

## **Senate Budget Committee No. 3 Informational Hearing**

**Title:** “The State of LTSS for California Seniors”

**When and where:** Thursday, November 15, 2018 at 10am in Sacramento

**Goal:** The goal of the hearing is to evaluate how prepared the state’s programs for seniors are for the coming demographic changes that could potentially lead to higher need and utilization of Long Term Services and Supports (LTSS).

### **II. Presentation: Data gaps in understanding changes in LTSS needs and utilization patterns**

(Written Comments submitted by Kathryn G. Kietzman, PhD. MSW, UCLA Center for Health Policy Research)

#### **Summary of major issues:**

California currently lacks data to identify population-level needs for LTSS, use of LTSS, and possible gaps in services and supports that are essential to older adults with chronic and long-term care needs.

- The lack of data reflects the fragmentation of LTSS, which are financed and administered by different programs, and delivered in multiple and diverse settings.
- Many programs do not uniformly collect and report data, and there is little capacity for sharing data across delivery sites.
- As a result, we lack understanding of how consumers use services across the “system” of LTSS.

#### **CURRENT DATA GAPS THAT UCLA AND THE LTSS COALITION IDENTIFIED IN ADVOCATING FOR THE ADDITIONAL FUNDING**

Using the funding allocated by the State, we are developing a follow-on survey to the California Health Interview Survey (CHIS) that will gather essential population-level data about LTSS in California. The CHIS, housed at the UCLA Center for Health Policy Research, collects data on a representative sample of approximately 20,000 households each year, and is the largest continuous state health survey in the nation.

The first survey will be administered in the CHIS 2019-2020 cycle and the complete set of data will be available for analysis and reporting in late 2021 (note: a subset of data collected in 2019 will be analyzed to generate an early snapshot of responses from people with LTSS needs, to be reported out by end of 2019).

The follow-on survey will be repeated in the CHIS 2023-2024 cycle (and a qualitative in-depth study of 100 LTSS survey participants will be conducted between these two CHIS survey cycles, in 2021).

We have engaged with a diverse and robust group of stakeholders from across the State who represent the continuum of LTSS care needs across the lifespan.

Members of the Workgroup include LTSS administrators and providers, advocates, and academics/subject matter experts, who are tasked with identifying data needs and recommending priority content for the follow on survey.

Specific data gaps identified to date include:

**Need for LTSS:** Demand for services? Receipt of services? Are services adequate/sufficient? What is the extent of *unmet* need? What are *specific* unmet needs?

**Consequences of Unmet Need:** How does unmet need affect quality of life, physical/mental health, financial well-being? To what extent does unmet need lead to health service utilization, such as ER visits, hospitalizations, medication mismanagement?

**Services:** Are people with LTSS needs aware of available services? What are the service gaps?

**Access to Services:** Who is receiving services? Who is not receiving needed services? What are the barriers, facilitators to accessing LTSS?

**Types of Services/Supports:** For those who are getting help, are they receiving formal/paid, informal/unpaid care? Are services public or private? Who is providing care? What is their relationship to person with LTSS needs?

**Quality of Services:** How do consumers of LTSS perceive the quality of care they receive? Is it effective, responsive, culturally/linguistically appropriate, person-centered?

**Consumer Experience:** How satisfied are consumers of LTSS? How well do services support choice and independence? Social/community engagement?

**Disparities:** Across all of the above listed domains, we need to learn who gets and who doesn't get needed LTSS; generate estimates by age group, gender, race/ethnicity, rural/urban, and rent/own home.

## **HOW THE FUNDING WILL HELP ADDRESS SOME OF THESE DATA GAPS**

The LTSS follow on survey will gather population-level data to generate statewide estimates of LTSS need and use by Californians across the lifespan. To date, information about LTSS has largely been limited to those who already use specific programs or services.

Because LTSS programs have different sources of financing, different administrative bodies, and services are provided in multiple diverse home and community-based and institutional settings, we don't know what combination of services and supports individuals are accessing across the system of care, and which are most effective.

National survey data related to older adult use of LTSS exists (e.g., Health and Retirement Survey, National Health and Aging Trends Survey) but sample sizes are not large enough to make estimates for California. The CHIS follow-on survey is being designed to address these data gaps. Furthermore, existing national data that informs policy on LTSS needs is typically not community-based. For example, the National Survey on Long-Term Care Providers uses survey and administrative data to assess trends in the supply, provision, and use of services from the provider perspective. These data do not represent the perspective of people who have LTSS needs but are not accessing care.

Specifically, the State funding supports development of a follow-on survey that uses the general CHIS household survey to identify Californians with physical, cognitive, and/or mental conditions that result in difficulties performing basic daily activities such as dressing or bathing, or getting out of the house to shop or to see the doctor.

The CHIS follow-on survey provides the opportunity to get a more comprehensive / holistic picture of the person with LTSS needs and the network of support they may or may not be accessing. These data will add context by leveraging information from the general CHIS survey about the respondent's household composition, employment, income, housing, food environment, a full range of health indicators, including measures of well-being: psychological, emotional, financial, health insurance coverage, delays in care, delays in prescriptions, medical debt, etc.

Ultimately, through this study we expect to learn more about the proportion of Californians who have LTSS needs. What proportion is using public programs/services? What proportion is using private paid services? What proportion relies on family/informal care? What proportion has unmet LTSS needs?

For those who use LTSS, we will assess what types of supports and services they use, what combination of services are they using, and how sufficient, how culturally and linguistically responsive and appropriate these supports are.

And for those with unmet LTSS needs, we will learn about the adverse consequences. What do these individuals go without? For example, how is unmet LTSS related to use of medical services (e.g., hospital admissions, ER use)?

#### **WHAT DATA GAPS MAY STILL REMAIN AFTER THE CHIS EFFORT IS COMPLETE**

The CHIS LTSS survey will address many, but not all data gaps.

The survey will provide descriptive information about general types of services and supports used, help received, but not about programs by specific name/funding source. As such, data will not evaluate program effectiveness per se – rather it will provide a portrait of service need and use; can provide participant assessment of what works best, what is essential to maintain independence, etc.

The household survey will also not provide information about LTSS and related health service expenditures.

Self-report data has its limitations – subjective by design, subject to recall bias/misinformation. On the other hand, the person with LTSS needs is best positioned to provide information about the sources of services and supports they access (or to disclose their lack of knowledge about these programs).

CHIS does not include individuals living in group quarters, such as institutional settings. We may get information, however, via proxy respondents for those unable to complete survey in non-institutional settings.

Sample size will be too small to generate certain County-level estimates of need – however, we may be able to generate some regional / pooled geographical estimates (e.g., compare people living in rural and urban geographies).

Point-in-time survey can be used to estimate service needs but cannot make causal claims – however, we can draw inferences from associations/correlations found in data. Also, the second survey cycle will enable us to identify potential trends – i.e. any notable changes between 2019-20 cycle and 2023-24 cycle.

### **Other information**

We also hope to tease out estimates of the proportion of the population at-risk for spend down, by identifying the characteristics of people who are most likely to spend down. We plan to use national data to develop a model (combination of variables/pattern) that identifies a profile of respondents who are at risk for “spend down” (e.g., some combination of increased illness or disability, declining income and assets, high out-of-pocket medical (and other) costs, lack of informal/family care/supports). We will apply the profile to similar respondents in the CHIS sample and then generate statewide estimates. In California, the high costs of housing (both mortgage and rental payments) may well need to be factored in to such a model.