

Strengthening the Long-Term Support Services Coordinator Role within One Care: A Qualitative Study and Analysis of the One Care Massachusetts Health Plan

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Executive Summary

This brief provides a snapshot of work completed in a qualitative study of One Care—the Massachusetts plan serving persons between the ages of 21 and 64 who have both Medicaid and Medicare, who are known as “dual eligibles.”¹ The research had three goals: (1) learn about the effectiveness of One Care Long Term Support Services Coordinators (LTSCs) from members who have experience working with an LTSC; (2) use project data to develop policy recommendations to improve the implementation of the LTSC role; and (3) elevate the perspectives and voices of people with lived experience of disability, using Community-Based Participatory Action Research (CBPAR) as a model for empowerment. The use of CBPAR as an empowerment model will be highlighted in a separate brief that will outline the experiences of the Lived Experience (LE) experts who conducted the research project.

LTSCs are conflict-free, meaning they work with One Care members but are not paid directly by the member’s care plan. The purpose of an LTSC being “conflict-free” is to decrease the risk that a member’s care coordination could be motivated by self-interest or the plan’s interest rather than by the member’s best interest.² Thus, LTSCs are members of integrated care teams. Teams usually include medical providers and may also include behavioral health professionals; however, teams do not consistently include persons with expertise in independent-living skills and principles.³ LTSCs are contracted by One Care plans from Independent Living Centers (ILCs),⁴ Recovery Learning Communities (RLCs),⁵ or Aging Services Access Points (ASAPs).⁶ LTSCs are unique to One Care and, by statute, all One Care members have the right to include an LTSC on their integrated care team.

The data in this brief comes from interviews conducted by three LE experts. All LE experts completed the Collaborative Institutional Training Initiative (CITI Program) and supplemental training. The LE experts were also provided training by the Disability Policy Consortium (DPC) and Brandeis University staff on qualitative interviewing, data analysis, and evaluation. The research was conducted according to Brandeis University’s Institutional Review Board protocol requirements and overseen by a Research Advisory Committee (RAC) composed of experts in the field of disability research and interviewees from the disability community.

This brief includes a qualitative analysis of 30 One Care members, two LTSCs, and four One Care plan representatives. It offers recommendations to: (1) create an LTSC training program that strengthens the LTSC role as an advocate with expertise in independent-living skills and principles; (2) require regular training of LTSCs, care coordinators, and utilization-management staff by an ILC or other community-based organization (CBO)⁷ run by and for persons with disabilities; and (3) rebrand the LTSC role.

Background

Disability discrimination and bias within the healthcare industry is well documented. Medicare primarily covers direct medical costs associated with hospitalization or direct services for preventing hospitalization, e.g., outpatient doctor visits. Medicaid is a beneficence-based health insurance model that covers long-term services and supports (LTSS) for people needing assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) in addition to other services. Because of the difference in emphasis between Medicaid and Medicare benefits, people with high ADL needs are at high risk of long-term institutionalization unless large financial investments are made in community-based LTSS.

Given the high risk of increased harm to persons with disabilities in managed care, disability advocates in Massachusetts created Disability Advocates Advancing Our Healthcare Rights (DAAHR), a coalition of 20+ disability and allied organizations in Massachusetts that was formed in 2011. DAAHR advocates for person-centered, culturally appropriate healthcare and community-based services that advance health equity and the opportunity for persons with disabilities to live meaningful lives in community settings.⁸ DAAHR was concerned that managed-care plans would reduce consumer choice, control, and healthcare quality, leading to increased health inequities and reduced quality of life. It cited concerns about closed provider networks, restrictive utilization-management practices, and pervasive medicalized perceptions of persons with disabilities. Embedded in these concerns was a general apprehension about the sheer power of the medical insurance industry and its potential to silence consumer voices.

To protect consumer voice and the fundamental rights of persons with disabilities in the new managed-care system, DAAHR successfully advocated for a law requiring all

One Care members to have the right to choose a conflict-free LTSC as part of their care team. The LTSC is required to have experience of disability or expertise in independent living and recovery principles. The goals of having an LTSC on care teams include:

- Advocating for person-centered innovation and utilization-management and care coordination that supports the pillars of the disability rights movement: choice, control, and dignity of risk. Each of these pillars is critical to protecting the human and civil rights of persons with disabilities within the medicalized health system.
- Disrupting the status quo of medical care by assisting members in developing personal agency, with their increased control of and engagement with care goal-setting and ownership of their health and wellness goals. At the most basic level, the role of the LTSC is to prevent persons with disabilities from suffering harm resulting from historical discrimination and ongoing bias against this population by healthcare providers and the larger healthcare industry.

LTSCs are responsible for assisting the member in finding an LTSC that fits each member's needs. The independent-living LTSC is a conflict-free member of an individual's care team responsible for promoting care guided by independent living and recovery principles. Integrated Care Teams⁹ include a care coordinator and a primary care provider. A primary responsibility of the LTSC is to support the member's agency and their ability to self-advocate for their needs with their care team and in the care-planning process. This means that the person's needs and preferences are known and communicated at the right time to the right people and that this information is used to ensure that the individual gets the services and supports needed to maximize their opportunity to meaningfully engage in the community in the manner of their choosing. In practice, this should begin with the person, the care coordinator, and individuals identified by the person as key participants in their care team. These can be paid and unpaid members including but not limited to a community health worker, a psychiatrist, a close friend, or a family member. Acting as a collective under the leadership of the person, the care team creates a person-centered care plan that outlines services and supports to be given to the person to aid the person in achieving their medical, social, and other goals.

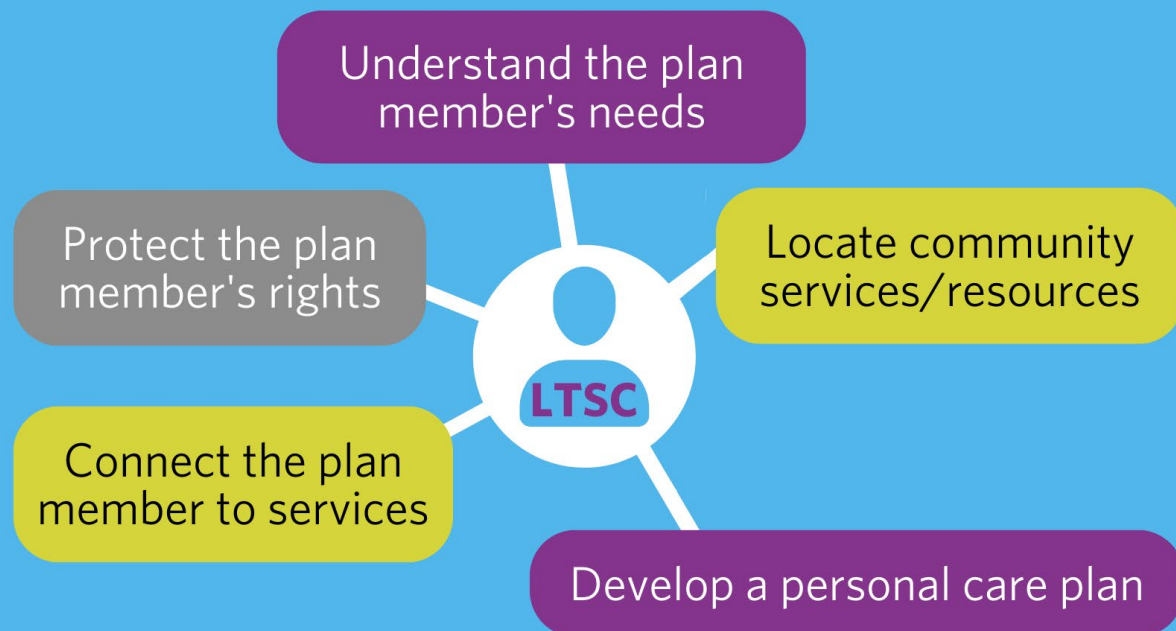
It is important to note the current limitations and understand how the LTSC is implemented. First, the authority of the LTSC to acquire services for members is limited to utilization-management systems within the plan. Second, while statutorily required, there was insufficient guidance given to the plans and contracted CBOs providing LTSCs on the LTSC role, which has led to inconsistency in how LTSCs interacted with members, the care teams, and the One Care plans.¹⁰

Since its implementation, advocates have voiced concerns about the effectiveness of the role and its fidelity to the original vision. In a document sent to then-Secretary Bigby of Health and Human Services for the Commonwealth of Massachusetts, DAAHR outlined concerns about how the state envisioned implementing the LTSC role. As stated in a letter:

“ The [initial One Care] RFR [Request for Response] does not contain any guidance on how care coordinators will be trained about cultural competency as it particularly relates to the provision of the LTSS.

While there has been some increased guidance, the percentage of One Care members who actively engage with LTSCs remains low. Presentations to the One Care Implementation Council by plans, LTSC-provider CBOs, and anecdotal evidence gave credence to concerns. In response to concerns about drift in the LTSC role, the DPC, in partnership with Brandeis University’s Lurie Institute for Disability Policy and Community Living Policy Center, both located within the Heller School for Social Policy and Management at Brandeis, started an independent-living research project aimed at: (1) establishing a baseline understanding of how the LTSC role is functioning in One Care from the perspective of One Care members and key stakeholders; (2) strengthening the One Care Independent Living (IL) coordinator role; (3) strengthening the whole-person approach to disability and recovery in One Care; and (4) increasing community capacity to engage in CBPAR. In keeping with DPC’s commitment to “about us, by us” and the principles of CBPAR, the project was designed, implemented, and analyzed by persons with disabilities.

Under One Care, a Member's Integrated Care Team Includes a Long-Term Services Coordinator (LTSC)



- **LTSCs work for the One Care plan member, not for the One Care plan.**
- **LTSCs should be independent and "conflict-free."**
- **They have experience in disability and/or a background in independent living and recovery principles.**
- **Their role is to advocate for the plan member's needs.**

Methodology

Outreach was conducted with 10 ILCs, 30 ASAPs, and five RLCs via phone and email. An information session with ILC leadership was held in partnership with the

Massachusetts Statewide Independent Living Council (MASILC). Information about the project was also disseminated through DPC's social media (Twitter and Facebook) and through DPC's weekly newsletter. The DPC research team also conducted three presentations to the One Care Implementation Council.

A total of 27 interviews were conducted with One Care members who have worked with an LTSC: 20 interviews from ASAPs, five interviews from ILCs, and two interviews with members who self-identify as culturally Deaf and receive services from Deaf and Hard-of-Hearing Independent Living Skills programs (DHILs). In addition to One Care members, interviews were conducted with other members of the care team: four CCA plan interviewees, two Tufts Health plan interviewees, and four LTSC interviewees. Interviewees were asked about their understanding of the LTSC's role, the LTSC's involvement in care teams, and the quality of the LTSCs. Interviews lasted between 40 minutes and one hour and interviewees were given a \$50 gift card.

Discussion

Different One Care plans have different titles for care coordinators, e.g., "care partner," "care manager," and "care navigator." In addition, members of One Care may have more than one care coordinator. This leads to tremendous confusion. A member might have multiple coordinators, but identify a physical therapist or medical specialist as their coordinator. This brief always uses the term "care coordinator" to distinguish a broader function from the role of the LTSC.

Distinct from other coordinators, the primary responsibility the LTSC is that of an advocate and not simply a coordinator of covered services. The interviews provide a mix of perceptions of how One Care plans and LTSCs are maintaining fidelity to the initial goals of the disability community. Consumer interviews reaffirm the importance of relationship and trust as essential to successful engagement between a member, their care coordinators, and their care team.

Experience with LTSCs

Analysis of the member interviews shows that LTSCs positively impact the lives of many of the member interviewees in this study. Member interviewees described having positive relationships with LTSCs, which seemed to correlate with interviewees feeling cared for by their LTSC. In addition to member interviewees

reporting feeling an LTSC's caring presence, member interviewees also discussed specific ways that LTSCs assisted them in accessing services:

“ [The LTSC] took the time out to help me, you know, let me know the resources I needed or any of the doctors that accept and offices that accept my insurance, so I didn't have to go through this work myself. [S]he mailed it out, it was very helpful.

In general, the majority of interviewees were satisfied with their health plan. A member interviewee talked about the importance of the LTSC helping the member solve problems by making phone calls and setting up services with a new home health aide. The LTSC ensured that the person had food in the house and helped with transportation complaints. The interviewee felt the LTSC was helping them to increase their sense of independence. One of the more positive responses provided a description of One Care this way:

“ [W]hen I was introduced to One Care, I wasn't too sure what it was and when I found out that it was very supportive, it was very good, positive.

Consistency in communication and member trust in provider organizations are essential factors in the successful implementation of the LTSC role. Interviewees expressed confusion when speaking of the distinctions between the LTSC and their care coordinator, bringing to light potential role-redundancy issues:

“ Yeah, and that just like goes to the LTSC and the *care coordinator*, because, well, my *care coordinator*, they're very nice people. It feels kind of—I don't see how the LTSC is any different than the *care coordinator* in some ways because of that.

This interviewee also made recommendations for improving the process:

“ [B]etter define what roles the LTSCs specifically are good at. So, maybe we could pinpoint what they'll be helpful with.... [A] lot of [care coordinator responsibilities] are overlapping...and if I knew...what they're really good at...then I'll always go to them when I need that type of thing.

Despite best efforts to ensure the LTSC acts as a conflict-free advocate for the member, it seems LTSCs may routinely be absorbed into the medical framework of

health plans, e.g., simply coordinating plan-approved services rather than getting the member what they really want or need in terms of community-living services.

The quality and consistency of communication was influenced by the COVID-19 pandemic as well. According to interviewees, COVID-19 was extremely detrimental for communication with all the members of care teams, including LTSCs. The importance of the relationship between the member interviewee and their LTSC was imperative. Loss of communication during the pandemic was expressed by one interviewee. The negative impacts of COVID-19 on communication and access to services was a common theme expressed by interviewees.

A significant finding of the study was that LTSCs addressed services not traditionally identified under the umbrella of LTSS. LTSS needs are often intersectional and include members' social determinants of health (SDOH) service needs, including food and housing. All in all, there appeared to be a consensus among both members and plan interviewees that the LTSC plays an important function in care teams and in the lives of members when the role is implemented in a consistent manner. Even member interviewees who had positive experiences with LTSCs expressed the need for someone they could trust within their health plan.

The interviews also emphasized the need to further examine the degree to which LTSCs are expanding member agency and ability to articulate choice, exercise control, and achieve dignity of risk beyond the most basic hierarchical needs.¹¹ There was also no evidence that LTSC assessments considered members' value systems, nor did they seem to promote member self-awareness related to larger life goals. LTSC training was raised by several interviewees—while all agree on the need for training, there was no consistent view on the content of the training.

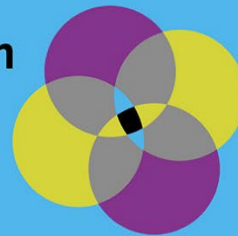
LTSCs and One Care Plan Interviewee Perspectives

Gathering information from LTSCs actively working with One Care members and interviewees was also important to the research process. As with member interviews, information gathered from interviews with LTSCs and plan interviewees are not generalizable. However, the information yields helpful recommendations in

The LTSC Is an Important Member of the Integrated Care Team

To be effective, there must be:

- **Plan Member Trust of the LTSC**
- **Maintenance of the LTSC's Independence from the Medical Framework of the Health Plan**
- **Consistent LTSC Training and Implementation of the LTSC Role**
- **Reliable Communication Between the LTSC and the Plan Member**
- **Understanding of the Intersectional Needs of Plan Members and Other Social Determinants of Health**
- **LTSC Understanding and Advocacy of the Full Range of the Plan Member's Needs, Values, Choices, and Goals**



considering the next steps for improving the role of the LTSC and advancing the operationalization of independent-living philosophy and recovery principles within One Care.

In general, plan interviewees described many positive aspects of LTSCs. Interviewees discussed at length the connection that ASAPs and ILCs have with the community. It is because of these existing relationships that they were able to connect with members. As noted by one plan interviewee:

“ I think that because of the breadth of the agency that we’re contracting with between the ASAPs and independent living centers...their knowledge of the community services, and ability to, sort of, partner with the members is...LTSCs can be, I would say, sometimes more accessible, and able to, able to connect with the members.

In general, plan interviewees did not have a uniform understanding of the role of the LTSC or knowledge of independent-living philosophy and recovery principles. The scope of the LTSC role seemed limited to specific services identified in the plan as covered services. A response by one LTSC reflects the perspectives of other LTSCs and plan representatives that may stray from consumer control; thus keeping with the medical model of care rather than an independent-living or recovery model.

One LTSC spoke of the need for increased transparency in how the LTSC option is offered and the amount of attention paid to the LTSC within early care-coordination efforts. The LTSC also echoed frustrations raised by member interviewees connected to the inability to access services due to a network inadequacy: The LTSC spoke about the many limitations faced when attempting to connect a member with services.

“ ...but listen, if you can’t get services for someone, it’s sort of like housing or transportation. There’s a big housing need. There’s a big transportation need. But there’s not a lot of resources out there or available housing units to get someone into. The same

thing with services. If there's no providers that can go in there, I don't know what we're supposed to do. And it's really a helpless feeling sometimes when someone really needs it and you can't find anyone. You've called 20 different homemaking agencies and they all say either they don't have capacity or they don't take One Care members.

The same interviewee described areas of concern that included quality of the agencies with whom their plan contracts and the potential benefits of increased training provided by MassHealth to strengthen the role of the LTSC.

The plan interviewee mentioned above also talked about the importance of face-to-face, in-person relationships as core to the One Care Model and provision of appropriate care coordination. Another plan interviewee described ASAPs and ILCs as having different strengths and weaknesses, stressing that it would be helpful if there were increased collaborations between LTSCs and care coordinators.

As was mentioned above, while LTSCs can express concerns and frustrations and make recommendations about their ability to deliver services, the fact remains that they are not ultimately in charge of such decisions. Other systemic limitations that bar LTSCs from providing needed services, such as lack of available housing, are beyond the control of LTSCs and the organizations that employ them.

Recommendations

Using the analysis of the interviews, documentation from the One Care Implementation Council, and DAAHR, this brief offers several recommendations. The purpose of these recommendations is to strengthen the capacity of the LTSC to: (1) accompany One Care members in their journey to increased agency and wholeness; (2) disrupt the status quo of healthcare as a mediator of bias and discrimination; (3) coordinate services of One Care members to support their ability to live lives of meaning in the community.

- Work with policymakers to ensure the LTSC role is fit for purpose. That is, the design of the LTSC, the LTSC job description, and the expectations of the LTSC could advance independent living principles for the individual and the longer-term goal of systems transformation.
 - Brand the LTSC role to ensure that messaging to One Care members, care coordinators, and other stakeholders is clear and consistent.
 - Ensure all advocates share the same understanding of the LTSC role, its purpose and goals, and the expected impact on One Care.
 - Articulate more clearly how the intersection of SDOH and LTSS impact health access and health outcomes for persons with disabilities.
- Engage with MassHealth and other stakeholders to:
 - Create a central ongoing training for LTSCs, care coordinators, and utilization-management team members. The training entity must be a conflict-free non-profit organization run by and for persons with disabilities and have direct working knowledge of One Care.
 - Ensure the training includes practical guidance on cultural competence in assessing and providing LTSS and cultural humility.

Limitations of the Study

The research was conducted using a convenience sample. Therefore, the findings are not generalizable to all One Care members who have experience with LTSCs in One Care. Without representation from all three organization types (ASAPs, ILCs, and RLCs), it is not possible to compare the quality of LTSC services provided to One Care members across providers. Additionally, interviews were conducted only in English and American Sign Language. Furthermore, some interviewees seemed

unclear about the role of the LTSC, unable to distinguish the role from the care-team care coordinator. Other interviewees were unclear about the One Care model and the concept of care coordination. This confusion made analysis of the data challenging. For example, if an interviewee could not clearly distinguish their care coordinator from the LTSC, it was not possible to attribute a positive or negative experience directly to the LTSC or another member of the care team.

Perhaps the most prominent limitation that impacted the research was COVID-19. As identified by researchers globally, “time constraints” and “physical distancing” limited our capacity to carry out high-quality research.¹² Another limiting factor was the impact of COVID-19 on organizations serving persons with disabilities. Persons with disabilities experienced high levels of isolation from the beginning of the pandemic.

Notes

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