



LTQA Webinar FAQ: Advancing Self-Direction in LTSS: Empowering Individuals and Mitigating the Direct Care Workforce Crisis

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Speakers:

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1. Does any of your research look at how people learn about/choose self-direction? Are there best practices for informing individuals of this option?

Current research does not deeply address how people learn about or choose self-direction, although it is a significant area for future work. Case managers or care coordinators play a crucial role in introducing self-direction, so it is vital to ensure that all eligible individuals hear about this option. Training case managers or care coordinators to present self-direction consistently and without bias is essential. Some states, like [Texas](#), use standardized tools such as introductory videos to provide neutral information and level the playing field for everyone. Often, people learn about self-direction from peers rather than through formal channels, highlighting the need for early and unbiased information dissemination.

In addition, care coordinators are the first point of contact and play a key role in ongoing conversations about self-direction. Ensuring they are well-informed and have access to internal resources and subject matter experts is crucial. Partnerships with organizations such as Applied Self-Direction can help managed care organizations (MCOs) integrate best practices nationally. Elevance Health systems also evaluate the effectiveness of these practices, ensuring they understand and improve the person-centered planning process and monitor self-direction trends to identify areas for process improvements. Data-driven strategies are essential for continually enhancing how we inform individuals about self-direction.

2. How should we square the circle between these great recommendations of this webinar and the legal environment that places additional requirements on the employer and Financial Management Services (FMS) to reduce risk?

Implementing recommendations within the constraints of legal requirements is challenging. Each state has significant discretion in designing its programs and operates under different rules and regulations. It's essential to understand the specific context and identify where flexibility exists. There are often misconceptions about federal requirements, such as background checks, which are not always mandated by the Centers for Medicare & Medicaid Services (CMS) for certain Medicaid waivers. Recognizing these flexibilities allows for more choice and flexibility within programs. Identifying necessary changes and understanding when advocacy is needed for issues like cumbersome enrollment processes are crucial steps in addressing these challenges.



3. Do the panelists have conjectures about why self-direction has decreased in California since 2011?

Self-direction enrollment in California has not decreased but rather steadily increased since 2011, as depicted below.

State	2011	2013	2016	2019	2023	Change from 2019-2023
California	480,000	450,374	540,190	606,078	726,304	19.84%

However, California’s share of the *total* national self-direction enrollment has decreased since 2011. California represented 60% of total self-direction enrollment in 2011, 56% of enrollment in 2013, 53% of enrollment in 2016, and 49% of enrollment in 2019. This decreasing percentage reflects a rise in national enrollment, as opposed to a decrease in California.

These and other findings can be found in the [2023 National Inventory of Self-Directed Long-Term Services and Supports Programs](#) for the AARP LTSS State Scorecard.

4. Can the panelists talk about why individuals with disabilities (especially those who self-direct) and disability-owned, disability-directed entities knowledgeable about self-direction are the best fit to conduct/provide the required information and analysis (I&A) in a state?

Often individuals and/or organizations that have lived experiences can bring diversity in insights on where there are opportunities to enhance the experience for other individuals that are self-directing. Self-directed programs can be complex to navigate; bringing perspective and understanding based on past/current experience into the I&A role can deliver supports that are grounded in processes that are individual and program-specific.

Additionally, these individuals and entities are usually equipped with unique comprehension of the nuance and complexities tied to disabilities, which can be beneficial in formulating the most practical and accommodating solutions. They are also likely to have established networks within the disability community, which is advantageous for disseminating information and gathering feedback.

Moreover, having disability-owned, disability-directed entities conduct I&A can inspire trust and confidence within the disability community, as their approach and understanding is likely to be inherently empathetic and inclusive. They are, in essence, supporting peers and thus, are driven by firsthand experience and a fundamental understanding of needs, challenges, and potential misconceptions.

For more information on why individuals with disabilities and disability-owned, disability-directed entities knowledgeable about self-direction are ideal to provide information and assistance and serve in other leadership roles in self-direction programs, consider viewing the recent webinar, [Participant-Direction in Health Payer Contracting for Centers for Independent](#)



Living, hosted by the Independent Living Research Utilization (ILRU). While it is geared towards a Centers for Independent Living (CIL) audience, it applies to all disability-led organizations.

5. Do the panelists have any insight into local programs that provide self-direction programs? For example, in Ohio there are several counties/organizations that have self-direction as a part of local levy-funded programs.

Each state and local communities have different programs around self-direction. Applied Self-Direction has a great resource on its website that provides an overview of programs within each State and links to the State resources appliedselfdirection.com/self-direction-programs/.

Two State examples are the WORK and STEPS programs within the [Working Healthy Program in Kansas](#), which is a Medicaid buy-in program. Both WORK and STEPS provide opportunities to access additional benefits, which are managed through a self-directed model.

However, the availability and specifics of these programs can vary by county, so it would be best to contact your local county office or the organization directly to get the most accurate information tailored to your specific needs.

6. Do the panelists see the recent New York initiative to move to a single statewide Fiscal Intermediary (FI) a step forward, step back, or neutral for self-direction?

Assessing the potential impact of New York's move to a single statewide Fiscal Intermediary (FI) is challenging at this stage, since it's a development that's still unfolding. The key focus of this transition would ideally be the continuity of care with a person-centered approach. Clear communication and comprehensive education about these changes are fundamental, along with a sensible timeline to ensure a smooth transition. The effectiveness of this transition will largely depend on a collaborative approach across all stakeholders and careful execution.

7. I have been self-directing for months now, my issue is finding resources for new caregivers. Do the panelists have recommendations?

If you're in search of more caregivers, it would be beneficial to check out the resources provided by your state and local authorities, which could assist in finding appropriate caregiver recruitment resources. There might be local platforms available where lists of potential caregivers are compiled. Some FMS entities make local worker registries available or your supports broker or service coordinator may have some suggestions for ways other individuals are locating workers.

Implementing best practices in recruitment can also be beneficial: (1) Begin by designing a job description that clearly outlines the responsibilities your caregiver will be expected to handle; (2) Once prepared, you can distribute this job description, permitting interested candidates to reach out to you; and (3) Potential platforms for posting the job description could include Facebook or other social media, job portals such as Care.com or Indeed.com, newspapers, or community boards. Some websites might charge a fee to post a job listing, but there may be programs that cover such costs. Therefore, it's worth discussing with your care coordinator to see what expenses your budget can include.

The following are useful resources for caregivers who are just starting out:

1. [AARP's Family Caregiving Resource](#): This website from AARP is loaded with articles, tips, and resources on various topics from health to housing that are tailored for family caregivers.
2. [The Alzheimer's Association](#): If you're caring for someone diagnosed with Alzheimer's, this can be a vital resource. The association offers online information and resources as well as an accessible 24/7 helpline.
3. [Caregiver Action Network](#): This is a free service provided by a nonprofit organization, delivering education, peer support, and resources to caregivers nationwide.
4. [Family Caregiver Alliance](#): This organization provides a wide array of online caregiving information and resources, operating programs at local, state, and national levels.
5. [The National Alliance for Caregiving](#): As a nonprofit coalition, they specialize in carrying out policy analysis and tracking national legislation related to caregiving issues.
6. [Eldercare Locator](#): A public service of the U.S. Administration on Aging, this connects you to local services for older adults and their families.
7. [Home Instead](#): This company offers non-medical home care services and companionship. Their website hosts a Help for Alzheimer's Families section.
8. [CMS](#): This government entity has developed free online training for individuals who self-direct their services, their family members, and representatives to use free-of-charge. This training includes content that may be particularly helpful both for recruitment ideas and training a new worker.
9. Local hospitals or care centers: Many of these facilities run educational seminars and support groups for caregivers.