

REPORT

FINAL REPORT

Summary Report from the DEHPG 2014 LTSS Research Summit

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I. INTRODUCTION

A. Overview and Purpose of the 2014 LTSS Research Summit

The first Disabled and Elderly Health Programs Group (DEHPG) Research Summit was held November 3 and 4, 2014 at the central offices of the Centers for Medicare & Medicaid Services (CMS) in Baltimore, Maryland. This summit brought together representatives from nine different Federal agencies, including CMS, to share a broad range of current and emerging research and to discuss research gaps and collaborations to address those gaps.

Ultimately, the goal of the summit was to help DEHPG develop a research agenda for the future that furthers the group's commitment to support state efforts to transform their systems and rebalance their Medicaid expenditures for long-term services and supports (LTSS) so that more people have the option of receiving LTSS in home and community settings. By bringing together DEHPG's federal partners who have a shared interest and whose work touches upon their own efforts to improve the LTSS systems, this summit presented an opportunity to share foundational work across agencies, to highlight research and innovative efforts related to LTSS, to build upon the lessons learned, and to work more collaboratively to leverage research and knowledge. The intention was to develop insights and connections that would enhance federal partnerships to develop collaborative research goals and future interagency activities.

B. Structure of the Summit and Agency Representation

A call for abstracts that went out in September 2014 resulted in the submission of 34 abstracts from five different agencies outside of CMS. The summit was designed around three half days of presentations and discussions. The first half day of the summit was devoted to discussions of the breadth of DEHPG research work. The second half of the day was composed of discussions of the research being conducted by other Federal agencies including:

- Assistant Secretary for Planning and Evaluation (ASPE)
- The Department of Housing and Urban Development (HUD)
- Administration for Community Living (ACL)
- Agency for Healthcare Research and Quality (AHRQ)
- The Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NHCS)

Audience members also included staff from:

- Social Security Administration (SSA)
- Health Resources and Services Administration (HRSA)
- Office of Management and Budget (OMB)
- United States Access Board

On the second day of the conference, which was a half day, summit participants broke out into three small working groups to discuss research gaps and how to address those gaps, including potential data sources and interagency collaborations

C. Roadmap to the Report

This report summarizes what was learned during the summit. Using the information presented in both the abstracts and at the conference itself, the following section organizes the research by the eight attributes of LTSS systems that have been the focus of DEHPG's grant and research agenda. The findings of DEHPG's grant programs have been synthesized in Irvin and Lester (2012). These eight attributes include:

- Accessible Home and Community-Based Services
- Systems that Support Transitions Among Settings and Service Systems
- Comprehensive No Wrong Door Systems for Accessing Community-Based LTSS
- Person-Centered Planning and Service Delivery
- Employment Supports for People with Disabilities
- Adequate Supply of Direct Service Workforce and Adequate Support for Caregivers
- Adequate Supply of Housing to Support Community-Based Living Options
- Quality Assurance and Quality Improvement Systems

The next section discusses critical research gaps that summit participants identified. Within the each topic area, a summary of recent and ongoing research is described first, followed by a description of emerging research that was only starting at the time of the Research Summit. Each topic closes with a description of the research gaps either cited during the presentations or mentioned by the participants during the last half-day meeting. The report ends with a description of new data resources coming online and described at the Summit and the potential interagency collaborations that were discussed. Lists of the participating federal agencies and personnel who attended the meeting are provided in Appendixes A and B. The agenda for the Research Summit appears on Appendix C.

II. SUMMARY OF FINDINGS

A. Accessible Home and Community-Based Services

High-performing long-term care systems make community-based LTSS easily accessible to everyone who needs these services (Irvin and Lester 2012 and Reinhard et al. 2014). These services primarily help people with the activities of daily living and they are not covered by Medicare and most forms of private health insurance cover only health services and not LTSS.

1. Recent and ongoing research

While none of the research projects discussed at the summit focused exclusively on access to LTSS, 18 of the 34 abstract studies submitted touched upon and informed this particular area of research. Most of the research discussed at the Summit is in early stages and considered emerging research, including 12 of the 18 abstract studies that touch on accessibility issues. The few recent studies included a process and outcome evaluation of the Aging and Disability Resource Centers (ADRCs) funded by ACL and known as the Process and Outcome Evaluation of the Aging and Disability Resource Centers (ADRC) project. The ADRC system resulted from a collaborative effort of ACL, CMS, and the Veteran's Health Administration (VHA) to support state efforts to streamline access to LTSS options for older adults and individuals with disabilities. ADRCs are designed to serve as highly visible and trusted places available to all populations and all payers. This evaluation has focused on determining the extent to which ADRCs are improving awareness of and access to LTSS for older adults and individuals with disabilities. An assessment of consumer reported options will measure whether consumers who access ADRCs report being more empowered to make informed decisions about their care options, are better able to plan ahead for their future long-term care needs, and have more understanding of, and access to, LTSS. Preliminary findings from the evaluation suggest that ADRCs have increased awareness of LTSS options. Over 80 percent of the ADRCs surveyed reported that the program has helped increase coordination among LTSS organizations and 95 percent of local sites report they have been able to improve their ability to provide integrated, comprehensive access to LTSS.

The CMS-funded resource guide of state Medicaid services for children with autism spectrum disorders (ASD) is an example of recent research on the availability of services for people with this disabling condition (L&M Policy Research 2014).¹ This resource guide provides state profiles of Medicaid services for children with ASD and their families. The report notes that the availability of services and supports vary widely across states. Factors that influence the availability of services include level of state resources, the existence of state legislation bolstering ASD services and supports, careful coordination across state systems of care, and advocacy by state and local organizations in support of individuals with ASD and/or intellectual disabilities.

¹ This report can be accessed at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf>.

2. Emerging research

Of the 18 abstracts that touched on accessibility issues, 12 represented new and emerging work. An example is the current ASPE-funded assessment of state health homes programs, known as the Medicaid Health Home Benefit Evaluation.² Health homes are designed to provide coordination of LTSS and other benefits for Medicaid beneficiaries with chronic conditions. Preliminary results suggest that the most common chronic conditions of participants include mental illness, diabetes, and asthma. In general, states are enrolling individuals who have higher rates of health care utilization and higher health care costs compared to the general population of Medicaid beneficiaries. North Carolina is one exception where health home participants are similar to the general Medicaid population in terms of service utilization and expenditures. To support the coordination of services, most states require health homes to either use an electronic health record or adopt one within a specified time after earning the health home certification. Other preliminary information suggests that health homes are improving care coordination and that participants have better access to community services and have better care transitions.³

Another set of three ASPE-funded research projects are assessing how access to community-based LTSS is influenced by several new programs and initiatives.

- One study, known as the Use of 1915(i) Medicaid State Plan Option, seeks to understand how states are using the 1915(i) Medicaid option to serve individuals with mental health and behavioral health needs and to support a more comprehensive service array. This qualitative study will examine how states are using the 1915(i) benefit to provide home and community-based services (HCBS) to new populations, and how states are thinking about the 1915(i) benefit in the context of broader health system change. It seeks to answer questions such as: What services are states providing under the 1915(i) authority? What populations are states targeting? How are states combining their 1915(i) program with other funding streams to provide a more comprehensive service array? How are states using 1915(i) waivers to support broader efforts at health system change?
- The second study is an evaluation of the Balancing Incentive Program and is known as the Evaluation of the Balancing Incentives Program. This study will use qualitative research methods to assess whether states participating in the Balancing Incentive Program met their goals, which includes making HCBS more accessible as states increase the community-based LTSS options available to Medicaid beneficiaries.
- The third study is assessing how outcomes vary between managed care programs that fully integrate Medicare and Medicaid services and those programs that do not. Known as the Analysis of Minnesota Managed Care Longitudinal Encounter Data, this study is using Minnesota as a case study where plans are responsible for HCBS (waiver and state plan personal care services) and the first 180 days of nursing home care. It is focusing only on Medicare-Medicaid enrollees and this study seeks to learn about the differences in the membership of fully integrated managed care plans and managed care plans that only cover

² A report from the base year of the contract can be accessed at <http://aspe.hhs.gov/daltcp/reports/2012/HHOption.shtml>.

³ Better care transitions was not defined during the Research Summit.

Medicaid services. The study also seeks to understand factors that influence the choice of plan and how patterns of service use differ across the two types of plans (controlling for the differences in plan members). Ultimately, the study seeks to determine whether a fully integrated managed care plan provides better care coordination across acute care services and LTSS as evidenced by fewer ambulatory care sensitive hospital stays, less use of emergency rooms, reduced nursing home use, and greater access to HCBS.

Other studies that are in their early phases assess the interaction between service utilization and the risk of nursing home entry and becoming dually eligible for Medicare and Medicaid. For example, the Longitudinal Analysis of the 2004 National Long-Term Care Survey Linked to Medicaid Claims: Use of Medicaid-Funded LTSS study funded by ASPE is investigating whether the use of Medicaid-funded HCBS postpones or prevents nursing home use. This study will use longitudinal data from the 2004 National Long-Term Care Survey that have been linked to Medicaid claims includes.⁴ In addition, this study seeks to determine the prevalence of spending down to Medicaid eligibility after entering nursing home care among individuals who had incomes and assets well above Medicaid means-tested levels and owned their homes while they lived in the community. Another ASPE-funded study, known as the analysis of Pathways to Dual Eligible Status study, is using data from the Medicare and Medicaid Linked Enrollee Analytical Data Source (MMLEADS) to establish a better picture of the pathways people take to dual eligibility status and how these pathways differ by age and service utilization.

The other emerging research presented at the Research Summit was the ACL-funded process and outcome evaluation of the Title III-E Caregiver Support Program, known as the Process and Outcome Evaluation of the Title III.E Caregiver Support Program study. This national evaluation of the National Family Caregiver Support Program (NFCSP) is assessing whether caregivers have easy access to a high quality, multi-faceted system of supports and services that meets caregivers' needs and preferences. In addition, it is assessing what systems need to be in place to achieve this easy access. The NFCSP was established in 2000, in 2012 it supported over 800,000 caregivers nationwide. Services provided include: information about available services; assistance in gaining access to services; counseling, supports groups, and caregiver training; and respite care.

3. Research gaps

Research Summit participants suggested a large number of different areas of study that relate directly to access to community-based LTSS. Work that would follow-on from current research efforts include more study of the role and utility of community needs assessments, common assessment forms, and data sharing among ADRCs. The ADRC system would benefit from a better understanding of what works in these particularly areas. In addition, the results from the evaluation of health homes provided so far has been based on qualitative analyses and more rigorous assessments are needed before firm conclusions about this option can be drawn. In addition, it is still not clear what care coordination necessarily means in the health home context

⁴ The 2004 National Long-Term Care Survey is based on a nationally representative samples of Medicare enrollees, those with and without disabling conditions. The samples include Medicare enrollees residing in nursing home, community-based residential care settings, and regular housing (their own apartments or homes). The website for the study can be accessed at <http://www.nltcs.aas.duke.edu/>.

and which strategies produce the best outcomes. The same types of questions apply to the demonstrations for Medicare-Medicaid enrollees that have been approved in 12 states.

The research on MLTSS programs also raises some key questions. Participants expressed concern about the future of the encounter data (and other data) that MLTSS programs should be generating. The discussion focused on whether the data will be reported and will be useable for research. In addition, the participants of the Research Summit noted that more research on care coordination within MLTSS programs is needed to understand what works well. These questions included:

- How does care coordination change when a state moves from a fee-for-service (FFS) system to MLTSS?
- Does MLTSS improve care coordination (and other aspects of access to LTSS)?
- What are the most effective conflict of interest protections in MLTSS programs?
- How are conflicts of interest assured and operationalized in MLTSS programs?

In addition to research needs focused on particular programs or models of care, the participants noted several more general areas of research that are needed. These areas include more research on:

- How accessibility is measured
- The affordability of LTSS and payment policies
- Whether universal waivers rather than a number of small, population-specific waivers make a difference for access to LTSS
- Best practices for making LTSS system less complex to access
- Which approaches to the integration of primary care, behavioral care, and LTSS seem to provide the best access to community-based LTSS

The participants at the Research Summit also had ideas for narrower and more detailed avenues of research. These avenues included research relating to:

- Barriers created by transportation systems
- Technologies that support remote monitoring of someone's activity
- Feasibility of using the HCBS taxonomy for common classification of services and the comparison of LTSS across states
- State implementation of the new guidance for services for children with ASD

B. Systems that Support Transitions Among Settings and Services

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 (Irvin and Lester 2012). 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 adult health care systems. The AARP state scorecard of state LTSS systems suggest that states with more effective approaches to transitions and transition planning have lower levels of nursing home use (Reinhard et al. 2014).

1. Recent and ongoing research

The National Evaluation of the Money Follows the Person (MFP) Demonstration and the Medicaid Health Home Benefit Evaluation are helping to improve our understanding of systems that support transitions among settings and services.⁵ Research findings from the MFP national evaluation suggest that the majority of transitions are successful, large percentages of MFP participants are able to remain living in the community for a year or more. Recent research on expenditures indicates that the overall expenditures of those who transition decline and medical care expenditures (such as those associated with inpatient care, emergency services, and primary care visits) do not seem to escalate after the transition (Bohl et al. 2014).

The evaluation of the health homes program are in preliminary stages and little is known right now about the effectiveness of the health home model and how these programs coordinate LTSS with health care services. Early qualitative research indicates that better patterns of provider communication are needed, particularly among health home providers, hospitals, and managed care organizations (MCOs) (Spillman et al. 2012). Coordination and linkages with social services and LTSS are not well supported by current health information technology (HIT) infrastructure. The lack of widespread interoperable information systems and regulatory restrictions on sharing patient information create barriers to the communication needed to support transitions among settings.

Work on developing the Continuity Assessment Record and Evaluation (CARE) tool may help address some issues around the interoperable of information systems that are needed to support care transitions (Mandl and McMullen 2014). Currently, patient and resident assessments are only uniform at the provider level; communication is not standardized across providers, which creates communication gaps and causes providers to double and trip document information. Data collected by providers are not interoperable; and data elements do not map as well as they should across settings. CMS continues to work on addressing these issues and one avenue has been the development of a Data Element Library that will serve as a repository for post-acute care assessment data elements and their mappings to HIT standards. Vendors and providers will be able to reference content in the library when implementing systems of electronic health records, health information exchange, and quality measurement.

Other relevant research includes studies of MLTSS programs, which suggest that the growth of MLTSS is associated with improvements in the balance of LTSS systems (Doty 2014). HCBS

⁵ The federal website and the latest reports for the MFP demonstration can be accessed at <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/money-follows-the-person.html>. A report from the base year of the health home contract can be accessed at <http://aspe.hhs.gov/daltcp/reports/2012/HHOption.shtml>. Information about health homes can be found at <http://www.medicaid.gov/State-Resource-Center/Medicaid-State-Technical-Assistance/Health-Homes-Technical-Assistance/Health-Home-Information-Resource-Center.html>.

expenditures account for a greater proportion of LTSS expenditures and nursing home use seems to be lower among states with MLTSS programs. However, the studies acknowledge that other factors may be driving these changes. In addition, it appears that during the early phases of MLTSS programs there is an emphasis on including traditional HCBS providers in the MCO networks, but this commitment tends to fade over time.⁶ In some cases, traditional case management providers became obsolete in states where the MCO's perform the entire function internally, although some case managers may simply move from the employment of the traditional provider to a managed care organization. Early evidence suggests that case managers are not incentivized to reduce services and care plans do not change after the introduction of MLTSS, at least not initially. However, if care does not change, then we would not expect outcomes to change either after MLTSS is introduced.

2. Emerging research

The Research Summit included descriptions of several research efforts that are currently underway and may shed more light on how systems need to be structured to support successful transitions among settings. APSE is sponsoring a qualitative assessment of HIT, known as the Health Information Exchange in Integrated Care Models project, which links acute care and LTSS providers participating in fully integrated care arrangements. The research includes a qualitative assessment of how payment policy impacts this type of HIT. The study will also provide insight on how integrated care models function at the provider level.

As part of the Development and Testing of Behavioral Health Quality Measures project, AHRQ and CMS have been developing quality measures for people with serious mental illness and several of these measures capture transitions among settings, focusing primarily on transitions from acute inpatient care to the community. This work includes the development of measures for post-acute care followup. The results of this research will support the tracking of utilization outcomes that can identify whether a plan or the Medicaid program is meeting a specified benchmark. In addition, the National Quality Forum (NQF) is launching a new initiative to develop a wide array of quality measures for LTSS and this initiative should produce some important research relating to the development of measures that capture the quality of care transitions.⁷

3. Research gaps

Research summit participants believed that more research is needed to understand which models and processes of care provide the most effective supports for transitions. Little is known about the best practices or most effective structures for transition and care coordination programs, particularly when the services need to be home based or these services are provided by a MLTSS program. Participants also thought that more research on transitions from the

⁶ Also see “How Have Long-Term Services and Supports Providers Fared in the Transition to Medicaid Managed Care? A Study of Three States,” available at: <http://aspe.hhs.gov/daltcp/reports/2013/3LTSStrans.pdf>.

⁷ Information about the NQF work can be accessed at http://www.qualityforum.org/Measuring_HCBS_Quality.aspx.

community to acute to subacute and the LTSS was needed, particularly the transition from home health to inpatient care.

The growth of MLTSS programs has brought a wide array of research and policy questions that current studies do not appear to be addressing. These questions include:

- How do transitions differ under MLTSS compared to fee-for-service?
- How do MLTSS program incentivize transitions?
- Which structural features seem to matter for member outcomes?
- Are states realizing a cost-benefit tradeoff that makes sense?
- What does network adequacy look like for MLTSS programs, particularly when services are delivered in the member's home rather than in a central location?
- What does it mean for a MLTSS network to provide timely, high quality, integrated care?
- What types of measures would adequately capture the quality of transitions among settings?

AHRQ and CMS have been developing some quality measures for people with behavioral health needs, but more work is needed to develop quality measures for community-based LTSS. In particular,

- Do the quality measures currently available adequately capture how well plans and states support effective transitions among settings, particularly from acute to post-acute and from post-acute to LTSS and from long-term institutional care to the community?

Some of the work done for the AARP LTSS scorecard may be informative for understanding acute care transitions for LTSS users and transitions between institutional-based and community-based LTSS.

C. Comprehensive 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 (Irvin and Lester 2012). The LTSS state-scorecard also notes that, regardless of income, all consumers and their families should be able to easily obtain information about all aspects of LTSS including, how to access all types of LTSS, how to line up care coordination, and how to determine someone's eligibility for public programs (Reinhard et al. 2014).

1. Recent and ongoing research

As mentioned previously, the Administration on Community Living (ACL) has been evaluating the Aging and Disability Resource Centers (ADRCs) which are the focal point for no wrong door systems in 52 states and territories, known as the Process and Outcome Evaluation of

the Aging and Disability Resource Centers (ADRC) project.⁸ The activities of fully functioning ADRCs can be grouped into six domains; they (1) provide information and referrals, (2) offer options counseling, (3) help people with the eligibility processes for public programs, (4) support person-centered transitions, (5) build partnerships with organizations and other stakeholders that serve older adults and people with disabilities, and (6) conduct quality assurance and continuous improvement of their own services (The Lewin Group 2013).

The ACL-funded evaluation of the ADRCs included a web-based survey for all state and local ADRCs and analyses of the data collected indicate that most ADRCs believe that the ADRC program has helped them increase general awareness of LTSS and coordination among partners, at both the State and local levels.⁹ Almost all local ADRCs report that they have improved their ability to provide integrated, comprehensive access to LTSS and this improved access is occurring at the same time as they are seeing an increase in the number of LTSS providers in the communities they serve (71 percent of survey respondents) and an increase in the quality of LTSS provided in the community (73 percent of respondents). Respondents to the ADRC web survey also indicate that they have used ADRC funds to increase staff skills (98 percent of state respondents and 87 percent of local respondents), the populations served (92 percent of state and 81 percent of local respondents), and the number of organizational partnerships (99 percent of state and 86 percent of local respondents). A qualitative assessment of information from a telephone survey of consumers also indicates a high rate of consumer satisfaction with ADRC services.¹⁰ For example, 83 percent of respondents said that the information they received was very clear and understandable and 74 percent were satisfied with the service they received.

2. Emerging research

An ASPE-funded evaluation of the Balancing Incentive Payment program may shed further light on comprehensive, no wrong door systems, although what type of detailed information this study will produce regarding no wrong door systems was not clear at the time of the Research Summit. As part of assessing the achievement of program goals, this study will also describe the progress that the participating states make on program goals, including the adoption of a comprehensive no wrong door system.

3. Research gaps

Both the completed and emerging research in this area are based on qualitative assessments and do not include rigorous analyses of outcomes of the various ways in which states have designed and implemented comprehensive no wrong door systems. No research to date has included an outcome study to determine whether state no wrong door systems have improved access to community-based LTSS. One group of participants noted that we currently do not have

⁸ More information about this project and links to reports can be found at http://www.aoa.acl.gov/Program_Results/Program_Evaluation.aspx.

⁹ The web survey had a 100 percent response rate from the State-run ADRCs and an 84 percent response rate from locally run ADRCs.

¹⁰ The telephone survey of consumers included approximately 600 consumers from 34 sites and the survey had a response rate of 62 percent.

a uniform approach to measuring the accessibility of LTSS which would make this type of research possible.

The recent ACL-funded assessment of the ADRC program indicates that not all ADRCs serve the nonelderly population with disabilities or whether ADRCs that focus on only the elderly population have strong referral systems to the Centers for Independent Living to ensure the nonelderly with disabilities have an equally well functioning no wrong door system. In addition, little research is available on whether the ADRCs are, in fact, highly visible within their communities so that people who need LTSS for the first time can readily find them. The survey of consumers was based on people who located an ADRC, but the consumer satisfaction information is not generalizable to the consumers who have not used the ADRC system. The ADRC study notes that more research and funding is needed to help ADRCs expand their partnership with Medicaid agencies, develop additional partnerships with Centers for Independent Living, and increase the use of common assessment forms and increase data sharing.

Some attendees believed more research was needed to answer the following types of questions:

- How well do state LTSS systems facilitate connections between HCBS and other community services that people with disabilities need and use?
- To what extent do the alternative benefit plans cover LTSS? When they cover these service, do no wrong door systems need to be strengthened in some way?
- How do MLTSS programs change the state's no wrong door system? How do MLTSS programs coordinate with the state's no wrong door system?
- What are the unique access barriers for people with substance abuse conditions and are no wrong door systems accommodating these issues for this population?

D. Person-Centered Planning and Service Delivery

A well-functioning long-term care system supports person-centered planning (Irvin and Lester 2012). According to the Person Centered Planning Education Site maintained by Cornell University, person-centered planning focuses on people and their needs and enables people with disabilities to direct their care planning and planners help people with disabilities determine how to get to where they want to go with their services.¹¹

1. Recent and ongoing research

Person-center planning puts the needs and goals of the consumer front and center in the service delivery process. The final HCBS rules announced by CMS on January 10, 2014 specify that person-centered planning for Medicaid beneficiaries under section 1915(c) and 1915(i) must

¹¹ See <http://www.personcenteredplanning.org/>.

reflect individual preferences and goals.¹² Self-direction programs where consumers have the ability to either manage a service budget or have the ability to hire and fire providers or both is a critical aspect of person-centered LTSS systems. The most directly related research on this topic presented at the Research Summit was an ASPE-financed five-state study of how self-direction may be changing as states introduce MLTSS programs, known as the Medicaid Managed Long-term Services and Supports: Lessons from Early Implementers study. This study used reviews of contract documents and key informant interviews to assess how states are adapting self-direction programs to the managed care service environment (Sciegaj et al. 2013). While four of the five states studied required the managed care organizations (MCOs) to introduce the self-direction option to members at key points (such as at enrollment), they found wide variation in the number enrolled in self-direction, the training of MCO service coordinators, and the approach to quality assurance. While all five states required the MCO to submit a quality assurance and improvement plan, only three states had specific reporting requirements specific to self-direction, and only one state had performance indicators for its self-direction program. The study concludes that because administration of self-direction programs is delegated to the MCOs and there are no standards and requirements for these programs, self-direction in MLTSS programs may not always conform to the philosophy, roles, and responsibility of different self-direction supports. The study also noted that a lack of standardized training for service coordinators resulted in wide cross-state variation in member experiences with this service, in part because the introduction, orientation, and on-going support for self-direction services can be time consuming for service coordinators. In addition, the lack of quality measures for self-direction prevents most states from evaluating program performance and distinguishing high quality programs from low quality programs.

Programs that teach consumers to self manage their chronic conditions may also be part of a well-designed person-centered delivery system. The ACL evaluation of the Chronic Disease Self-Management Program (CDSMP), a community-based workshop to help people better manage their chronic conditions, determined that racial and cultural minorities were some of the most successful program participants.¹³ In addition, program sustainability was more likely when there was strong leadership and vision at the state level and the state unit on aging and public health department had a symbiotic partnership. Nevertheless, the long-term viability of community-based disease management programs may depend on their ability to integrate into the new delivery system and financial models that are being developed and tested.

Studies of the health home state plan option are also providing some insight into how this type of care can be part of a person-centered delivery system. Health home programs have the goal of improving the coordination and integration of primary, acute, behavioral, LTSS, and community-based services for Medicaid beneficiaries with chronic conditions. Data from surveys fielded in eight states for a CMS Report to Congress suggest that health homes are increasing patient empowerment and patients in a health home are more proactive and engaged

¹² See <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html> for links to the final regulation and fact sheets that provide summaries.

¹³ More detailed information about this study and links to reports can be found at http://www.aoa.acl.gov/Program_Results/Program_Evaluation.aspx.

in their care.¹⁴ In addition, health homes are associated with improved care coordination, expanded access to community services, and improved care transitions.

2. Emerging research

In addition to more research emanating from evaluations of the home health programs, other research on the Balancing Incentive Payment program, the Medicare-Medicaid enrollees demonstrations, and the testing of LTSS assessments and personal health records are likely to shed light on how to improve and strengthen the person-centered attribute of LTSS systems. For example, the Medicare-Medicaid enrollee demonstrations emphasize person-centered planning and integration among primary care, acute care, LTSS, and behavioral health services. The evaluation of these demonstrations will provide insight into the characteristics of effective integration for people dually eligible for Medicare and Medicaid. Similarly, CMS initiatives to develop an LTSS assessment tool, which will adapt a subset of assessment items from the Continuity Assessment Record & Evaluation (CARE) instrument, and a personal health record for LTSS users will provide information on how these tools can be designed to support informed decision making and person-centered care across settings (Lida 2014).¹⁵

As CMS implements its framework for measurement, we are likely to improve our understanding of the characteristics associated with effective person-centered delivery systems. This framework specifies that measures should be patient centered and outcome oriented whenever possible. Measure concepts in each of the six domains that are common across providers and settings form a core set of measures in this framework. These domains include (1) clinical quality of care, (2) care coordination, (3) population and community health, (4) efficiency and cost reduction, (5) safety, and (6) person and caregiver experience and outcomes (Mandl and McMullen 2014). The overall objective of the framework for people with LTSS needs is to increase effective patient-centered care and communication to attain quality of life goals.

3. Research gaps

The study of self-direction in MLTSS recommends that steps be taken to identify best practices in design, operation, and evaluation of self-direction programs to guide their development in managed care settings (Sciegaj et al. 2013). These steps would also include identifying standardized self-direction training curriculum and techniques for MCO staff and the development of standardized quality measures specific to self-direction. Participants at the research summit also thought it would be important to compare longitudinally the health care

¹⁴ At the time of the Research Summit, this information was only available in the abstract Beth Wahtera (Beth.Wahtera@cms.hhs.gov) submitted for the summit. Information about health homes can be found at <http://www.medicaid.gov/State-Resource-Center/Medicaid-State-Technical-Assistance/Health-Homes-Technical-Assistance/Health-Home-Information-Resource-Center.html>.

¹⁵ More information about the TEFT demonstration can be found at <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/grant-programs/teft-program.html>.

costs of beneficiaries in self-direction programs to similar beneficiaries not self directing their LTSS to identify important cost implications of self-directed care.

Participants at the research summit also suggested that more research is needed to understand:

- How person-centered planning relates to the training direct service workers receive and the ultimate competencies of the workforce in person-centered care principles
- How electronic assessments and care planning tools, such as the CARE assessment, align with the concepts of person-centered care

Lastly, Research Summit participants did not understand whether states have to incorporate person-centered planning into all their HCBS waiver applications and, if so, what types of outcomes they must report to CMS to assure the waivers provide person-centered planning. These outcome measures may form the basis for standardizing how states measure the person-centeredness of their LTSS systems.

E. Employment Supports for People with Disabilities

As Irvin and Lester (2012) describe, employment can be an important component in someone's quality of life and level of integration in the community. Systems that support the employment of everyone who wants to work will ensure that any LTSS required, such as personal assistance services and durable medical equipment, is available and used effectively. Barriers to these types of services can effectively create barriers to employment.

1. Recent and ongoing research

Little research on employment supports for people with disabilities was presented or discussed at the Research Summit. Although not presented at the summit, the MFP evaluation has done a small number of qualitative assessments of employment supports for MFP participants (see Irvin et al. 2013 for the most recent research the MFP evaluation has published on this topic). The ADRCs help consumers access federal disability benefits, but they do not necessarily help consumers access employment support programs or this assistance is idiosyncratic to the ADRC. Lastly, the Autism study has information about the transition from school to work which is considered under the topic of care coordination.

2. Emerging research

No emerging research was presented or discussed at the summit. The Medicare-Medicaid Linked Enrollee Analytic Data Source (MMLEADS) database includes some information from the Social Security Administration (SSA) relating to benefit receipt (Anderson 2013).

3. Research gaps

Given the lack of research presented at the summit, it is evident that this topic area has not been a top priority of the participating agencies. One research area that was discussed among the work groups was the possibility of developing quality measures relating to employment supports. These measures could be part of measure sets that capture the patient-centeredness of care, or functional status, or quality of life of people using LTSS services.

Other research ideas for this element mentioned by participants include:

- Whether pairing housing and employment, particularly for people with substance use disorders, would improve beneficiary outcomes
- For states expanding Medicaid to new populations, how will habilitation be implemented for the expansion groups and how will states align this type of service for these new populations within their existing programs (such as the 1915(c) waivers)
- How do employment supports for the population with physical disabilities compare to supports for other populations such as individuals with intellectual disabilities or behavioral health needs
- Given that SSA is considering changing eligibility for the Supplemental Security Income (SSI) program, how might Medicaid programs respond

In addition, several participants were not clear on whether CMS collaborates with ACL and the Department of Labor (DOL) on employment research and policies. Not all summit participants understand how CMS views employment as a goal and whether CMS has expectations that states waiver programs have Medicaid beneficiaries set employment goals.

F. Adequate Supply of Direct Service Workforce and Adequate Support for Caregivers

Because key LTSS services, such as personal assistance services, require direct service workers, recruiting and retaining a sufficient supply of direct service workers is critical to the overall vitality of state LTSS systems (Irvin and Lester 2012 and Reinhard et al. 2014). Despite the key role direct service workers play in LTSS systems, ensuring an adequate supply continues to be a significant challenge.

1. Recent and ongoing research

Most of the research presented at the summit relating to the supply of the direct service workforce and caregivers was based on qualitative assessments of survey data. The home health workforce study financed by ASPE used data from the 2007 National Home Health Aide Survey to compare the characteristics of subgroups of home health workers, including home health aides, certified nurse assistants (CNAs), home care aides, personal care attendants, and hospice aides (Stone et al. 2013). This study found that the degree to which this workforce is disadvantaged varied by category of worker, with hospice aides faring better than other categories in terms of wages, benefits, and access to full time employment. Hospice aides were also less likely than their peers to express an intention to leave their job. The study authors theorize that the differences between job quality experienced by hospice workers is likely attributable to differences in Medicare and Medicaid regulatory and reimbursement policies that are likely to drive actions at the agency level. The study notes that as policymakers explore strategies for reforming the Medicare and Medicaid programs they need to consider how programmatic changes, such as refinements to the home health and hospice prospective payment systems, are likely to affect home health agencies' ability to recruit and retain home health and hospice workers. Similarly, policymakers need to examine how managed care organizations and MLTSS programs affect the quality and stability of the frontline home health workforce.

Research on caregivers presented at the Research Summit focused on the needs of caregivers of frail older adults. An analysis of data from the National Survey of Older Americans Act Participants (NSOAAP) indicates that many caregivers who receive services from state units on aging or area agencies on aging are themselves older adults who may need and be eligible for LTSS (Fazio 2014). Using data from the 2011 National Health and Aging Trends Study (NHATS), the Urban Institute, with funding from ASPE, estimated that in 2011 approximately 17.9 million caregivers provided 1.3 billion hours of unpaid care to more than 9 million older adults (Spillman et al. 2014). Family members were the main source of informal care: spouses were about 20 percent of caregivers and provided nearly one-third of the aggregate hours, and adult children provided nearly half of aggregate hours. Caregivers reported providing an average of 75 hours of care per month, but spouses provided significantly more (110 hours per month) as did caregivers living with the care recipient (114 hours per month). About 10 percent of caregivers reported substantial negative consequences from their caregiving activities.¹⁶ Negative consequences were most common among caregivers who provided high levels of care, assisted individuals with dementia, and had their own health problems. Most of the older adults in this study who needed caregiving services had at least two people providing care and this number increased with the person's level of disability.

Other related research focused on community-based LTSS providers more generally. ACL's process and outcome evaluation of ADRCs suggest that most ADRCs (71 percent) believe that the supply of community-based LTSS providers has been increasing (The Lewin Group 2013). The ASPE-funded study of MLTSS programs looked specifically at how MLTSS programs have been affecting LTSS providers. Because MCOs differ in policies and procedures, the transition from fee-for-service to MLTSS gives rise to a much more complex environment for providers that contract with multiple MCOs. This study found that at least during the initial years of new MLTSS programs, the contracts emphasize the inclusion of traditional LTSS providers but overtime these protections for traditional LTSS providers tend to fade from the contracts (Kasten et al. 2013). At the time of the study, LTSS providers were still viable in the MLTSS environment, but they were seeing increasing administrative costs associated with interacting and learning the billing practices of more entities. This study found billing issues pervasive and service authorizations tended to take longer in MLTSS programs. The study suggests that overtime these types of issues create cash management pressures for providers and these pressures may threaten the financial viability of small providers in particular. The study also found that some independent care management providers were negatively impacted by the development and spread of MLTSS programs. When the MCOs conduct all care management tasks internally, the independent care management organization became obsolete and their care management staff frequently transitioned their employment to the MCOs. The study concluded that LTSS providers need more training and education to adjust to the competitive environment of MLTSS programs and that states need to provide more robust oversight of the MCO contracts to include prompt payment of LTSS providers.

¹⁶ Substantial negative consequences were not explicitly defined, but included financial difficulties, emotional difficulties, physical difficulties, having more things than the person can handle, and not having time from him or herself.

2. Emerging research

Current research funded by ACL on the National Family Care Giver Support Program (NFCSP) is expected to shed light on the effectiveness of this program specifically on whether the NFCSP is meeting its goals, what types of outcomes and impacts the program has had on caregivers and care recipients, and whether the program has contributed to system efficiency. The NFCSP was established nationwide in 2000 and through FY 2012 has provided support to more than 800,000 caregivers. Services include: information about available services; assistance in gaining access to services; counseling, support groups, caregiver training; respite care; and supplemental services. The process evaluation study will include surveys of state units on aging, area agencies on aging, and local service providers (Ryssman 2014). A survey of caregivers will occur later in the study and will include samples of caregivers who do and do not receive NFCSP respite and/or training services. The study will provide information to better understand the level and types of services that are most likely to help informal caregivers to continue providing care in the community and reducing the likelihood that care recipients will enter nursing or other costly care facilities.

3. Research gaps

Participants mentioned several different areas where more research is needed. For direct service workers, several participants mentioned that more research is needed on:

- How the Fair Labor Standards Act (FLSA) regulations, which applies protections for personal care workers, are operating in practice
- The diversity of licensing issues across states
- Gaps in benefits for direct service workers
- Whether new assistive technologies are changing the work environment for direct service workers in any way
- The role of direct service workers when someone in subsidized housing needs help connecting with additional services in the community
- How direct service workers can be used as support extenders to the health team

For caregivers, participants mentioned that more research is needed on

- The type of training caregivers need, both in general and specific training to handle medical tasks
- Whether other residents in settings, such as subsidized housing or other group living arrangements, can be trained to provide non-medical support for those who need assistance
- Improving the role and utilization of volunteers

In addition, the research on MLTSS programs suggest that many MLTSS programs allow the MCO's to conduct care coordination themselves. Participants cited a need to develop a better understanding of how care coordination models are evolving as states transition from fee for service to MLTSS.

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

People who are frail and have disabling conditions need affordable and accessible housing if they are to remain living in the community successfully. However, securing an adequate supply of such housing remains a major challenge for states (Irvin and Lester 2012). In addition to supply issues, states cite other barriers that make solving the housing challenge difficult including, a lack of coordination among housing agencies and service providers that coordinate HCBS for individuals and a lack of funding for services and supports required to live in the community successfully. The MFP demonstration has highlighted and emphasized the challenges low-income individuals with disabilities face when trying to find affordable and accessible housing and 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 (Morris et al. 2015, Peebles and Kehn 2014, Lipson et al. 2014, and Irvin et al. 2013).

1. Recent and ongoing research

Research on housing and housing supports were featured at the Research Summit. Three recent and ongoing research projects focused on supportive housing and the linkage of administrative data from the Department of Housing and Urban Development (HUD) and CMS. An ASPE-funded study assessed the role of Medicaid in permanent supportive housing (PSH) programs for the chronically homeless (Burt et al. 2014). In this study, permanent supportive housing included some form of subsidized housing (such as housing vouchers, public housing, shelter plus care, or state or locally-funded housing assistance) coupled with tenancy supports and access to primary care, behavioral health care, and voluntary support services. Based on case studies in six metropolitan areas, this study found that while some communities used a combination of funding from Medicaid and Health Resources and Services Administration to provide services through local Federally Qualified Health Centers (FQHCs), other communities relied on specific Medicaid benefits (such as Medicaid rehabilitative services, targeted case management services, HCBS, and health homes) or MCOs to provide supportive services. Louisiana uses its 1915(i) waiver program to provide supportive housing services for the homeless and for those transitioning from institutional care. When California became an early Medicaid expansion state, Los Angeles County took some of its local funding that would have gone to covering uncompensated care and invested it in permanent supportive housing services. The study also found that most PSH programs combine Medicaid funding and then use other funding sources to cover services that Medicaid does not.

A current HUD/ASPE/Agency on Aging-financed study is assessing the effects of Vermont's Support and Services at Home (SASH) program on health care utilization and Medicare expenditures (RTI International 2014).¹⁷ A SASH services coordinator and wellness nurse provide in-home supports and help connect a panel of residents with services and promotes the coordination of care. SASH is funded largely through payments from CMS through the Multi-Payer Advanced Primary Care Practice Demonstration. Using a sample of 2,500 Medicare fee-for-service beneficiaries that included both SASH participants and two control groups (one from within Vermont and another from New York), the study's preliminary findings suggest that SASH is associated with lowering the growth of health care costs. However, SASH participants

¹⁷ Also known as the Seniors Aging Safely At Home program.

appear to use more hospital services compared to the control groups. These results should be considered preliminary because they are based on the first year of the program and do not include Medicaid expenditures, although many participants are thought to be dually eligible for Medicare and Medicaid.

HUD and ASPE also funded a study that linked HUD and Medicare and Medicaid administrative data for HUD-assisted individuals in 12 geographic areas (The Lewin Group 2014). They found that approximately 68 percent of HUD-assisted Medicare beneficiaries were dually enrolled in Medicare and Medicaid. HUD-assisted Medicare-Medicaid enrollees (MMEs) had more chronic conditions compared to other MMEs not assisted by HUD (55 percent of HUD-assisted MMEs had five or more chronic conditions compared to 43 percent of community dwelling MMEs not assisted by HUD). The higher rates of chronic conditions translated into higher rates of Medicare and Medicaid expenditures and higher utilization of home health, ambulatory surgery center visits, physician office visits, and emergency department visits. Compared to other community dwelling MMEs, HUD-assisted MMEs used over 200 percent more Medicaid-financed personal care assistant services, 80 percent more other HCBS, and 67 percent more durable medical equipment.

2. Emerging research

HUD is also sponsoring several forthcoming research studies and evaluations. In 2015 the Housing Accessibility of the US Housing Stock project funded by HUD will produce a study of the 2011 American Housing Survey.¹⁸ When the report becomes available, it will provide summary measures of housing accessibility for the U.S. housing stock at the national level and within 29 metropolitan areas. Data will provide information on accessibility by housing market characteristics (such as tenure, housing price, building size and type, region, and metropolitan location). It will also provide information on the mismatch between need and the availability of accessible housing units for all households, for specific types of households (including very low-income renters with disabilities, those with housing needs, and HUD-assisted households), and by economic and demographic characteristics of housing markets. HUD is also using HUD and CMS administrative data to assess the extent to which supportive housing allows elderly persons to live independently and age in place, improve general well-being and health, and create cost savings in the healthcare system. This project is known as the Evaluation of a Supportive Services for the Elderly Program for HUD Housing.

HUD's evaluation studies are assessing the outcome of two different supportive housing programs, the Section 811 Supportive Housing for Persons with Disabilities program and the HUD-Veterans Affairs Supportive Housing (HUD-VASH) program (Souza 2014 and Rudd 2014). HUD's 811 program is for extremely low-income non-elderly households with disabilities who are either residing in institutions or are homeless or at risk for these situations. Participants must also be eligible for LTSS. The evaluation of the 811 program is in its initial phase. Using a case study approach, the process evaluation will assess the extent to which the 811 demonstration grantees have been successful at producing housing for persons with disabilities; reaching, referring, and housing the target population; and creating successful partnerships

¹⁸ Publications can be found at <http://www.huduser.org/portal/publications/ahsrep/AHSDisability.html>.

between state housing and health and human services agencies to provide services and supports. It will assess the program implementation's challenges and successes and identify the most successful approaches. Preliminary outcomes will assess the level of rental assistance, additional leverage of resources, turnover, and access to services and supports.

The HUD-VASH program evaluation is assessing barriers and facilitators to participation. This program provides permanent housing subsidies to homeless Veterans and their families combined with case management and clinical services. HUD wants to understand how and why Veterans exit this program, the barriers to getting and keeping housing with a HUD-VASH voucher, and where Veterans go after exiting HUD-VASH. This study will also compare utilization of VA medical, behavioral health, and homeless services before, during, and after HUD-VASH participation. Study results will inform efforts to improve the program's capacity to help chronically homeless Veterans maintain permanent housing.

3. Research gaps

The national evaluation of MFP and other research indicates that the lack of affordable, accessible housing is a barrier for community living for many low-income individuals with disabling conditions (Irvin et al. 2013). This inadequate supply is a primary barrier for people who wish to transition from institutional settings to the community. At least one summit participant noted that housing vouchers are not particularly useful if the supply of affordable housing is almost nonexistent.

Summit participants noted several avenues for future research in housing and housing supports.

- Among those who make the transition from institutional settings to the community, what type of housing are people transitioning to and does this information help us design better approaches to transition planning? In addition, is that housing stable and sustainable?
- Supportive housing, what works for whom? Which services make a difference?
- What can be learned from the states that have been more successful at accessing and developing supplies of adequate affordable housing?
- How do HCBS settings affect housing developers and their approach to maximizing development?
- What is the best approach to blending housing, health, and social services?
- What are the cost/benefit tradeoffs of different supportive housing models?
- What types of infrastructure improvements are needed to make housing more accessible (such as WIFI set ups for accessing electronic health records)?
- What does it take to help people age in place? What type of housing is needed and how do we achieve an adequate supply?

In addition to these specific research topics, summit participants also believed that ACL and HUD needed to coordinate their survey efforts. ACL could consider including questions in its services that are part of HUD's American Housing Survey. In addition, the American Housing

Survey might look to ACL and the populations it serves for informing the information it collects on housing accessibility.

H. Quality Assurance and Quality Improvement Systems

High quality HCBS are needed if people who are frail and have disabling conditions are to live in the community successfully, the quality of the HCBS determines, in part, the effectiveness of these services (Irvin and Lester 2012).

1. Recent and ongoing research

CMS has pursued a number of different initiatives in quality assurance and improvement systems for populations that use LTSS. In addition to developing the Continuity Assessment Record & Evaluation (CARE) tool, CMS has been developing a measurement framework that provides a useful guide for all LTSS quality assurance and improvement systems (Mandl and McMullen 2014). This framework includes six domains that are common across providers and settings: (1) quality of clinic care, (2) care coordination, (3) population/community health, (4) efficiency and cost reduction, (5) safety, and (6) person- and caregiver-centered experience and outcomes. The CARE tool itself has been expanded to include institutional LTSS settings such as nursing homes, long-term care hospitals, and inpatient rehabilitation facilities, and several community-based settings such as hospice and home health. However, it is still under development for other forms of HCBS. In addition, CMS has helped states establish drug utilization review processes to ensure that prescription medications provided to Medicaid beneficiaries are appropriate, medically necessary, and not likely to result in an adverse event (Coster 2014).

Quality measures for community-based LTSS has not progressed as quickly as for acute care services and the ASPE-financed studies of MLTSS programs highlighted the wide diversity in how states approach quality of care in managed care settings (Jackson et al. 2013 and Rivard et al. 2013). Case studies of eight well-established MLTSS programs found that a great deal of diversity exists in the measures states use to monitor MLTSS programs, although most incorporated some aspect of the CMS quality-related essential elements in their quality strategies. Another component of this work focused specifically on person-directed services and found that the lack of quality measures for this service in particular prevented most states from evaluating program performance and distinguishing between high and low quality programs (Sciegaj et al. 2013).

Some measure development work has been conducted for populations with behavioral health conditions. A project jointly funded by the Substance Abuse and Mental Health Services Administration and ASPE has been developing measures for populations with behavioral health needs (Brown et al. 2015 and Potter 2014). This study identified measure gaps and piloted eight ambulatory quality of care measures for co-morbid conditions among people with serious mental illness and/or substance use disorders enrolled in health plans.¹⁹ The study piloted measures at

¹⁹ The measures included: tobacco screening and follow up, body mass index screening and follow up, blood pressure screening and follow up, screening for alcohol use and brief counseling, depression screening and follow up, comprehensive diabetes care, blood pressure control, and follow up after an emergency department visit for a mental health or abuse of drugs.

three health plans (two Medicaid only plans and one that served Medicare-Medicaid enrollees). Testing was based on information the plans abstracted from medical charts and Medicaid claims were used for the emergency department measure. The study found that the low rate of ambulatory use contributed to poor performance on these quality measures and performance on the HEDIS diabetes and hypertension control measures were 14 to 18 percentage points below the average rates for Medicaid plans in general. The screening and follow-up measures also showed room for improvement. The project submitted all but the blood pressure and depression screening measures for NQF endorsement.

A similar joint CMS/ASPE project tested four chart-based measures and one claims-based measure for the Medicare Inpatient Psychiatric Facility (IPF) quality reporting program.²⁰ Findings from this study, as well as an NQF/ASPE Alzheimer's project that updated, identified, or reviewed 85 care guidelines and 125 existing quality measures, were not presented at the research summit.²¹

2. Emerging research

CMS has several ongoing initiatives to develop quality assurance systems, as well as quality measures more generally. Its development of a cross disability HCBS experience of care survey is one of four key components of an overall strategy to develop quality assurance tools for states and waiver programs (Lida 2014). This survey, which is based on other Consumer Assessment of Healthcare Providers and Systems (CAHPS) instruments, will elicit beneficiary feedback on experience with Medicaid HCBS. CMS intends to seek the CAHPS trademark and NQF endorsement for this survey. The second component is the adaptation of a subset of the CARE assessment items for LTSS populations. The focus of this work is to develop an assessment tool that leverages existing standards for the interoperable exchanges of CARE items, supports person-centered care across settings, and facilitates quality monitoring across providers and settings. The third component of strategy to develop quality assurance tools for states is the development of a personal health record (PHR) for LTSS beneficiaries and their caregivers. Goals for the PHR are to provide information for informed care decision making, provide care providers improved access to a range of personal LTSS and health information for the LTSS beneficiary, and improve the coordination of LTSS and health care services. The fourth component, led by the Office of the National Coordinator (ONC), is the development of a new electronic standard for LTSS records. All four components are still in development and testing stages.

CMS is developing an Assessment Data Element Library that will serve as a repository for assessment data elements (questions and their response codes) and their associated mappings to HIT standards (Mandl and McMullen 2014). Vendors and providers will be able to reference

²⁰ The four chart-based measures included screening for risk of suicide, risk of violence, substance use, and metabolic disorders. The one claims-based measure was the receipt of follow-up community-based mental health care after discharge from an IPF.

²¹ The title of the Alzheimer's project was "Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Dementia, including Alzheimer's Disease." The project report is located at http://www.qualityforum.org/Prioritizing_Measure_Gaps_-_Alzheimers_Disease_and_Related_Dementias.aspx.

content in the library for electronic health record implementation, information exchanges, and quality measurement. The assessment tools and instruments to be included in the library are: the CARE tool, the nursing home minimum data set (MDS), the Long-term Care Hospital Continuity Assessment Records & Evaluation Data Set (LCDS), the Outcome and Assessment Information Set (OASIS), and the Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF-PAI). Measures in current development include two for IRF settings (change in self-care and mobility scores for medical rehabilitation patients) and two for LTCH settings (change in mobility among patients requiring ventilator support and percent of LTCH patients with functional assessments at admission and discharge and a care plan that addresses functioning). CMS is also in the process of developing a core set of quality measures for the health home programs.

Another important CMS initiative in the area of quality is the Medicaid Innovation Accelerator Program (IAP) (Llanos 2014).²² This program will help state Medicaid programs develop their capabilities in the areas of data analytics and quality measurement among other things. States have several different ways in which they may participate, but the first level involves in-depth, one-on-one technical assistance for states that are ready for data-centered learning collaboratives that will employ data-based tools for continuous quality improvement. Another option for states is to use the IAP website and webinars that will provide “how to” resources, data tools, and quality metrics (such as metric suites to promote alignment and support state implementation of new measures). Among other areas of technical assistance, IAP will offer data analytics (such as standardization of measure definitions) and quality measurement assistance that supports better alignment across existing metrics, develops and/or refines metrics (including targeted development in key gap areas or refinement of existing measures to better reflect the Medicaid population), and the development and testing of risk adjustment tools specific to Medicaid.

3. Research gaps

Despite the advancement of quality measures, the measures continue to lack harmonization at the data element level and more work is needed in this area. Research summit participants also noted that there are many ongoing measure activities and they perceive confusion about all the information and the lack of coordination. In addition to advocating for the development of measures that capture the quality of HCBS and the continuity care, they thought measures were needed to assess the quality of:

- Housing and the accessibility of housing (this work would need to include the development of a definition for housing accessibility)
- Incident management systems (which may require more standardization of these systems)

Several participants believed that CMS could get involved in measuring outcomes based on using activity monitors and smartphones to track what people are doing. They also thought that CMS should be leveraging other “cross systems” data to bring together Medicaid data with data from Medicare, housing, Department of Labor, the Social Security Administration, Department of Justice, and the Department of Education among others. In addition, some participants noted

²² Additional information about the IAP can be found at <http://www.medicaid.gov/state-resource-center/innovation-accelerator-program/innovation-accelerator-program.html>.

that Medicaid information systems needed to move to real time data exchange and validation to support service delivery at the point of care and that data should be used to proactively identify people at high risk for institutional care to provide access to care as prevention and diversion measures.

III. NEW DATA SOURCES

A. CMS Data Sources

CMS has administrative data from both the Medicaid and Medicare programs available for the research it sponsors, including uniform Medicaid enrollment and claims data that states submit to the Medicaid Statistical Information System (MSIS) which is currently being upgraded to Transformed MSIS (TMSIS). MSIS has historically been useful for studying Medicaid populations in fee-for-service systems, but studying populations in managed care has been difficult because many states do not submit encounter records to MSIS, or the encounter records they submit are believed to be incomplete. This data quality issue is supposed to be addressed by TMSIS, but getting all states to submit all encounter claims records may take time. Other CMS data available to conduct research on populations using LTSS include the nursing home Minimum Data Set (MDS) and the Outcome and Assessment Information Set (OASIS) that all Medicare-certified home health agencies report.

CMS is expanding the data available for research on LTSS through its effort to develop an HCBS experience of care system (Lida 2014). CMS has been working with nine states to develop an HCBS Experience of Care Survey that is cross disability and elicits beneficiary feedback on their experience with Medicaid-financed HCBS. In addition, the survey was designed to align with existing CAHPS instruments and CMS plans to seek the CAHPS trademark for this survey and endorsement from NQF.

Another new CMS data source presented at the Research Summit is the Medicare-Medicaid Linked Enrollee Analytic Data Source (MMLEADS) (Anderson 2014). The MMLEADS database includes information on eligibility and enrollment for the population of people dually eligible for Medicare and Medicaid. This information is at the beneficiary level and includes annual and monthly summaries of all expenditures, Veteran's Administration status, reason for entitlement, Medicare status, disability insurance benefit information and primary and secondary impairment codes. MMLEADS also captures information on chronic conditions, service utilization, and expenditures (fee-for-service expenditures, as well as Medicare capitated payments). De-duplicated services are linked at the claim level, which allows for unique utilization counts. MMLEADS also includes de-duplicated Medicare Part B prescription claims, as well as Medicaid prescription claims records. Reports have provided national and state profiles of Medicare-Medicaid enrollees and the prevalence of chronic conditions and comorbidity among fee-for-service Medicare-Medicaid enrollees.²³

In addition to these new data sources, CMS also sponsored a Medicaid Adults CAHPS survey that all Medicaid programs are currently implementing.²⁴ While these data will not be

²³ These reports can be found at <http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Analytics.html>.

²⁴ Information about this survey initiative can be found at <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/quality-of-care/nationwide-adult-medicaid-cahps.html>.

specific to LTSS users, they may be useful for benchmarking purposes. The adult, child, and health home core quality measure sets that CMS has developed may also be useful for benchmarking.

B. Data Sources from Other Federal Agencies

Research Summit participants reported on several all data sources that may be useful for research on LTSS that other Federal agencies maintain.

The National Health and Aging Trends Study (NHATS), sponsored by the National Institute on Aging, captures information about adults 65 and older who have care needs and their caregivers.²⁵ NHATS began in 2011 and the most recent data available include Round 3, which covers 2013. The data have been used to describe the prevalence of different types of physical limitations, the number of family caregivers and the volume of care they provide, the relationship between the level of care needed and the number of family caregivers, characteristics of family caregivers, and caregiver perceptions and experiences. Future research will identify characteristics of caregivers at risk of stress and strain, assess the relationship between caregiver traits and nursing home utilization, and examine changes in people's caregiving networks.

The precursor to NHATS is the National Long-Term Care Survey (NLTCS).²⁶ The Research Summit included information about analyses of the 2004 NLTCS which gathered data from a nationally representative cohort of Medicare enrollees age 65 and older living in the community (homes, apartments, and other community-based residential settings) and nursing homes. The NLTCS database includes information about respondents' demographic characteristics and self-reported information about health status and disability, including need for assistance with basic and instrumental activities of daily living, use of assistive devices, receipt of human assistance with activities of daily living/instrumental activities of daily living (ADL/IADL) tasks, how much, and from whom (formal/informal helpers), and reports of unmet needs. A companion Informal Caregiver Survey (ICS) includes interviews with family caregivers of all NLTCS main survey respondents who reported receiving informal help with ADLs and IADLs. The NLTCS/ICS data have been linked to several years of Medicare fee-for-service claims data, Medicaid claims files, MDS nursing home and OASIS home health assessments, and other CMS administrative data files that include data about provider supply by geographic areas.

The National Study of Long-Term Care Providers (NSLTCP) is a new dataset developed by the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention.²⁷ The purpose of this database is to provide reliable, accurate, and timely statistical information that informs long-term care policy. The data are designed to help efficiently monitor the supply, use, and characteristics of paid, regulated long-term care service providers in the United States. These providers include adult day services centers, assisted living and similar residential care communities, home health agencies, hospices, and nursing homes. Initial research using these data has developed information about the supply and use of these providers;

²⁵ Information about the NHATS can be found at <http://www.nhats.org/>.

²⁶ Information about the NLTCS can be found at <http://www.nltcs.aas.duke.edu/>.

²⁷ Information about the NSLTCP <http://www.cdc.gov/nchs/nsltcp.htm>.

key policy-relevant characteristics and practices of these providers; and key characteristics of users of these services. The data can also be used to obtain information about the people served by these providers. The NLSTCP includes two types of data: (1) survey data on 5,000 adult day services centers and 11,700 residential care communities; and (2) CMS administrative data on home health agencies, nursing homes, and hospices. The first round of survey data were collected in 2012 and the second round was in the field at the time of the Research Summit.

The National Survey of Older Americans Act (OAA) Participants (NSOAAP) is funded by ACL.²⁸ This annual survey of approximately 6,000 people receiving OAA Title III services helps to quantify the survey of selected Title III services; gauge the effect of service use on the lives of participants, with an emphasis on their ability to maintain community living; assess client-reported service quality; identify characteristics of service recipients; and identify LTSS policy implications. The NSOAAP includes six telephone survey instruments that collect information on Title III-funded congregate meals, home delivered meals, transportation, homemaker services, caregiver services, and case management. The two-stage sampling design is based on first selecting a sample of area agencies on aging (AAA) and then randomly sampling participants from each selected AAA by service types. The data are publicly available from ACL at <https://aoasurvey.org/default.asp>.

The Research Summit also provided information about two housing data sources. The first is the American Housing Survey, which is the most comprehensive national survey of housing in the U.S.²⁹ It is a longitudinal survey conducted in odd years by the Census Bureau for HUD. In 2009, HUD added six core disability questions and the 2011 survey included questions on 21 accessibility features, including 7 wheelchair accessibility features, use of mobility devices, difficulty with tasks in the house, and specific home accessibility problems. The second is a linked data base of HUD administrative data and various national housing survey data collected by the NCHS (the National Health Interview Survey and the National Health and Nutrition Examination Survey), as well as Medicare and Medicaid administrative data and mortality information. The linking has been done for individuals in HUD housing programs between 1999 and 2012. These data can be used to produce nationally representative estimates of health outcomes, healthcare utilization, and costs for HUD-assisted populations. In addition, the data support studies of health disparities and should be helpful at disentangling causality and selection when determining how assisted housing contributes of health. The data can also be used to inform collaborative policy interventions that use housing as a platform for improving health outcomes.³⁰

²⁸ Information about the NSOAAP can be found at <https://aoasurvey.org/default.asp>.

²⁹ Information about the American Housing Survey can be found at <http://www.census.gov/programs-surveys/ahs.html>.

³⁰ A table created, that allows users to create tables of descriptive data, can be found at <http://www.census.gov/programs-surveys/ahs/data.html>.

IV. OPPORTUNITIES FOR INTERAGENCY COLLABORATION

Due to time constraints, the Research Summit participants had little open discussion about opportunities for new interagency collaborations. Staff from ACL noted that they are interested in coordinating the National Survey of Older Americans Act Participants (NSOAAP) with other partners such as ASPE and university research institutes. As part of this work, they are considering using questions from preexisting surveys to increase opportunities for cross-survey comparisons. Other surveys mentioned included the National Health Interview Survey and the National Health and Aging Trends Study. ACL was forming redesign workgroups at the time of the Research Summit. In addition, it was noted that the National Institute on Disability, Independent Living and Rehabilitation Research and the Accessibility Board are working together on research that was not shared at the Research Summit.

CMS has had a long history of collaborating with ACL, AHRQ, and ASPE on research relating to community-based LTSS and these collaborations are expected to persist and evolve as the policy environment changes. In addition to these long-standing collaborations, an assessment of the research gaps discussed under each aspect of a LTSS systems suggests additional areas of collaboration with other agencies.

- Tapping the expertise of transportation experts may be useful if CMS and other agencies want to better understand how transportation issues affect access to community-based LTSS. This type of interagency collaboration would also benefit from the inclusion of housing experts because the location of affordable and accessible housing relative to an area's transit system is likely to be directly related to the accessibility of community-based LTSS for low-income people.
- The AHRQ-CMS collaboration around quality measures could be expanded to include the development of measures that capture the quality of care transitions.
- ACL and CMS have long collaborated on the development of state no wrong door systems and this collaboration could be expanded to include SAMHSA and expertise in the unique needs of people with mental illness and substance abuse conditions.
- Given the lack of research on employment and employment supports for people with disabilities and that several participants were not clear on whether CMS collaborates with ACL and DOL on employment research and policies, joint research among these agencies may be another area for interagency collaboration. This type of collaboration could also be expanded to include SSA as that agency considers modifications to its disability programs.
- While CMS has been collaborating with HUD in several areas of supportive housing, this collaboration could be further expanded to more fully assess and measure the functionality of affordable and accessible housing for people with disabilities who need to receive some LTSS in their homes and the harmonization of survey questions that agencies field among people with disabilities.

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APPENDIX A

LIST OF PARTICIPATING FEDERAL AGENCIES

Agencies are listed in alphabetical order.

- Administration for Community Living
- Agency for Healthcare Quality and Research
- Assistant Secretary for Planning and Evaluation
- Centers for Disease Control and Prevention
- Centers for Medicare & Medicaid Services
- Health Resources and Services Administration
- National Institutes of Health
- National Institute on Disability, Independent Living and Rehabilitation
- Office of Management and Budget
- Social Security Administration
- United States Access Board
- United States Food and Drug Administration
- United States Department of Housing and Urban Development

APPENDIX B

LIST OF PARTICIPANTS

First Name	Last Name	Agency
Kirsten	Beronio	ASPE
Mary	Botticelli	CMS
Sonya	Bowen	CMS
Thomas	Brown	CMS
Jennifer	Burnett	CMS
Margaret	Campbell	National Institute on disability, Independent Living and Rehabilitation Research
William	Clark	CMS
John	Coster, Ph.D., PRh.	CMS
Venesa	Day	CMS
Pamela	Doty	ASPE
John	Drabek	ASPE
Brian	Du	CMS
Barbara	Edwards	CMS
Mary Pat	Farkas	CMS
Elena	Fazio	Administration for Community Living
Rochelle	Fink, MD, JD	FDA
Anne	Fletcher	HUD
Veronica	Gales Short	SSA/ODRP/ODP/OVEPP
Melissa	Harris	CMS
Lauren	Harris-Kojetin	CDC/ National Center for Health Statistics
Jennie	Harvell	ASPE
Barbara	Holt	CMS
Robert	Hornyak	Administration for Community Living
John	Hough	DHHS, Centers for Disease Control and Prevention, National Center for Health Statistics
Jhamirah	Howard	ASPE
Melissa	Hulbert	CMS

First Name	Last Name	Agency
Erin	Iturriaga	NIH/National Heart, Lung, and Blood Institute
Susan	Jenkins	Administration for Community Living
Dianne	Kayala	CMS
Jamie	Kendall	Administration for Community Living
Gavin	Kennedy	ASPE
Helen	Lamont	ASPE
Kerry	Lida, Ph.D	CMS
Shari	Ling	CMS
Sue	Ling	HRSA
Karen	Llanos	CMS
Leah	Lozier	HUD
Stella	Mandl	CMS
Carolyn	Milanowski	CMS
Jennifer	Nading	Office of Management and Budget
Nicole	Nicholson	CMS
Jeane	Nitsch	CMS
John	O'Brien	CMS
Rex	Pace	United States Access Board
Eunice	Park-Lee	CDC/ National Center for Health Statistics
Kathy	Poisal	CMS
D.E.B.	Potter	AHRQ and ASPE
Vincent	Rome	CDC/ National Center for Health Statistics
Elizabeth	Rudd	HUD
Alicia	Ryce	CMS
Alice-Lynn	Ryssman	Administration for Community Living
Yelile	Saca	CMS
Manisha	Sengupta	CDC/ National Center for Health Statistics
Annette	Shea	Administration for Community Living

First Name	Last Name	Agency
Mike	Smith	CMS
Teresa	Souza	HUD
Jon	Sperling	HUD
Carol	Star	HUD
Barry	Steffen	HUD
Christina	Stillwell-Deaner	CMS
Shawn	Terrell	Administration for Community Living
Rita	Vandivort-Warren	HRSA
Beth	Wahtera	CMS
Mary	Weick-Brady	US Food and Drug Administration/Center for Devices and Radiological Health
Michael	Weinrich, M.D.	NIH
Todd	Wilson	CMS

APPENDIX C

RESEARCH SUMMIT AGENDA



Disabled and Elderly Health Programs Group (DEHPG)
2014 Research Summit
November 3-4, 2014
CMS Auditorium

AGENDA

November 3, 2014 (8:30 a.m. – 4:00 p.m.)

Moderator: Jeane Nitsch

8:30 – 9:00 Registration

9:00 – 9:30 Welcome and Opening Remarks (Barbara Edwards)

9:30 – 10:30 Overview of DEHPG Activities and Research

- Division of Benefits and Coverage (Melissa Harris)
- Division of Long Term Services and Supports (Dianne Kayala)
- Division of Community Systems Transformation (Jeane Nitsch)
- Division of Pharmacy (John Coster)
- Division of Managed Care Plans (James Golden)
- Division of PACE, Health Homes, and Coordination Of Benefits/Third Party Liability (Mary Pat Farkas)

10:30 – 10:45 Break

10:45 – 12:00 Key CMS Research

Key CMS Initiatives (12-15 minutes)

- Medicaid Innovation Accelerators Program (Karen Llanos)
- Data Element Uniformity, Assessment, Standardization, and Cross Setting Quality Measures (Stace Mandl, Tara McMullen)

Recent and Emerging Research (3-5 minutes each)

- CMS Data: Study of Medicare-Medicaid Dual Enrollees (Karyn Kai Anderson)
- Testing Experience and Functional Assessment Tools Demonstration Grant (Kerry Lida)
- Medicaid Annual Drug Utilization Review (John Coster)
- State of State Medicaid Services for Children with Autism Spectrum Disorders (John O'Brien)
- Early Results from the Health Homes Program (Beth Wahtera)
- National Evaluation of the Money Follows the Person Demonstration Grant (Michael Smith)

12:00 – 12:45 Lunch

12:45 – 1:45 Housing and Housing Supports

Recent Research Results (8-10 minutes)

- Chronic Homelessness, Permanent Supportive Housing and Medicaid (Gavin Kennedy)
- Picture of Housing and Health: Medicare and Medicaid Among Older Adults in HUD-Assisted Housing (Elizabeth Rudd)
- Support and Services at Home Evaluation (Elizabeth Rudd)

Emerging Research (3-5 minutes)

- Housing Accessibility of the US Housing Stock (Teresa Souza)
- HUD-NCHS Data Matching: Progress and Potential (Barry Steffen)
- Evaluation of the HUD 811 Project Rental Assistance Demonstration (Teresa Souza)
- HUD-VA Supportive Housing Evaluation and Exit Study (Elizabeth Rudd)
- Evaluation of a Supportive Services for the Elderly Program for HUD Housing (Leah Lozier)

1:45 – 2:00 Break

2:00 – 3:00 Supports for Community Living

Recent Research Results (8-10 minutes)

- Evaluation of the Aging and Disability Resource Centers (ADRCs) (Susan Jenkins)
- Process Evaluation of the Chronic Disease Self-Management Education Program (Susan Jenkins)
- Medicaid Managed Long-Term Services and Supports: Lessons from Early Implementers (Pamela Doty)
- Development and Testing of Behavioral Health Quality Measures (D.E.B. Potter)

Emerging Research (3-5 minutes)

- Evaluation of the Title III-E Caregiver Support Program (Alice-Lynn Ryssman)
- Health Information Exchange in Integrated Care Models (Jhamirah Howard)
- Use of 1915(i) Medicaid State Plan Option (Jhamirah Howard)

3:00 – 3:45 National Surveys

Recent Research Results (8-10 minutes)

- The National Study of Long-Term Care Providers: A New Resource to Support Research, Policy, and Practice (Lauren Harris-Kojetin)
- Informal Caregiving: Findings from the National Study of Caregiving (Helen Lamont)
- National Survey of Older Americans Act Participants (Elena Fazio)

Emerging Research (3-5 minutes)

- Longitudinal Analysis of the 2004 National Long-Term Care Survey Linked to Medicaid claims: Use of Medicaid-funded LTSS (Pamela Doty)

3:45 – 4:00 Closing Remarks and Overview of Second Day

November 4, 2014 (8:30 a.m. – 12:00 p.m.)

Moderator: Jeane Nitsch

8:30 – 9:00 Registration

9:00 – 9:15 Welcome to the Second Day

- Review of First Day and Key Themes
- Overview of Second Day

9:15 – 10:45 Working Group Discussions

- Key Themes
- Key Areas of Significance
- Research Gaps

10:45 – 11:00 Break

11:00 – 12:00 Future Directions (Kerry Lida)

- Group Reports to All Summit Attendees
- Key Learnings
- Research Gaps
- Future Research Areas
- Next Steps

12:00 Adjournment

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