exclusively for initiatives such as the Community Choice Act and devote more time and energy to building infrastructure in the community.

Mr. Claypool stated that institutional bias exists, but he hopes that enlightened legislators will work to address this. Mr. Claypool questioned whether there are incentives that we could provide state and local governments to promote an organizational structure that can be sustained in a chaotic political environment. A critical question is, "Will state legislators ever be able to step up to address payment issues?" We need a strategy to help legislators understand that payment systems for community-based services require as much attention as payment systems for facility-based settings.

Mr. Claypool mentioned that he appreciated hearing the comments about workforce issues from other presenters. As a recipient of personal assistance services himself, Mr. Claypool stated that he knows the workforce issues well. He maintained that care received from friends and family is a valid economic transaction and that their time has value. We cannot minimize the role of the unpaid caregiver, because we need these providers to sustain the long-term care system. In addition, Mr. Claypool stated that it is a fallacy to hold out hope that we can expect caregivers to provide services over the long term without paying them for their time and effort.

To address the problem of financing services, Mr. Claypool suggested targeting poor performing states and helping them move in the right direction. States need to be held accountable, and enforcement has its place. However, providing incentives would be preferable, as enforcement just addresses isolated events and does not promote system reform. There is no doubt that the Olmstead decision prompted the massive rebalancing movement of the past decade, and we must encourage states to continue to move forward.

Mr. Claypool maintained that care coordination is crucial. Many individuals who use long-term services have multiple chronic conditions or extraordinary health-care needs. He stated that we must reconnect with the long-term care system that we have "demonized." We must devise a way to work with health-care practitioners and reconnect to the health-care reform debate.

Finally, Mr. Claypool mentioned that HHS has a lot of work to do concerning the mental health system. Although the specific needs of individuals with mental health impairments may differ from those with functional impairments, the need for support is still there. The mental health system is underfunded, and there needs to be more collaboration. HHS is looking to provide leadership on that front.

> ***Rebalancing is not about complying with a court order,***
> ***but rather it is about modifying and building systems*.**
> --Henry Claypool

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