Assisted Living: Fulfilling the Promise

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I. Introduction

Thank you Senator Nelson, Chairman Kohl, Ranking Member Corker, and other members of the Committee for the opportunity to share my thoughts on sustaining high quality affordable assisted living. I am Robert Jenkens. I currently direct The Green House Project, a partnership between NCB Capital Impact, The Robert Wood Johnson Foundation, Dr. Bill Thomas, and the pioneering states and providers that have joined with us.

The Green House Project assists nursing home and assisted living providers to implement a radically different approach to long-term care, one that truly operationalizes the founding values of the assisted living movement – autonomy, dignity, and privacy. Prior to The Green House Project, I directed the Coming Home Program. The Coming Home Program was also a partnership between NCB Capital Impact and The Robert Wood Johnson Foundation. Coming Home assisted nine states - Alaska, Arkansas, Florida, Iowa, Maine, Massachusetts, Vermont, Washington, and Wisconsin – to implement policies and programs to support the creation of high quality affordable assisted living for Medicaid-eligible individuals who cannot remain at home.

Coming Home worked with its state partners to implement or refine Medicaid waiver, regulatory, and housing finance programs essential to the creation and sustainability of high quality and affordable assisted living projects. The successful approaches and tools created by these states delivered 42 affordable apartment-style assisted living demonstrations. The policy, program, and financing tools created under Coming Home continue to assist in the development of new projects today.

Through the Coming Home Program and The Green House Project we have learned just how good assisted living can be. It can deliver on the promise of high quality resident-directed care combined with meaningful control, privacy, dignity, and better direct care jobs - all in a model affordable to Medicaid-eligible individuals. For more information about The Green House Project see www.thegreenhouseproject.org. For more information on the Coming Home Program see www.ncbcapitalimpact.org.

II. Observations

So how do we square the successes I have seen created through committed public/private partnership with the horrific stories bravely brought to light by the Miami Herald? How can we think about these opposites and use the successes to inform us on how to prevent abuses without stifling the innovation necessary to respond to evolving needs, preferences, and resource limitations? Four observations from

my experiences with Coming Home and The Green House Project may help illuminate a path to the solution we need.

First, we must ask if the providers responsible for these terrible events are the exception or the norm. As the Miami Herald found, the incidents of willful and significant abuse and neglect represent a small fraction of the providers operating in Florida. This is good news because it means that the majority of organizations that are providing quality services can be part of the solution.

Second, we should note that in many cases, the existing state complaint and review process was not followed or enforced despite repeated warning signs and formal complaints. The Miami Herald coverage suggests that if these complaints had been appropriately pursued, some of the worst outcomes may have been avoided. While the lack of enforcement in these cases is troubling, it means that elements of a solution may already be in place.

Third, we know from this example of regulatory failure and similar failures in other states, that financial and political pressures do not always allow the soundest state level quality assurance systems to be formulated or funded. This limits their performance. Just as we have learned from the nursing home experience, when Federal dollars are involved the Federal government has an appropriate role in establishing and holding states accountable for meaningful quality assurance practices. This is an area where, with some additional creative thinking, we can foster significant improvement.

Forth and finally, it is important to note that assisted living quality is not a Federal/state versus provider problem. The providers and trade associations I work with daily are united in their calls for cases of abuse and neglect to be punished swiftly and fully. They are motivated by their personal missions to improve the lives of people who need care and their business interests which are hurt severely when rogue providers are tolerated. This is important because it means that interests are largely aligned between consumers, regulators, and providers and that a creative solution likely exists.

III. Recommendations

So, what should be done? Do we need more state action? If so, what kind? Is there a different Federal role needed and, if so, what should that role be? From more than 20 years of experience in bridging policy to practice in long-term care, I can say yes to each of these questions. We do need more state action and an enhanced Federal role is required. For some of you in the room today, just voicing of these beliefs causes deep concern. This is especially true in light of current economic pressures and the potential cost of new regulations. It is also a concern due to the potential impact of additional regulations on the continued innovation necessary to address rapidly evolving consumer preferences.

However, enhanced government involvement at the state and federal levels needn't cause concern. I believe strongly that the goals of quality enforcement and innovation are not mutually exclusive and, if created in partnership with advocates and providers, do not need to add costs or stifle innovation. In fact, I think they are necessary compliments and that we already have the overall state/federal regulatory framework in place that we need. The current framework provides the correct structure to balance appropriate minimum process and outcome standards, accountability, and creativity. We simply need to refine and bolster the framework in certain areas to allow it to fulfill its intended purpose. While these needed refinements are significant, they do not have to upset the Federal/state balance.

My first recommendation is targeted at refining the balance between state flexibility and accountability for minimum standards and outcomes. Currently, the Federal Medicaid waiver approval process allows states to propose the quality standards and monitoring system that work best for their goals and resources. While this is the essentially the right place to start, clear Federal expectations based on successful practices and outcomes should form the foundation of any state proposal. It is not enough, in my opinion, to defer to a state's judgment entirely. In fact, my experience in both Coming Home and The Green House Project points to the benefit that many state staff and legislators see in having clear Federal guidelines for the review of proposed state quality assurance processes, standards, and outcomes – guidelines that help them resist approaches that they are not confident in.

To create appropriate guidelines for quality assurance, standards that make sense to advocates, consumers, and providers, the Centers for Medicare and Medicaid Services (CMS) should be asked to develop these guidelines through an inclusive stakeholder initiative. An element of the quality assurance discussion should be on how to determine what minimum reimbursement rates are required for quality outcomes. This stakeholder initiative could be modeled on the successful Assisted Living Workgroup (ALW) formed in response to this Committee's 2001 challenge to the industry to "develop recommendations designed to ensure more consistent quality in assisted living" or the more recent 2011 efforts of the successor organization, the Center For Excellence in Assisted Living's (CEAL). Building on the processes and recommendations from the ALW and CEAL, and with the assistance of a team of CMS advisors who are experienced in assisted living issues, guidelines could be developed and refined over the next 6 months. At the direction of Congress, these guidelines could form the firm basis on which CMS evaluates and approves states' quality assurance proposals.

My second recommendation is targeted at accountability. The severity and duration of the quality crisis uncovered by the Miami Herald provides evidence that the CMS oversight role in waiver programs is not yet sufficient. We know this is not because CMS staff do not care enough, but rather because they lack the tools and resources to effectively monitor and enforce waiver performance. Rather than the regular Minimum Data Set monitoring and federal "look behind" surveys conducted by CMS for nursing home services, CMS monitoring of waiver quality assurance is based on complaints, and data self-reported by states annually and at waiver renewal. The CMS central and regional Medicaid offices do not have staff or a structure to perform verification of state quality assurance for home and community-based waiver services in the way that Congress has provided for survey oversight of inpatient facilities.

While we do not want to impose the often burdensome Federal nursing home approach to assisted living providers, the workgroup brought together to develop waiver quality-assurance guidelines could also make recommendations on a more effective Federal monitoring and enforcement role, including intermediate sanctions. Congress could then evaluate these recommendations, direct CMS to implement selected enhancements, and provide additional funding as required to assure that beneficiaries and this essential industry does not suffer unnecessarily due to lax oversight.

Thank you again for the opportunity to testify today. I look forward to answering your questions.