

June 22, 2015

The Honorable Orrin Hatch
Chair, Committee on Finance
United States Senate
Washington, D.C. 20510

The Honorable Ron Wyden
Ranking Member, Committee on Finance
United States Senate
Washington, D.C. 20510

The Honorable Johnny Isakson
United States Senate
Washington, D.C. 20510

The Honorable Mark Warner
United States Senate
Washington, D.C. 20510

Dear Chairman Hatch, Ranking Member Wyden, Senator Isakson, and Senator Warner:

The undersigned organizations share a commitment to advancing the health, independence, and economic security of older adults, people with disabilities, and their families. We are writing in response to the Senate Finance Committee request for input on policy initiatives to facilitate the delivery of high-quality care for people with Medicare living with multiple chronic conditions. We applaud the Committee for engaging in a transparent process to seek input on proposals to address long-standing concerns regarding care for these populations.

We agree that Congress should prioritize solutions to improve care quality for persons with multiple chronic conditions. The health care needs of older adults and people with disabilities should be at the center of these efforts. As such, we urge the Committee to broaden the focus of its inquiry to include not only chronic disease management as framed in the request for feedback, but to also consider functional and cognitive needs.

Many individuals with multiple chronic conditions are also likely to need assistance with activities of daily living, like bathing and dressing, or more intensive long-term services and supports. At the same time, some of these individuals may be living with dementia or other cognitive illnesses that require specialized care. We strongly encourage the Committee to advance legislative solutions focused on person- and family-centered care that addresses all needs, including physical and cognitive functioning as well as behavioral and social wellbeing.¹

We understand the Committee has identified three overarching goals to guide the development of bipartisan legislation. These include increased care coordination; streamlined payment systems to incentivize appropriate care; and improved quality, outcomes, and program efficiency. As you draft policy, we ask that you consider the following principles related to each of the Committee's stated goals. Many of the organizations included on this letter are submitting detailed comments related to these broader principles, and we encourage the Committee to refer to those letters for more specific policy suggestions.

Proposed policies to increase care coordination among individual providers across care settings should:

- **Incorporate lessons learned from ongoing demonstrations and test new models.** As the Committee contemplates new models for Medicare coordinated care, we strongly recommend considering the experience of current demonstrations. In particular, the Affordable Care Act (ACA) authorized the Centers for Medicare & Medicaid Services (CMS) to develop demonstrations to align the financing and delivery of Medicare and Medicaid benefits for dually eligible individuals.² In 10 states, these demonstrations are testing capitated

¹ For a definition of person- and family-centered care, see: National Quality Forum (NQF), "Finding Common Ground for Healthcare Priorities: Families of Measures for Assessing Affordability, Population Health and Person- and Family-Centered Care," (NQF: July 2014), available at: <http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=76728>

² For more information on these demonstrations, see: <http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/FinancialModelstoSupportStatesEffortsinCareCoordination.html>

payment models and their ability to pay for care coordination and enhanced long-term services and supports. States are in the early stages of implementing these demonstrations. Understanding these existing coordination efforts and their lessons on enrollment complexities, communicating with beneficiaries, and aligning acute and long-term services and supports provide important background for future coordination efforts.³

In addition to drawing on lessons learned from existing demonstrations, we urge the Committee to ensure that any new models of care are adequately tested. The Center for Medicare & Medicaid Innovation (CMMI) provides an existing venue for such testing. As the Committee develops legislation, we urge that you carefully pilot test any care initiatives not yet thoroughly vetted.

- **Clearly define a care coordination framework.** While the idea behind care coordination—that the care individuals receive should be coordinated between each of their health care providers and across the settings where they receive care—is simple, it is a multifaceted concept that does not have a universally adopted framework. Thus, we believe the first step towards addressing the development of care coordination teams, including for individuals with multiple chronic conditions, is producing an agreed upon framework. The following elements are critical to the design of any such framework:
 - Interdisciplinary teams coordinate care obtained from multiple providers and facilities, and patients and families are treated as integral members of the care team;
 - Individuals and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making;
 - Individuals and families are encouraged and supported in participating in care and decision-making at the level they choose. Shared decision-making processes are routinely implemented;
 - Processes are in place to effectively monitor and manage all tests, referrals, and procedures;
 - Medications are actively managed and reconciled to avoid adverse interactions;
 - The care team is available by phone, email, or in-person during evenings and weekends, and in-office appointments are scheduled promptly;
 - Individuals are asked who, if anyone, they want involved in their care and define who is considered family. Practices respect that choice and actively encourage family involvement;
 - Practices foster strong linkages with community resources, including those that provide non-medical services and supports to vulnerable populations; and
 - Practices robustly utilize health information technology (HIT) and health information exchange.

As the Committee develops legislation, we encourage you to promote policies that seek to better coordinate care for individuals with multiple chronic conditions that build on these essential elements.

- **Promote person- and family-centered care and facilitate meaningful consumer engagement:** People who experience chronic disease or disability are the best experts on living with their conditions. In the management of complex conditions, self-direction, person-centeredness, and consumer empowerment are key tools to sustaining and improving health. Individuals and families know best what will work for their lives. When they are in the driver’s seat, they can work with their health care providers to develop a care plan that has a much greater chance of success than a care plan that fails to incorporate their perspectives, goals, and values.

From a policy standpoint, this means that care models should include patient involvement at all levels of care: individuals and caregivers must be engaged in care design and redesign, in policy and governance, and at the community level. Meaningful consumer engagement goes beyond a focus group or survey; rather, it must encompass mutually beneficial partnerships at every level of care. While carefully constructed education initiatives are critically important to the design of any care model, as discussed below, we encourage the Committee to adopt a definition of “consumer engagement” that goes further than basic education as it

³ Medicaid Payment and Access Commission (MACPAC), “Experiences with Financial Alignment Initiatives Demonstration Projects in Three States,” (2015), available at: www.macpac.gov/wp-content/uploads/2015/05/Experiences-with-Financial-Alignment-Initiative-demonstrations-in-three-states.pdf

develops new, or expands existing, care models for individuals with chronic health needs.⁴

Finally, we believe individuals can play a greater role in their health when they are involved in shared decision-making. We urge the Committee to consider policies that would encourage more support for shared decision-making tools and processes through robust program requirements and quality measures in new or enhanced models of care. Individualized care plans are a core element of effective care coordination, and we continue to support an emphasis on care planning in all new models. As the Committee drafts legislation, we encourage you to promote the concept of shared care plans, which are jointly maintained and updated by beneficiaries, family caregivers, and members of their care team.

- **Include carefully designed education initiatives.** Adequate educational initiatives are needed to inform both consumers and health care providers about new or enhanced programs for individuals with multiple chronic conditions. Beneficiary-facing content should be thoughtfully designed, with input from consumer advocates. This content should also be appropriately vetted through beneficiary focus group testing.

Additionally, existing networks, like the State Health Insurance Assistance Programs (SHIPs), should be engaged and provided additional resources as new programs are rolled out or expanded. In addition to providing basic information about any new programs, educational content must be developed to make any relevant quality information useable and understandable. Central to usability is ensuring all content is available in multiple accessible formats and languages. As the Committee develops legislation, adequate education should be a cornerstone of any new or enhanced care models.

- **Engage and support family caregivers at all levels.** Family caregivers are often seen as the backbone of our nation's long-term services and supports—with 43.5 million adults having provided unpaid care to an adult or a child in the prior 12 months. On average, caregivers spend 24.4 hours a week providing care and usually become de facto care coordinators for care recipients.⁵ In 2009, it was estimated that caregivers provide the equivalent of \$450 billion in uncompensated care annually—saving federal, state, and local governments millions of dollars.⁶

As the Committee develops legislation, we urge you to explicitly address needed supports for family caregivers. Areas of the highest need include identification of caregivers most at risk for deteriorating health and financial security; training for caregivers performing activities of daily living, medical/nursing tasks, and interacting with formal care providers; and planning for future needs, like end-of-life care.⁷

- **Advance chronic disease self-management:** Individuals with chronic conditions face a number of barriers in terms of coping with their illness and optimizing their health, which include lack of social support, low skill levels for symptom management, and low confidence in their abilities to manage their conditions. Self-management is heralded as a key component in the improvement of health outcomes associated with chronic disease. According to the Institute of Medicine, self-management is defined as “the tasks that individuals must undertake to live well with one or more chronic conditions.”

Scientific studies show that participation in chronic disease self-management education programs (CDSME) can improve health and functional outcomes and save health care dollars by reducing hospitalizations and emergency room visits. For example, a 2013 national study found \$364 in per capita savings resulting from

4 For more on meaningful consumer engagement, see: Carman, K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., and J. Sweeney, “Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies,” *Health Affairs*, 32, no. 2 (2013): 223-231

5 AARP Public Policy Institute and National Alliance for Caregiving, “Caregiving in the U.S.,” (June 2015), available at: <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-us-research-report-2015.pdf>

6 Feinberg, L., Reinhard, S.C., Houser, A., and R. Choula, “Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving,” (AARP Public Policy Institute: 2011), available at: <http://assets.aarp.org/rgcenter/ppi/lte/i51-caregiving.pdf>

7 AARP Public Policy Institute and National Alliance for Caregiving, “Caregiving in the U.S.,” (June 2015), available at: <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-us-research-report-2015.pdf>

reduced emergency room visits and hospital utilization among 1,170 CDSME attendees from 2010-2011. The same study projected potential savings of \$6.6 billion if only 10 percent of those with one or more chronic conditions participated in these peer-led, community-based workshops.⁸ As such, we urge the Committee to incorporate chronic disease self-management programming in any new or expanded care models.

- **Encourage advance care planning.** Individuals living with multiple chronic illnesses often face advanced illness or are nearing the end of life. These individuals need and deserve person and family-centered care that is well coordinated and honors their dignity, values, and health care choices at each stage of their illness. Individuals must have access to the full range of high-quality medical care and treatment, including curative care, palliative care, and hospice care.

As such, we encourage the Committee to address advanced care needs as it develops new, or enhances existing, models of care for people with multiple chronic conditions. In particular, the Committee should ensure that policies support individual planning and self-determination; encourage communication among individuals, their families, and their health care providers; increase access to hospice and palliative care; respect the health care preferences of individuals; prevent overuse, underuse, and misuse of health care services; and incorporate practitioner education.

- **Integrate Medicare prescription drug (Part D) plans.** Access to prescription drugs is vitally important to the health and wellbeing of individuals with multiple chronic conditions. Any attempt to adequately coordinate care for these individuals must address their medication needs. Stand-alone Part D prescription drug plans are not well positioned to participate in care coordination activities given that, by design, they lack relationships with health care providers and access to data about their enrollees' health needs.

Yet, Part D plans are critically important to individuals with Traditional Medicare and their involvement will be vital to any successful effort to enhance care coordination for individuals with multiple chronic conditions—facilitating communication among prescribers, pharmacists, and beneficiaries. As such, we urge the Committee to pursue avenues to integrate stand-alone Part D plans into any new or expanded care models.

Proposed policies to streamline payment systems to incentivize appropriate care should:

- **Bridge the gap between acute care and long-term services and supports (LTSS).** As the Committee develops legislation, we caution against a policy that focuses exclusively on Medicare payment for acute services. We recommend that the policy integrate acute care and LTSS. As evidenced by recent proposed regulations for Medicaid managed care, the health care landscape is changing, and there is an enhanced focus on aligning health care systems.⁹

It is commonly accepted that poorly coordinated care transitions between health and LTSS settings are associated with high hospital readmissions, emergency department visits, medication errors, and adverse drug events.¹⁰ Further, it is widely accepted that LTSS providers are key partners in improving transitions and coordination across the acute care spectrum.¹¹ Given this, we urge the Committee to adopt a holistic approach to services, incorporating LTSS and removing outdated restrictions that prevent Medicare from utilizing a broad array of home and community based services in coordination with Medicaid.

Committed leadership in Congress and at CMS is necessary to create and monitor demonstration authorities that can be used to construct community-anchored care systems that are capable of providing both medical and

⁸ National Council on Aging (NCOA), "National Study of the Chronic Disease Self-Management Program: A Brief Overview," (2013), available at: <http://www.ncoa.org/assets/files/pdf/center-for-healthy-aging/National-Study-Brief-FINAL.pdf>

⁹ 80 Fed. Reg. 31098 (June 2, 2015)

¹⁰ Assistant Secretary for Planning and Evaluation (ASPE), Department of Health and Human Services, "Long-Term and Post-Acute Care Providers Engaged in Health Information Exchange: Final Report," (2013), available at: <http://aspe.hhs.gov/daltcp/reports/2013/HIEEngage.shtml>

¹¹ Id.

LTSS services to older adults and people with disabilities. Additionally, both Congress and CMS must be willing to support the development of new or expanded quality and financial metrics that will ensure appropriate transparency and accountability in the context of care models that are designed to meet both individual and population health goals.

- **Adopt promising practices around community integration.** The vast majority of older adults and people with disabilities prefer to receive services in their homes and communities, and often have better outcomes and lowered costs when they do so. As such, we urge the Committee to tap into existing resources in the Aging and Disability Networks. Together, this nationwide network provides programs and services to support the health, independence, and wellbeing of people with disabilities and older adults in communities across the nation.¹²

The services offered through the Aging and Disability Networks include educational programs, management of chronic conditions such as diabetes, daily independent living supports, case management, caregiver support, meal delivery, transportation services, and many others. In particular, the Aging Network, which also includes over 20,000 individual service providers, is expanding partnerships with a wide range of health care organizations.

This experience ideally situates the Aging and Disability Networks to provide older adults and people with disabilities with the health-related supports they need and to provide these services at a lower cost than prevailing care paradigms. As such, we urge the Committee to consider policy options to create and incentivize stronger links between existing health care programs, especially Medicare and Medicaid, and existing community-based providers and organizations that comprise the Aging and Disability Networks as well as related service providers.

- **Promote models to combine housing plus services for low-income seniors.** Low-income housing can be a platform for providing health and social services, reducing Medicare and perhaps Medicaid costs. Affordable housing properties linked with health and supportive services provide an option for meeting the varied needs of low-income older adults, while also helping address multiple public policy priorities. Low-income, dually eligible beneficiaries are the biggest users of health and long-term care services; housing with services enhances access to necessary services and supports, helping individuals to better manage their conditions and coordinate their care needs.

Housing Plus Services models focus on low-income seniors in subsidized housing, building on the existing infrastructure of housing, health, and community-service networks. With the concentration of high-risk, high-cost residents, many of whom are dually eligible for Medicare and Medicaid, senior housing offers an economy of scale that can increase delivery efficiencies for providers and affordability for older adults. Older adults gain easy access to services, which encourages greater utilization and follow through. We encourage the Committee to explore opportunities to integrate Housing Plus Services models in future legislation.

- **Support Independence at Home (IAH).** The IAH demonstration program requires teams of health care professionals led by primary care practitioners who provide care to eligible beneficiaries in the home and requires these programs to achieve minimum savings of five percent annually while producing good outcomes and beneficiary/caregiver satisfaction as a condition of participation. IAH programs that fail to achieve at least five percent savings for two consecutive years have their agreements terminated.

No other program has such a “self-culling” process which ensures only successful programs continue in the program. As the Committee develops legislation, we encourage including a conversion of the IAH Medicare demonstration set forth in detail at section 1866E of the Medicare Act. Experts at the University of

¹² This comprehensive network includes Area Agencies on Aging, Aging & Disability Resource Centers, State Units on Aging, Centers for Independent Living, Protection & Advocacy Agencies, Developmental Disabilities Councils, and University Centers for Excellence in Developmental Disabilities.

Pennsylvania School of Medicine independently estimate that a fully implemented IAH program would generate savings over 10 years of about \$60 billion.

- **Address quality measurement gaps.** Although a growing number of states are integrating their health and long-term services and support systems, there is no metric to comprehensively evaluate these integration efforts. Several states have developed interim methods to evaluate the integration services, and the National Quality Forum (NQF) is working in earnest to determine a conceptual framework for measuring home and community-based services.¹³ We recommend the Committee ensure comprehensive metrics to evaluate LTSS and acute care services are incorporated in final legislation. In addition, we recommend expanding the Patient-Centered Medical Home (PCMH) self-management quality standards to other delivery models for Medicare.¹⁴
- **Preserve the integrity of the star ratings system.** Any program designed to serve individuals with multiple chronic conditions should maintain the integrity of the quality ratings system. Therefore, we alert the Committee to our concerns regarding risk adjustment of quality measures for complex individuals. Research suggests that individuals from under-resourced communities are more likely to receive poor care.¹⁵ As such, we are concerned that altering quality measures based on sociodemographic factors risks masking existing disparities in care, and could create two divergent standards of care, while concealing the actual root of these disparities through the inflation of performance scores.

More specifically, we believe risk adjustment of quality measures is premature. Efforts by CMS are underway to explore the link between sociodemographic factors and quality scores.¹⁶ We believe this inquiry should continue and that the agency's findings should inform the development of policy in this area. As such, at this time, we urge the Committee to refrain from incorporating any changes to performance measurement that risk masking healthcare disparities in legislation.

Proposed policies to facilitate the delivery of high quality care should:

- **Approach beneficiary cost-sharing incentives with caution and avoid increases in cost-sharing.** We strongly encourage the Committee to proceed carefully as it considers any changes to beneficiary cost-sharing, whether in Medicare Advantage (MA) plans, Traditional Medicare, or otherwise. Some academics, health plans, and others suggest that cost-sharing should be altered on the basis of value or clinical nuance, known as value-based insurance design (V-BID).

In general, we support eliminating or lowering cost-sharing to facilitate access to needed, high-value health care services, such as the policies advanced through the ACA that eliminated Medicare cost-sharing for select preventive care. Yet, we urge the Committee to avoid any policies allowing cost-sharing increases intended to steer older adults or people with disabilities away from perceived low-value care.

At the same time, should the Committee adopt V-BID concepts as part of a legislative package, we urge transparency, accountability, and educational initiatives be incorporated in the design of any such program. For example, assertions about which care counts as "high-value" should be supported by an evidence-base that is made publically available in formats accessible to beneficiaries and their health care providers.

¹³ For more on NQF's efforts, see: <http://www.qualityforum.org/ProjectEventsList.aspx?projectID=77692>

¹⁴ For suggested metrics, see: "Recommendations for Measuring Rebalancing in Dual Eligible Demonstrations and MLTSS Waivers," available at: http://dualsdemoadvocacy.org/wp-content/uploads/2014/01/Rebalancing-in-MLTSS-and-Dual-Eligible-Demo_01.13.14.pdf; Also, see: NCQA, "Patient Centered Medical Home (PCMH 2014) Standards Parts 1 & 2 Training," (2014), available at: <http://www.ncqa.org/Programs/Recognition/RelevanttoAllRecognition/RecognitionTraining/PCMH2014Standards.aspx>

¹⁵ Agency for Healthcare Research and Quality (AHRQ), "National Healthcare Disparities Report," (last modified Nov. 3, 2014), available at <http://www.ahrq.gov/research/findings/nhqrd/nhdr12/highlights.html>

¹⁶ For example, regarding star ratings for MA plans, see: Announcement of Calendar Year (CY) 2016 Medicare Advantage Capitation Rates and Medicare Advantage and Part D Payment Policies and Final Call Letter, April 6, 2015, Duals discussion pgs 101-105: <http://www.cms.gov/Medicare/Health-Plans/MedicareAdvgtgSpecRateStats/Downloads/Announcement2016.pdf>

- **Incorporate ample and specific beneficiary protections.** Naming adequate consumer protections is vital to the design of any program intended to serve individuals with multiple chronic conditions. First and foremost, beneficiary choice must be preserved through opt-in and opt-out mechanisms. When needed, special considerations should be made around program marketing, restricting or prohibiting marketing when warranted. As such, we ask the Committee to name specific beneficiary protections in future legislation.

In addition, any legislative proposal to create new delivery systems or modify existing models, whether in MA, Traditional Medicare, or otherwise, should ensure beneficiaries and consumer advocates are positioned to provide ongoing feedback throughout program development and implementation. We urge the Committee to ensure involvement by beneficiaries and consumer advocates is explicitly referenced in any legislation to devise new care models or expand on existing programs for individuals with chronic care needs.

- **Ensure rigorous oversight and require transparency.** Transparency and reporting are critically important to any new policies intended to alter the delivery of care for those with multiple chronic conditions. We strongly encourage the Committee to create mechanisms to make publicly available data and information about any new or expanded programs to improve care for individuals with chronic health needs. As appropriate, we urge the Committee to request regular reports, Government Accountability Office (GAO) analyses, and independent evaluations to continuously assess any new or expanded care models.
- **Address alarming trends concerning beneficiary denials and appeals.** Individuals with chronic conditions are more likely to need multiple services and prescription drugs, and are therefore more likely to face coverage restrictions and utilization controls, most notably in MA and Part D plans. Annual audit findings by CMS suggest significant room for improvement by MA and Part D plans in the administration of utilization management tools and beneficiary appeals processes.¹⁷

As the Committee expressly references MA plans in its request for feedback, we ask that you explore opportunities to improve the beneficiary experience with denials of coverage, appeals, and grievances as part of any legislative package to improve care delivery for those with multiple chronic conditions. We believe the Committee's efforts should complement initiatives already underway at CMS to improve the Part D appeals process, through enhancements to beneficiary denial notices, a pilot program to improve the beneficiary experience at the point-of-sale, and strengthened data collection at each stage of the appeals process.

In closing, we hope the principles outlined above will help guide the Committee's efforts to develop bipartisan legislation to advance care delivery models to improve the health and wellbeing of individuals with multiple chronic conditions. As the Committee narrows the focus of its inquiry to specific proposals, we would welcome the opportunity to provide more detailed comments. Thank you for the opportunity share our collective feedback.

Sincerely,

ACCSES
Aging Life Care Association
AMDA-The Society for Post-Acute and Long-Term Care Medicine
American Association on Health and Disability
American Occupational Therapy Association (AOTA)
American Society on Aging
American Therapeutic Recreation Association

¹⁷ For an explanation of recent audit findings and sanctions, see this October 2014 letter from consumer advocates to the Medicare Payment Advisory Commission (MedPAC): <http://www.medicarerights.org/pdf/101014-medpac-part-d-appeals.pdf>; For the most recent audit findings, see: Centers for Medicare and Medicaid Services (CMS), "The 2013 Part C and Part D Program Annual Audit and Enforcement Report," (2014), available at: <http://www.cms.gov/Medicare/Compliance-and-Audits/Part-C-and-Part-D-Compliance-and-Audits/Downloads/2013CandDProgramAuditAnnualReport.pdf>

Association of University Centers on Disabilities
Autism Speaks
Autistic Self Advocacy Network (ASAN)
B'nai B'rith International
Center for Elder Care and Advanced Illness, Altarum Institute
Center for Medicare Advocacy, Inc.
Christopher & Dana Reeve Foundation
Compassion and Choices
Easter Seals
Epilepsy Foundation
International Association for Indigenous Aging
Justice in Aging (formerly National Senior Citizens Law Center)
Lakeshore Foundation
LeadingAge
Lutheran Services in America (LSA)
Meals on Wheels America
Medicare Rights Center
National Academy of Elder Law Attorneys (NAELA)
National Adult Day Services Association (NADSA)
National Alliance for Caregiving
National Association of Area Agencies on Aging (n4a)
National Association of Social Workers (NASW)
National Committee to Preserve Social Security and Medicare
National Council on Aging (NCOA)
National Down Syndrome Society
National Hispanic Council on Aging (NHCOA)
National Multiple Sclerosis Society
National Partnership for Women & Families
OWL-The Voice of Women 40+
The Arc of the United States