

**Testimony to the 2021 Joint Legislative Budget Hearing on Health**  
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**SUBJECT: Home Health Care, Nursing Homes and COVID-19**

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Good afternoon, my name is Doug Hovey and I am the President and CEO of Independent Living, Inc. (ILI), a consumer-controlled, cross-disability service organization, and Independent Home Care, Inc. (IHC), an affiliated agency exclusively dedicated to the provision of **Consumer Directed Personal Assistance Services** and to meeting the long-term care needs of people with disabilities in the Lower Hudson Valley. I also serve as a member of the **Most Integrated Setting Coordinating Council**. Thank you for the opportunity to provide testimony on behalf of the hundreds of families we work with each year, and all New Yorkers who find themselves caught up in the whirlwind of facts, fantasies and uncertainties that often occurs when a family member unexpectedly becomes disabled and requires long-term care.

Although there are a number of viable long-term care solutions, the option that clearly dominates most LTC thinking and decision-making continues to be placement in a nursing home, based on the institutionally biased belief that congregate care facilities are the “safest” choice. Ironically, assumptions made about the safest option have been deeply challenged as thousands of nursing home residents needlessly lost their lives to COVID-19. The impact of these deaths has been immeasurable, with friends and family members continuing to grieve while we are here today.

Clearly, we have been traveling down the wrong path. In the 21<sup>st</sup> century, institution-based services are neither our ONLY option nor our BEST option for ensuring the safety and well-being of our most vulnerable citizens. Despite continuing efforts to improve the institutional model, conditions in nursing homes today are very much the same as they were when my agency was founded, more than 30 years ago. IT'S TIME TO ADOPT A NEW VISION...

ONE THAT EMBRACES THE RIGHT OF ALL INDIVIDUALS TO ACTIVELY PARTICIPATE IN DECISIONS THAT AFFECT THE CARE THEY RECEIVE AND TO LIVE WITH DIGNITY IN LEAST RESTRICTIVE SETTINGS. And... it's time to systematically phase out the last vestiges of a broken system, the costs for which can be measured in both dollars spent and lives lost, a system that necessitates that the government grant immunity as a protection against its intrinsic flaws.

I am firmly convinced that New York State can lead in the transformation of long-term care practices *from a 20<sup>th</sup> century model* shaped by historical biases, misguided assumptions, and special interests to a new age of community care that places the genuine interests of each individual at the center of the service paradigm. As much as people have a fundamental right to enjoy the first two phases of their lives, they also have the right to equally enjoy the third, as senior citizens, and we have a moral obligation to improve the community-level supports needed to ensure that barrier-free living is more than a theoretical construct.

Not only must we reform this system, but we also must improve the coordination between the state and localities so that local government units (counties) and community-based organizations are working in concert to respond proactively to families needing unbiased information about long-term care options. We need an energized process at the local level that is supported by the state, much like the Single Point of Access (SPOA) implemented by the State Office of Mental Health which meets weekly to address the housing and service needs of people diagnosed with a mental illness.

The simple fact is that we need a similar approach for people with physical and age-related disabilities. We need a local planning process that focuses on:

- keeping people in their own homes as a first priority,
- when this is not possible, helping individuals and families to find alternative accessible and affordable housing and linking them with support services, and
- if left with no other option, providing well-managed temporary group living opportunities while actively pursuing non-congregate alternatives – sub-acute nursing facilities being a short-term remedy rather than a permanent housing solution.

In our hearts we ALL know that warehousing large numbers of frail elderly individuals in hospital-like settings, in double or triple occupancies with shared bathrooms, where staff turnover can be as high as 95% percent, inescapably creates high-risk conditions that almost inevitably compromise both resident safety and quality of care. The fact is that, even before the pandemic, 82 percent of all nursing homes were cited for *infection prevention and control deficiencies*, according to the U.S. Government Accountability Office.

We can blame the 13,000+ nursing home deaths on the virus, but the real fault is not with the virus but with the institutional model that creates conditions enabling-it to spread. The plain fact is that people are exposed to and die from infections at a significantly higher rate in congregate care facilities than in smaller personal living environments; this has always been true.

In response to the thousands of deaths in NYS, multiple recommendations for change have been made, including ensuring an adequate supply of personal protective equipment, regularly testing staff and residents, implementing disaster plans that facilitate quarantining, providing more training, and heightening the level of monitoring and oversight. However, none of these “policy and procedural” changes begin to address the foundational problem: institutional care begets institutional culture, which inherently gives rise to patterns of neglect and abuse.

NOW is the time to put local and regional plans in place for providing effective alternatives.

The COVID-19 pandemic has provided us with both a tragic wake-up call and an opportunity to reimagine long-term care solutions in ways that replace facilities with communities, nursing homes with real homes and segregated approaches to care with fully integrated assistance shaped by the needs and preferences of those being served.

Accomplishing this will require a fundamental realignment of attitudes and priorities beginning with:

- Viewing facility placement as a temporary solution.
- Replacing large facilities with smaller, more home-like living environments that guarantee personal privacy and include private bathrooms.

- Ensuring homecare workers are fully recognized and compensated commensurate with the critically important services they provide, raising their base wages to at least 150% of minimum wage.
- Flattening staff hierarchies, encouraging flexibility and requiring cross-training.
- Exclusively supporting facilities clearly evidencing an organizational culture-that prioritizes residents' goals, interests and preferences.

Fortunately, there are best practice models available to guide this transformation. The Green House Project founded by Bill Thomas is one example that has consistently earned high satisfaction scores. Additionally, supported housing models that have been successfully implemented to serve both individuals with developmental disabilities and people with mental illness could easily be adapted to meet the needs of those who are nursing home eligible.

The dam has burst... segregated institutional solutions have failed us time and again. LET'S STOP TRYING TO PLUG THE LEAKS, AND BUILD A NEWER, SMARTER AND MORE COMPASSIONATE SYSTEM THAT HONORS, RESPECTS, VALUES AND PROTECTS OUR MOST VULNERABLE CITIZENS AND SAFEGUARDS THEIR RIGHT TO LIVE IN THE MOST INTEGRATED SETTING.

I urge you to reimagine and *invest* in a system that allows people to live with those they love, in their communities and homes.

*The COVID-19 pandemic ravaging nursing home residents and other people with disabilities in congregate care settings underscores the deep-seated ageism and systemic disability discrimination that have shaped our institutional models of care. Not only are nursing home residents denied opportunities for community participation, but they have also been excluded from local government emergency preparedness planning, as has become tragically obvious over the past year. NOW IS THE TIME TO TAKE DECISIVE ACTION AND TRANSFORM OUR LONG TERM CARE SYSTEM... WE CAN DO THIS TOGETHER, WE'RE NEW YORK TOUGH!*