

I just finished reading the “Final report of the senate select committee on aging and long-term care.” This committee was chaired by Senator Carol Liu. On January 28, 2015, I sent her a letter with my thoughts and concerns. Senator Liu did not have the courtesy to respond, so I will share what I wrote:

I applaud your leadership in this effort. It is long overdue. I have several comments that I hope you will find constructive.

The report leads with this paragraph, “A person-centered, culturally responsive LTC system would enable individuals to receive services in the most affordable, home-like settings available. California was once a leader in providing services to support the full integration of older adults and persons with disabilities into community life. Over the past several years, however, the LTC system has been adversely impacted by system fragmentation, a lack of usable data, poor planning, unaddressed workforce issues, capacity issues, and of course devastating budget cuts during the recession.”

The two most important phrases in the paragraph are, “person-centered” and “enable individuals to receive services in the most affordable, home-like settings.” I underlined several words, and will address these in this letter. The paragraph also addressed budget cuts. It was probably not politically possible, but you failed to add that Governor Schwarzenegger’s false claims of “rampant fraud” tainted any realistic dialogue about these issues.

Another paragraph states, “Person-Centered Planning: The plan should develop principles and standards for person centered service planning in an integrated system of care to ensure that individuals and families have the opportunity to engage in service planning across the health and LTC continuum in a manner that reflect their needs, desires, and preferences.” My concern is with the words “standards” and “integrated system of care.” Standards are often helpful, but standards can also lead to an outcome in which someone sitting at a desk in an ivory tower develops a “one size fits all” scheme and tries to shove it down our throats. Consumers of LTC services are a diverse group, and our needs and desires vary greatly. “Standards” can be used to push for many things that are not in our best interest. In addition, “service planning” and “integrated system of care” are words that appear to promote a third party decision maker.

It is not until page 32 of the report that In-Home Support Services (IHSS) is mentioned. The report acknowledges that “IHSS is the cornerstone of California’s home and community-based services system that enables low income, aged, blind, and disabled individuals to remain safely in the home and avoid institutionalization.” But the report also states, “However, no specialized training is required for an IHSS worker to perform services of a paramedical nature – leaving many of them without the core competencies necessary to provide more complex care.”

I believe this last sentence indicates a lack of understanding about IHSS. The IHSS program was designed to be consumer-oriented and consumer-directed. The basic objective has always been to provide services that the disabled person, of any age, would provide for themselves, if their varying disabilities didn’t interfere with their ability to do these things by themselves. The IHSS program does not provide complicated medical procedures. Why? Because no IHSS consumer would do complicated medical procedures on themselves. The term “paramedical services” is

often misunderstood. Paramedical services, in this context, includes changing dressings, helping with medications, assistance with prosthetics, and even insulin injections. These are medically related activities that many thousands of Californians do every day for themselves. No “specialized training” is required of non-disabled individuals who give their own insulin injection, change their own dressings, or take their own medications. Why is this being suggested for those who happen to have a disability? We have a disability. We are not incompetent!

At the close of the IHSS paragraph the report states, “The state should implement a certified, standardized, voluntary training curriculum that offers a career ladder and increased pay for IHSS workers who increase their capacities to deliver care.” I am pleased that the report included the word “voluntary,” but “standardized” is a term that is fraught with danger. Whose standard will be used? One consumer might have vision impairment and another consumer might have quadriplegia. Among quadriplegics there are differences too. One might have a complete, high level spinal injury and another might have had polio. They might look alike, but many of their needs differ.

In addition, while higher pay is certainly needed, providing a “career ladder” through IHSS is another issue that deserves more thought. IHSS consumers will agree that higher pay is needed, but I doubt that many want to be a medical mannequin while a stranger learns how to work in a nursing home. “Career ladder” sounds very much like a union recruitment slogan. And, quite frankly, the inclusion of “end-of-life care/decision-making” in any publically funded training troubles me ... even scares me. I do not appreciate the thought of an IHSS provider being taught what some third party “teacher” believes is my correct “end of life” decision.

“Stakeholders” were mentioned several times in this report. Examples included “state agencies and departments” and “members and staff from budget, health, and human services committees” and, in the “call to action” section of the report, it says, “The committee convened academic, government, labor leaders, and experts in the fields of aging and disability at two public hearings.” This apparently does not include those most affected. In fact, on page nineteen, the report says, “numerous discussions with consumers, stakeholders, and experts in the field,” as if consumers were not even considered as “stakeholders.” I find this very troubling!

The Senate Select Committee held two hearings. The first on July 8, 2014, in Glendale. This hearing was titled, “California’s Service Delivery System for Older Adults: Envisioning the IDEAL.” The report says that presenters were asked to provide answers to five questions:

1. What values underlie an IDEAL system?
2. What is the IDEAL system?
3. What are the essential components of an IDEAL system?
4. What are the major barriers/challenges to achieving an IDEAL system?
5. How do we achieve the IDEAL?

Another hearing took place on August 12, 2014, in Sacramento. This hearing was supposed to present the findings and conclusions of the first meeting. The report says that, “Invited to participate in both hearings as presenters were some of California’s leading experts and scholars in the field of aging and long-term care.”

Later in the report it says, “Information gathering also took place through individual face-to-face meetings with multiple providers in the field of aging and long-term care and organizations representing elders and people with disabilities.” I have underlined these words to emphasize that, apparently, no actual consumers were invited to participate; only those who “represent” them and providers who are paid to “serve” them.

I respectfully ask, who is a more qualified expert than the one who deals with these issues on a daily basis? Why were “representatives” of older Californians and those with disabilities asked to speak, but actual older people and disabled people were not asked to speak. I know that Fernando Torres-Gil uses a wheelchair, and I respect his expertise, but that does not negate my question. There is a slogan we often use: “Nothing About Us Without Us!” (Latin: “Nihil de nobis, sine nobis”). This communicates the idea that no policy should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy.

Richard Daggett, President, Polio Survivors Association  
Member, American Academy of Home Care Medicine