



National Institute on Disability, Independent Living, and Rehabilitation  
Research  
Building the Research Pipeline:  
Home and Community-Based Services and the Dual-Eligible Population  
Summary Report

**Thursday, January 14, 2021 — 11:00 a.m. – 4:00 p.m. ET**

### Executive Summary

The focus of this meeting was to discuss important topics related to home and community-based services (HCBS) and how to attract new investigators to this field. This meeting was created through a partnership between the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), the Centers for Medicare and Medicaid Services (CMS) Medicare-Medicaid Coordination Office, and Arnold Ventures, a foundation with a complex care research agenda and priorities in this area. To begin the meeting, representatives from NIDILRR, CMS, and Arnold Ventures discussed their priorities as they relate to HCBS and the dual eligible population.

The first session of the event focused on centering research and policy on consumers. Emily Stewart, the Executive Director of Community Catalyst, described Community Catalyst's step-by-step approach to examining consumer needs in research and policy development. Some of the methods that Community Catalyst has used to facilitate consumer engagement are: (1) partnering with community-based organizations and task forces, (2) establishing consumer panels and advisory boards, and (3) conducting focus groups. Ms. Stewart emphasized how essential consumer voices are in the research and policy process.

The second session of the day focused on the value of policy relevant research. Melanie Bella the chair of MACPAC, a policy advisory body to Congress on the Medicaid and CHIP programs, discussed several research topic areas that MACPAC is currently thinking about. Policymakers are interested in examining the effects of integration on outcomes, demographics and eligibility, and which elements within a care model or intervention impact outcomes. Ms. Bella emphasized the endless opportunities for policy-relevant and actionable research that could benefit MACPAC and other policy agencies.

Dr. Allen Heinemann, Director at the Center for Rehabilitation Outcomes at the Shirley Ryan AbilityLab, led the third session of the meeting about models for building the research capacity pipeline. His presentation explored the scope of research capacity-building activities related to HCBS topics, explored NIDILRR's unique niche in research capacity building, and discussed principles on which to focus discussion of research capacity-building for HCBS. Dr. Heinemann provided recommendations on promoting HCBS-relevant careers and insights on problem identification and research capacity metrics for HCBS research capacity building. He emphasized that the research community should encourage future scientists to consider issues of disability and HCBS through a continuum of research funding opportunities.

The fourth session focused on opportunities and limitations surrounding available data on HCBS and dual eligibles. Dr. Timothy Waidmann, a Senior Fellow at the Urban Institute, presented on data types available to study dual-eligibles and HCBS. He described findings from their recent project using the Transformed Medicaid Statistical Information System Analytic Files (TAF). He offered insight into how to use datasets and provided resources for linking Medicare and Medicaid data. Dr. Waidmann recommended new researchers look at the [Research Data Assistance Center](#) run by CMS.

Dr. Monika Mitra, Director of the Lurie Institute for Disability Policy, led the fifth session of the meeting about health equity and including diverse populations in research. Dr. Mitra presented on how the Lurie Institute for Disability Policy at Brandeis University builds the research pipeline for disability researchers. She described their cascading mentorship framework and emphasized the importance of starting “upstream” to recruit students even as early as undergraduate school and to provide research opportunities early on. Dr. Mitra provided an overview of current projects at the Lurie Institute related to HCBS.

The last session of the event divided the attendees into breakout sessions on the following four topic areas:

- *Program Facilitating Medicare and Medicaid Integration*
- *Improving Enrollment in Integrated Coverage Options*
- *Home and Community-Based Services and Supports*
- *Social Support Services for People with Disabilities and Older Adults*

Each breakout session was led by a facilitator working in the respective field, who reported the results of the group’s discussion back to the larger meeting.

For the first breakout group, *Program Facilitating Medicare and Medicaid Integration*, Dr. Carrie Graham shared that they discussed the importance of identifying best practices for partnerships between plans and community organizations. The group also discussed the importance of studying “pre-duals” (people at risk of becoming dual eligible) and the difficulty of studying MA plans and supplemental benefits.

In the second breakout group, *Improving Enrollment in Integrated Coverage Options*, Debra Lipson stated that the breakout group discussed the path to dual status and incentives to get people enrolled into integrated care options. Ms. Lipson outlined potential research areas at a federal level. She said their group determined that while many anecdotes exist about integrated care programs taking steps to mitigate churn, there is no objective research on this to date.

In the third topic area, *Home and Community-Based Services and Supports*, there were three separate breakout groups due to significant interest in this topic. Dr. Timothy Layton, an Associate Professor at Harvard Medical School, led the first group. He stated their breakout group covered four main themes: demand, targeting, long-term care, and questions about caregivers. Allison Rizer of RTI Advisory led the second group on this topic and described how their discussion centered on state data blind spots, including racial disparities and HCBS access. Their group also emphasized the topic of housing and the importance of educating policymakers on what types of settings are allowed to be covered. Outcomes across settings of care and value-based contracting were two additional themes that emerged. The last group on this topic was led by Dr. Jacob Wallace, an Assistant Professor at the Yale School of Public Health. Dr. Wallace said that the centrality of health equity questions emerged as a theme. The group also discussed the unique composition of the younger population that accesses HCBS. Other main themes identified were stakeholder engagement and education and the need to address return-on-investment questions head on.

The fourth breakout group topic, *Social Support Services for People with Disabilities and Older Adults*,

was led by Dr. Taressa Frazee, an Assistant Professor at the University of California. Dr. Frazee said that one main theme that emerged was thinking about how to center research, activity, and policy on the individuals accessing services and supports. The breakout group discussed the importance of consumer feedback, as well as the importance of patients developing strong relationships with the healthcare system. The group also discussed how family caregivers can support enrollees and the need to collect data on this population.

The meeting concluded with closing remarks from Anne Tumilson, the CEO of Anne Tumilson Innovations. Ms. Tumilson discussed making the necessary changes to ensure HCBS and caregiving is prioritized within our society. She explained that our current system is heavily biased toward institutionalization and that COVID-19 has highlighted this. Ms. Tumilson encouraged the research community to build bridges with policymakers and administration staff and be ready to move quickly when the opportunity arises to build HCBS research.

## Welcome

*Kristi Hill, Ph.D., Acting Director, NIDILRR*

Dr. Kristi Hill opened the meeting by welcoming all attendees to the event. She explained that as the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) continues to evolve programmatically and organizationally, capacity building remains foundational to NIDILRR's mission. NIDILRR sponsors more than 24 postdoctoral programs that train disability and rehabilitation researchers, covering a broad array of research topics. Dr. Hill explained that the meeting would focus on important topics related to home and community-based services (HCBS) and how to attract new investigators to this field. She described NIDILRR's partnership with the Centers for Medicare and Medicaid Services (CMS) Medicare-Medicaid Coordination Office, which is focused on the dual-eligible population, and with Arnold Ventures, a foundation with a complex care research agenda and priorities in this area.

*Timothy Engelhardt, Director, Medicare-Medicaid Coordination Office, CMS*

Timothy Engelhardt explained that the office he works for, CMS' Medicare-Medicaid Coordination Office, represents the 12 million people on both Medicare and Medicaid. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services found that [dual-eligible status is the most powerful predictor of poor outcomes among the social risk factors evaluated for all Medicare enrollees](#). In addition, dual-eligible individuals are four times more likely than non-dual-eligible individuals to experience a COVID-19-related hospital stay. Mr. Engelhardt stated that these outcomes are not inevitable and that addressing these disparities is one of the most urgent priorities of our time.

He outlined three different types of research papers that are good examples of actionable and policy relevant research: (1) [a study funded by the Medicaid and CHIP Payment and Access Commission \(MACPAC\) and conducted by the Urban Institute that found that only half of people eligible for Medicare Savings Programs \(MSPs\) are enrolled in them](#), (2) work by several teams, [some funded by MACPAC](#), on how state Medicaid policies that cover Medicare cost-sharing impact access to care for older adults and people with disabilities, and (3) [an ASPE-funded study conducted by Research Triangle Institute that found that 30 percent of new dual-eligibles will lose eligibility within their first year of enrollment](#).

Mr. Engelhardt explained that research like this is helpful in guiding CMS' policymaking. He also recognized that it can be difficult to do research on long-term care, and one of CMS' biggest blind spots is

the intersection of their programs with all the programs outside of CMS, such as the justice system, housing, the Supplemental Nutrition Assistance Program, and Social Security. Some of the best research questions going forward should address how to improve and streamline processes within these government programs.

*Arielle Mir, Vice President of Healthcare, Arnold Ventures*

Arielle Mir welcomed the group and explained that she leads the complex care team at a philanthropy, Arnold Ventures. Arnold Ventures' work on health care is motivated by a deep concern about the affordability of health care in the United States and the fact that today's system does not do a good job of taking care of people that have a complex array of needs. The focus of the complex care team is on improving outcomes for the dual eligible population—they seek to fund research that will inform policymakers about how to do this. Ms. Mir stated that her hope for the meeting is that attendees can leave the event with an idea for a project to help address this overarching question and build the field of research in this space.

## Centering Research and Policy on Consumers

*Emily Stewart, Executive Director, Community Catalyst*

Emily Stewart outlined an approach to examining consumer needs in research and policy development that consisted of the following steps: (1) build trust, (2) engage consumers from the beginning, (3) tap into community resources, and (4) be flexible and patient. She explained that the process of determining consumers' needs can often be a sensitive and that building trust can often be difficult. She emphasized the importance of paying people for their time when participating. Some of the methods that Community Catalyst has used to facilitate consumer engagement are: (1) partnering with community-based organizations and task forces, (2) establishing consumer panels and advisory boards, and (3) conducting focus groups. Ms. Stewart recommended the paper [\*Three Models of Community-Based Participatory Research\*](#) by Janet Weiner and Jasmine McDonald as a guide to how to engage with consumers. She concluded by emphasizing how essential consumer voices are in the research and policy process.

## The Value of Policy-Relevant Research

*Melanie Bella, Chair, MACPAC*

Melanie Bella introduced her work at MACPAC, a policy advisory body to Congress on the Medicaid and CHIP programs. As it relates to the dual-eligible population, there are four main topics MACPAC is thinking about: (1) How do you increase enrollment in integrated programs? (2) How do you make integrated programs widely available? (3) How do you increase integration in these programs? and (4) How do you create a program that addresses the various needs of enrollees (behavioral health, medical, long-term care, etc.)?

Policymakers are interested in examining the effects of integration on outcomes, including hospital stays, emergency room visits, utilization of home and community-based services (HCBS), etc. Another area where more outcomes-related research is necessary is regarding programs that address the social determinants of health. Ms. Bella noted that the dual eligible population is heterogeneous and therefore research on outcomes should be conducted at the subpopulation level as well. Generalizations about the dual-eligible population can do a disservice to trying to create better services groups of people with distinct needs.

In terms of demographics and eligibility, it is important for researchers to examine how people are making choices, for example how they choose to opt in or opt out of integrated programs. Pathways to

dual status is another important research area, such as looking at churn among dual-eligibles and how many people lose their status due to eligibility requirements and administrative policies. There is also broad interest in better understanding the enrollment and eligibility experiences of people who are eligible for the full range of Medicaid benefits (the full-benefit dual eligible) and those that are only eligible for assistance in paying their Medicare copays and premiums (partial benefit dual eligible individuals).

Under the category of care model and benefits, policymakers are interested in having more information on what within a care model or intervention has an impact on outcomes. Additionally, MACPAC is interested in how algorithms are being used in service planning and how dual-eligibles are using supplemental benefits and which benefits they are choosing to use. Ms. Bella emphasized that these topic areas and categories are not an exhaustive list, and there are endless opportunities for policy-relevant and actionable research that could benefit MACPAC and other policy agencies.

## Models for Building the Research Capacity Pipeline

*Allen Heinemann, Ph.D., Director, Center for Rehabilitation Outcomes, Shirley Ryan AbilityLab*

Dr. Allen Heinemann stated that the goals of his presentation were to: (1) examine context and scope of research capacity-building activities relevant to HCBS topics, (2) describe NIDILRR's unique niche in research capacity building, and (3) discuss principles on which to focus discussion of research capacity building for HCBS. He also provided eight recommendations for promoting HCBS-relevant careers:

1. Allow grant budgets to include salary support and provide "protected time" for research and mentorship.
2. Offer training opportunities at several stages of a potential researcher's career, with a special emphasis on early career.
3. Offer clinical research training opportunities of several different levels of depth.
4. Encourage involvement of people of different academic backgrounds.
5. Expose students to the concept and examples of clinical research as part of their educational curriculum.
6. Provide financial and institutional support for well-matched faculty mentorship of potential clinical researchers.
7. Furnish rewards/awards for accomplishments of both research trainee and mentor.
8. Accentuate to policymakers the link between better clinical research training and better health for the population.

Dr. Heinemann provided insights on problem identification and research capacity metrics for HCBS research capacity building. He also provided an overview of the changing context of disability and HCBS research, discussing both demand-side and supply-side issues like the aging population, public emphasis on economic self-sufficiency, and privatization of public-funded social, employment, and health services. He explained that NIDILRR's challenge with capacity building is that disability and rehabilitation research spans a wide range of fields, disciplines, and settings. NIDILRR's mission also encompasses varied disability groups and needs, so it must balance where to invest limited resources. Dr. Heinemann suggested to focus the research capacity-building discussion on the following: (1) develop partnerships with relevant stakeholders, (2) identify key research themes and topics relevant to HCBS, (3) identify relevant disciplines, (4) define needs for HCBS research capacity, (5) define core competencies of trainees. He concluded by emphasizing that as NIDILRR's budget remains severely limited and capacity building is one of several priorities, the research community should encourage future scientists to consider issues of disability and HCBS through a continuum of research funding opportunities. This will

help engage a cadre of investigators and scientific leaders and assure capacity to maintain and enhance excellence in HCBS investigation and delivery.

## Available Data: Opportunities and Limitations

*Timothy Waidmann, Ph.D., Senior Fellow, Health Policy Center, Urban Institute*

Dr. Timothy Waidmann presented on data types available to study dual-eligibles and home and community-based services. He explained that while Medicaid data—which is of particular use for these analysis—has been released, data quality continues to be a question. He presented some of their findings from a project using the newly released dataset—the [Transformed Medicaid Statistical Information System Analytic Files \(TAF\)](#). Using 2016 data, they found that there is 84 percent agreement between Medicare enrollment files—the Master Beneficiary Summary File (MBSF)—and the Medicaid dataset—the TAF—on who is a dual-enrollee. Their study also found that there is 86 percent agreement on full/partial dual status and MSP level classification between the two datasets; however, there is high variability by state. They also found that “integrated” model participation was poorly reported in TAF compared to MBSF.

When thinking about how to use these datasets, Dr. Waidmann said that the MBSF is a good source of identification of dual-eligibles and annual person-level summaries and TAF does not have an equivalent person summary file. While most acute services are best analyzed using Medicare claims, if researchers are interested in calculating total cost of care (inclusive of Medicare and Medicaid), long-term care, HCBS, behavioral health, and Medicare cost-sharing, this information is largely covered through Medicaid and thus require using the TAF.

In regards to linking Medicare and Medicaid data, Dr. Waidmann suggested looking at the [Chronic Conditions Data Warehouse](#), which generates unique person-level IDs across multiple data sources. Additionally, he offered thoughts on non-claims data. Dr. Waidmann said that surveys are more likely to provide a better picture than administrative data on demographics, socioeconomic factors, functional health and disability, and social supports. He mentioned that there are links to Medicare claims for several surveys to include MCBS, the Health and Retirement Study, and the National Health and Aging Trends Study (NHATS). However, NHATS data only covers those over age 65.

Dr. Waidmann suggested that all new researchers to this space look at the [Research Data Assistance Center](#) run by CMS. He said that every data set is documented on this website and that their staff are extremely helpful and ready to answer questions and guide you through the data use agreement process.

## Health Equity: Inclusion of Diverse Populations

*Monika Mitra, Ph.D., Director, Lurie Institute for Disability Policy, Brandeis University*

Dr. Monika Mitra presented on how the Lurie Institute for Disability Policy at Brandeis University builds the research pipeline for disability researchers. The goal of their research is to help shape policies, programs, and practices that improve the lives of people with disabilities across the lifespan. Their institute’s three main activities are research, engagement, and mentorship. The institute hosts the National Center for Parents with Disabilities and the Community Living Policy Center. The Community Living Policy Center is a cross-disability initiative to engage in research and knowledge-translation activities to improve policies and practices that promote community living and participation outcomes for people with disabilities of all ages.



Dr. Mitra explained the Lurie Institute’s cascading mentorship framework, where there are primary and secondary mentors for postdoctoral fellows, and postdoctoral fellows mentor graduate students and undergraduate fellows. She emphasized the importance of starting “upstream” to recruit students even as early as undergraduate school and to provide research opportunities early on. To recruit students, the Lurie Institute has a close relationship with disability organizations, national Ph.D. programs, and professional organizations. They also ensure their program is accessible via web search and advertise through social media platforms. Dr. Mitra introduced several of their doctoral students and their areas of research. She also provided an overview of current projects at the Lurie Institute related to HCBS.

## Breakout Sessions

During this section of the event, the attendees were assigned into breakout groups based on their preselected topics of interest. The breakout sessions met for approximately 45 minutes, each led by a facilitator. Afterwards, the breakout groups each reported back to the entire group. The results reported out from the breakout sessions are recorded below.

### Programs Facilitating Medicare and Medicaid Integration

*Facilitator: Carrie Graham, Ph.D., Associate Professor, Department of Social & Behavioral Sciences, Institute for Health & Aging, University of California, San Francisco*

Dr. Carrie Graham shared that the breakout group discussed the importance of identifying best practices for partnerships between plans and community organizations. There was an emphasis on how the culture can be different between the medical model of disability in health plans and the social model of disability in community-based organizations. The group discussed some ways health plans can create culture change within their organizations to determine the social determinants of health and what supplemental benefits could be most effective for consumers. In addition, Dr. Graham relayed their discussion on the importance of opportunities to study “pre-duals” (people at risk of becoming dual-eligible). She explained that these people are often already in Medicare Advantage (MA) plans, so researchers could look to MA Plans to study this and how to put interventions in place for prevention. The group discussed how hard it is to study MA Plans and supplemental benefits. Due to MA plans being in a competitive environment, they do not want to share their “secrets.” The group discussed the importance of opportunities for third parties to come in and study this population without threatening MA plan marketing capabilities. Dr. Graham said that another main topic of discussion was data access. She explained that in California they are currently trying to create partnerships between the state and academic researchers to facilitate better data access. The group discussed the importance of research that is not solely looking at big data sets, but instead is involving the consumers. Dr. Graham described how mixed-methods research can facilitate this.

### Improving Enrollment in Integrated Coverage Options

*Facilitator: Debra Lipson, Senior Fellow, Mathematica Policy Research*

Debra Lipson explained that her group discussed the path to dual status and incentives to get people enrolled into integrated care options. Further discussion covered the roles of state health insurance program counselors. Ms. Lipson said participants discussed how these counselors may not know a lot about integrated care options and may advise against these options if they do not know enough about them. Participants in the group also discussed how to build on policies to ensure that people are getting into the right plan for them with the right types of providers. Ms. Lipson outlined potential research areas at a federal level, such as (1) if the change of special enrollment periods to quarterly beginning in 2019 had an effect on enrollment, and (2) if default enrollment in dual-eligible special needs plans (available only in a few areas) have an effect on enrollment. The group discussed the need for research on how plan performance on LTSS quality indicators impacts enrollment. Ms. Lipson said their group determined that

while many anecdotes exist about integrated care programs taking steps to mitigate churn, there is no objective research on this to date.

### Home and Community-Based Services and Supports #1

*Facilitator: Timothy Layton, Ph.D., Associate Professor, Harvard Medical School*

Dr. Timothy Layton described four main themes from their breakout group's discussion. The first theme was demand. The group discussed the need to better understand the demand for HCBS services and how that can be measured. These studies are particularly important to inform states that are making benefit coverage decisions. The second main theme Dr. Layton described was targeting. The group discussed how to get the right services to the right people and how policies and institutions can help with this. Thirdly, the group discussed managed long-term care. Themes that emerged included: (1) How do researchers know what these programs are doing? And (2) how can researchers put together data sources to study this area? The last major theme discussed included questions about caregivers. The group discussed how caregivers are affected by HCBS policies. Additionally, the group said that if HCBS allows caregivers to return to work, then covering these benefits could partially pay for itself through the tax revenue produced through the resulting increased employment.

### Home and Community-Based Services and Supports #2

*Facilitator: Allison Rizer, Principal, ATI Advisory*

Allison Rizer said that her group started off by discussing state data blind spots. They also discussed racial disparities and HCBS access and how there is a lack of data in this area. The breakout group members brought up various testing pilots they were familiar with, including one on transitioning individuals with intellectual and developmental disabilities into adulthood. The group discussed the importance of understanding how waitlist procedures for HCBS might perpetuate racial disparities. Housing is another major theme that emerged from the discussion. The group talked about the importance of educating policymakers on what types of settings are allowed to be covered, including the impact of the HCBS settings rule across housing types. The group agreed that another important area for research is looking at outcomes across the settings of care, from home-based to institutional care and others across this continuum. Another theme of discussion was value-based contracting. Ms. Rizer said that the group recognized that the data and the research in this area are siloed into Medicare or Medicaid only. The group identified the need to determine how to bridge these two areas. Furthermore, the group discussed the need to define outcomes that work with value-based contracting approaches to improve quality. Ms. Rizer discussed the importance of encouraging states to expand access to HCBS. She said states often do not have the underlying infrastructure to support this expansion, and the key is growing the direct care workforce. The group discussed the importance of gathering evidence about how to grow the direct care workforce. Lastly, the group talked about how to go "behind the scenes" to understand the consumer's experience with HCBS.

### Home and Community-Based Services and Supports #3

*Facilitator: Jacob Wallace, Ph.D., Assistant Professor, Yale School of Public Health & the Institution for Social & Policy Studies*

Dr. Jacob Wallace reviewed what this breakout session discussed related to HCBS, emphasizing that it is a complex topic. The centrality of health equity questions emerged as a theme. While this is a crosscutting topic, the group determined that this topic also deserves elevation as its own area of focus. Several participants in the breakout session commented that researchers know a lot more about the use of HCBS in the over 65 population than the under 65 population. They discussed the unique composition of the younger population that accesses HCBS. Another main theme identified was stakeholder engagement and education. The group mentioned that local providers of data, such as states and care providers, are not



well educated or well-inclined to collect, provide, and understand the data. Dr. Wallace said that researchers can do a better job about educating stakeholders about the importance of data collection. The group mentioned that currently we have “cylinders of excellence,” but “umbrellas” of teams that cross agencies and institutions that contemplate taking on impediments for new researchers would be more useful. An example of an impediment these teams could take on is access to data. Dr. Wallace identified another theme that emerged — the need to better understand institutional LTSS care. The group identified that during COVID-19 there has been an even greater push to move people out of institutions due to the high risk for disease transmission. However, many consumers in institutions may not be aware what HCBS services they have access to outside of an institution. The group agreed that as states are facing historic budget deficits, they will be facing decisions about return on investment. Dr. Wallace highlighted that researchers will need to be prepared to tackle these return-on-investment questions head on.

### Social Support Services for People with Disabilities and Low-Income Older Adults

*Facilitator: Taressa Frazee, Ph.D., Assistant Professor, Department of Family & Community Medicine, University of California, San Francisco*

Dr. Taressa Frazee said one main theme that emerged from the group’s discussion was thinking carefully about how to center research, activity, and policy on the individuals who are accessing services and supports. The group determined that the field should be asking if we are designing policy that makes these services and supports accessible to people with disabilities. Participants mentioned that researchers should not default simply to what works for health care organizations, but instead center design on the users and what they need or want. Dr. Frazee pointed out that sometimes research can jump ahead and make assumptions about what people need before gathering feedback from consumers. She also mentioned researchers’ role in helping to streamline the process and help policymakers understand which services or supports are essential versus which may not be necessary. The group discussed recent flexibilities in regulations during the COVID-19 pandemic and how some of these changes could be made permanent. For example, the group discussed how direct service providers are now allowed to get paid when an individual is in the hospital, as the provider is still engaging with and coordinating that person’s care. The group talked about the importance of patients developing strong relationships with the health care system and having someone to advocate for them. Another major theme discussed was disparities and how to understand the earliest influencers and then focus on prevention. Dr. Frazee mentioned that their group talked about how to “break open the HCBS pipeline” to include more stakeholders’ voices in the research. She mentioned the need to build the storytelling collective and have stakeholders engaged in the design of research studies to ensure different voices are heard. Lastly, the breakout group discussed family caregivers and how they can help support enrollees. Participants mentioned the need to collect data on this population, ensuring they are integrated and informed.

### **Closing Remarks**

*Anne Tumlinson, CEO, Anne Tumlinson Innovations*

Anne Tumlinson closed the meeting by commenting on several themes discussed throughout the meeting and provided some additional thoughts on HCBS. She stated that you cannot integrate services that people do not have. Ensuring people have access to HCBS is critical, and increasing integration will help ensure we can offer HCBS to a larger group of people. She provided a quote from Joe Biden: “Don’t tell me what you value. Show me your budget and I’ll tell you what you value.” Ms. Tumlinson offered the following question: Have policymakers and researchers truly valued HCBS? She stated that HCBS has steadily increased over time, yet HCBS comprises less than half of Medicaid spending on LTSS for older adults and people with physical disabilities. She said family caregivers are beyond stretched thin and if we want to create a society that values caregiving, then changes need to be made to prioritize it. She

described how the system is heavily biased toward institutionalization and that COVID-19 has highlighted this.

Ms. Tumlinson described that with a new President and administration coming shortly, there is going to be a huge opportunity to obtain increased funding for HCBS. Additional funding will be offered to shift long-term care into the community and out of nursing homes, but we still have a lot to learn to inform this policymaking. Ms. Tumlinson encouraged the research community to ask the following questions: (1) What racial lens are we using? (2) How do our biases impair the articulation of what the problems and questions are? and (3) How can we make the work we do make a difference in the policy arena? Ms. Tumlinson explained that building bridges with policymakers and administration staff and quickly moving when the opportunity arises will be vital to taking advantage of this unique opportunity to build HCBS research.