

Introduction

This brief provides information about a unique intervention called the Long-Term Services and Support Coordinator (LTS Coordinator). Disability advocates worked with federal and state policymakers to establish the LTS Coordinator to advance the Independent Living (IL) Philosophy and Recovery Model for people with disabilities who are enrolled in an integrated care plan under Massachusetts' One Care Program. One Care is a capitated financial alignment demonstration program also known as the Massachusetts duals demonstration. Plans in One Care are responsible for delivery and management of all covered medical services, behavioral health services, Long-term Services and Supports (LTSS), additional community support services, and care management for enrollees.

One Care currently consists of two health plans established to integrate Medicare (Commonwealth Care Alliance, Tufts Unify) and Medicaid benefits for people covered under both Medicare and MassHealth. MassHealth is the name of the state's Medicaid program. One Care plans currently provide care to about 26,000 enrollees covered under Medicare and MassHealth who usually present with a range of chronic conditions and disabilities including behavioral health (BH) and long-term services and support (LTSS) needs. [1] [2]

The LTS Coordinator was established to: (1) provide all One Care enrollees with access to a conflict-free expert in IL and recovery principles to coordinate their LTSS; and, (2) to shift the care team's approach from a medical model to a more dynamic and responsive whole-person-centered model.

Background

The Patient Protection and Affordable Care Act (ACA) included provisions to better align Medicare and Medicaid regulations, policies, and operations to reduce cost and increase quality of care. The "Financial Alignment Initiative" (FAI) offers states several models for alignment between Medicare and Medicaid. All states are required to include rebalancing measures to reduce reliance on institutional care, preventable emergency department visits and hospitalizations by investing in LTSS. [3]

One model is capitated managed care. In the capitated managed care model, a state Medicaid program and CMS enter into a three-way contract with selected health plan(s). Plans are paid capitation rates from Medicare and state Medicaid in exchange for the plans' responsibility to provide enrollees with access to all Medicare and Medicaid benefits and to provide comprehensive, integrated and coordinated care. Capitation rates include all LTSS spending. By providing better aligned funding streams, plans have greater flexibility in spending on Medicare and Medicaid payments.

Massachusetts Context

MassHealth, the Medicaid program in Massachusetts, applied to establish a capitation rate established by FAI model in 2011. At the same time, disability advocates and allies came together to form Disability Advocates Advancing Our Healthcare Rights (DAAHR) to promote the rights of consumers in the development of the managed care model. In 2013 One Care, the Massachusetts dual eligible demonstration, was launched.

Population impacted by the demonstration:

- Approximately 115,000 dual eligibles aged 21-64. **[1]**
- The majority live in their communities, not institutions. **[1]**
- Nearly 60% have diagnoses in two or more of three major diagnostic categories (physical, behavioral, and developmental). **[1]**
- Approximately 65% have behavioral health issues. **[1]**

Expenditures

- Medicaid spent \$1.3 billion on the population while Medicare spent \$1.2 billion. **[4]**
- 6% of dual eligibles accounted for 30% of combined Medicare Medicaid expenditures on duals. **[4]**
- 70% of duals had an annual per capita expenditure by Medicaid and Medicare of less than \$20,000. **[4]**
- 72% of Medicaid spending was for duals requiring long-term supports in the community. **[5]**

Identified unmet needs in the population:

A study on unmet home and community-based services (HCBS) among working-age adults with disabilities in Massachusetts provides evidence of need for enhanced care

coordination that is currently not available in the fee-for-service system (FFS). [6] The research, published in the Disability and Health Journal, October 2011 found that in addition to unmet IADL services, the most prevalent unmet needs identified included information about disability-related services and legal rights, the need for primary, specialty, mental health care, and case management services. [6] The research further found a high prevalence of unmet needs for HCBS was high, with over two thirds of respondents reporting a minimum of one unmet need and over 25% of respondents reporting four or more unmet needs. [6] Unmet needs identified include ADL and IADL needs, transportation, habilitation services (i.e physical and occupational therapy, assistive technology and home modifications). [6] The recommendations included enhancing access to in-home supports and improving access to informational services and benefits. People with disabilities are disproportionately represented among all people experiencing homelessness, this includes nearly one-quarter who experience chronic homelessness. [17] More than two-thirds of people with disabilities who experience chronic homelessness have no access to emergency shelters. [17]

Additionally, people who comprise this population experience direct and de facto discrimination requiring statutory protections under the Americans With Disabilities Act (ADA), and further protections contained within the Supreme Court's Olmstead decision. [14] As such, it is important to highlight the fact that dually eligible people with complex needs rely on robust culturally appropriate and whole-person-centered LTSS to live meaningfully in the community and realize the rights afforded to them under the ADA and Olmstead decision.

Disability Advocates Advancing Our Healthcare Rights (DAAHR)

In response to the national move towards managed LTSS, and the more immediate decision by MassHealth to move forward with the duals demonstration, disability advocates and allies in Massachusetts established DAAHR in 2011. Spearheaded by the Disability Policy Consortium (DPC) in partnership with the Boston Center for Independent Living (BCIL), DAAHR was created to ensure the voice of the disability community was engaged at every level of the health reform being undertaken by MassHealth.

DAAHR endorsed the creation of the capitated managed care model believing it provided opportunities for innovation in whole person-centered care and enhanced LTSS not available in FFS. Such innovations had potential to increase health equity and reduce disparities for people with disabilities. Advocates also believed success of MLTSS was contingent on two factors:

- The active voice of people with disabilities and lived experience-based expertise at the table working in partnership with MassHealth and,

Disability Advocates Advancing our Healthcare Rights (DAAHR) Achieved Several One Care Successes and Established Innovations

Innovation 1. IL-LTSS Coordinator. The requirement of Independent Living Long-Term Services and Supports (IL-LTSS) coordinator being available to all One Care members as a means of promoting a whole person-care across the spectrum of the person's needs in integration of medical and nonmedical services.

Innovation 2. Consumer-led Implementation Council (IC). The One Care IC remains one of only two councils of its kind in the country.

Innovation 3. Independent Ombudsman. One Care includes an independent ombudsman program that integrates IL and recovery principles as fundamental elements of person-centric care.

- Measurable impact of participation of the disability community on the demonstration as measured by the integration of independent living philosophy and recovery principles in the capitated model.

DAAHR leadership was also pragmatic; based on national trends and the strong footing of managed care in Massachusetts, they predicted plans, driven by the desire to realize short-term return on investment would restrict access to appropriate medical care while also limiting access to adequate and appropriate LTSS, mental health, substance use disorder and other community-based services rooted in lived experience and decades of advocacy.

DAAHR recognized in the duals- demonstration was a once in a generation opportunity to advance the human and civil rights of people with disabilities in healthcare. These opportunities included:

Innovating whole person-centered care planning that supports a person's opportunity to grow in personal agency, and aspiration to meaningfully engage in the community through socialization with friends and family, volunteering, employment or other means.

- Leveraging financial alignment resources to put in place mechanisms that rebalances spending to optimize access to goal-centered choice of LTSS.
- Operationalization of independent living philosophy and recovery principles at all levels of the managed-care system.
- Integration of care planning and implementation between medical providers and grassroots community-based organizations e.g. Independent Living Centers (ILCs), Recovery Learning Communities (RLCs), Aging Services Access Points (ASAPs).
- Promoting safeguards that expand transparency and accountability.
- Advancing the science of measuring the quality of LTSS generally, and MLTSS in particular.

DAAHR held to the fundamental belief that the managed care model should prioritize increased health and wellness that includes meaningful engagement in the community. be guided by; to do so requires a commitment to policies, practices, and procedures that maximize the opportunity for health and wellness of the most vulnerable, medically complex populations eligible to participate in the new plan. It committed itself to measurably impacting the development, implementation and evaluation of health reform. These measures included the ability of DAAHR to:

- Stay true to addressing the concerns of the grassroots consumer voice,
- Continue collaborative engagement with MassHealth and CMS,
- Shape the three-way contract between MassHealth, CMS and other plans.

As a first step, DAAHR engaged the disability community at the grassroots level, holding a number of forums in eastern and central Massachusetts. Each forum drew hundreds of consumers, community service providers, representatives from MassHealth, CMS and potential health plans. The forums generated elicited concerns on a range of topics:

- Loss of consumer choice, control and dignity of risk.
- Withholding of medical services.
- Loss of continuity of care.
- Reduced access to specialists.
- Reduction in personal care attendant hours.
- Worsening of quality and access to durable medical equipment (DME).
- Erosion of independent living and recovery learning community system.
- Denial of privacy rights.

In response to direct input from forum attendees, disability leaders, and allies, DAAHR established a broad set of guiding principles to guide its advocacy efforts. These principles included a call for: (1) culturally competent care that addresses health disparities, person-centered care directed and led by the individual, (2) upstream preventative strategies to address risk factors leading to secondary disability, (3) financial incentivization of plans to integrate independent living and recovery principles across MCO systems, (4) quality of care enhancement strategies, and (5) innovation in quality measures to address quality measurement gaps, LTSS in particular.

It is important to note that cultural competence was an important value infused into the advocacy of DAAHR. Representatives from DEAF culture were consistently engaged in DAAHR activities both at forums and targeted outreach; similarly DAAHR took seriously the cultural needs of cultural groups whose first language is not English.

The Master-Feltin Model: A Framework to Build On

- design care planning in a manner that places the focus on the unique human dignity of each person
- prioritize prevention of secondary disability through investment in LTSS and other community services,
- give people direct access to decision-makers with credentials needed to make medical decisions and provide care in real time e.g. Nurse Practitioners and Physician Assistants
- entrust care teams with decision-making authority, and if present, streamline prior authorization processes entrusting final decision-making to the care team,
- medical doctors worked at the top of their license in people's homes, addressing the medical and social needs of the individual,
- strong, trusting relationships formed between the person and their care coordinator were the bedrock of this model of care that worked to keep people well and out of the hospital and nursing homes. person integration of medical and nonmedical services.

DAAHR pressed for a capitated care model committed to the high-touch, whole-person capitated care model initiated by Dr. Robert Master and Dr. Marie Feltin; this model of

care was foundational to the Boston Community Medical Group. The goal of BCMG is to promote the human dignity of people with complex medical needs and under the leadership of Dr. Master (in partnership with BCIL and Health Care for All), BCMG grew in scale to become Commonwealth Care Alliance (CCA). [7]

Dr. Master and his colleagues supported the dual-eligible demonstration believing that the managed capitation demonstration with appropriate funding had the potential to greatly enhance their ability to address the needs of a larger cohort of people with complex needs. DAAHR hoped that the Master-Feltin model would flourish under capitation and innovate new models of person-centric care in other capitated plans. [7]

One Care: An Integrated Model of Care

Enhanced services, including:

- One person to coordinate your care
- A personal care plan
- All prescriptions through one plan
- No co-payments for covered prescription and over the counter medications
- More options for:
 - Dental services Vision services
 - Community support services
 - Behavioral health services

AND

- An LTS Coordinator
- Medical equipment, supplies, and repair
- Nonmedical transportation
- Personal assistance services
- Other services also available include complementary medical services (acupuncture, massage etc.), home modifications, habilitation services including physical therapy, occupational therapy and more based on personal care goals care team authorization.

Now in its sixth year, One Care is an integrated plan with an established model of care that includes an assessment and a person-centered care planning process. The plan brings Medicare and Medicaid covered services together under a capitated managed care financing model with risk protections for plans. People eligible for One Care are

eligible for Medicare and Medicaid (also known as dually eligible people 21-64 years of age). Those eligible for One Care are diverse in race and ethnicity with a range of disabilities including physical, intellectual/developmental, serious mental illness, substance use disorder, multiple chronic illnesses, functional or cognitive limitations and have high levels of needs for long-term services and supports/behavioral health. As of 2019, One Care consists of two plans: Commonwealth Care Alliance (CCA) and Tufts Health Unify. **[4] [8] [9]**

One Care is the only duals-demonstration in the country that limits eligibility to dual eligible people, 21 and 64 years of age. Adults who are dually eligible are among the highest-costing populations with the greatest medical, behavioral health, LTSS, and social determinant of health (SDOH) needs in this nation. **[4] [8] [9]** By focusing on those aged 21-64, MassHealth established a unique opportunity to innovate best practices in recovery services and the operationalization of the social model of disability in healthcare. As an important note, the focus on this population and associated commitment to rebalance and provide for enhanced, whole person-centered policies and practices to bring about health and wellness at the community and individual levels.

MassHealth took seriously the requirement by CMS to integrate stakeholders into the development of the duals-demonstration. The commitment of MassHealth, coupled with the strong investment and advocacy of the disability community led to a number of innovations.

These include contractual language requiring:

- All interdisciplinary care team members to participate in “training on the person-centered planning processes, cultural competence, accessibility and accommodations, independent living and recovery, and wellness principles;” **[8] [10]**
- Plans provide “Qualified peer support for Enrollees with mental health and substance use disorders to assist such Enrollees in their recovery, and for Enrollees with physical disabilities to assist such Enrollees in the pursuit of independent living; and...Community supports for newly housed Enrollees who have experienced chronic homelessness.” **[10]**
- ‘Coordination of care within the Provider Network, including instructions regarding policies and procedures for maintaining the Centralized Enrollee Record...Assisting disabled Enrollees to maximize involvement and decision making in their own care...Maximizing the independence and functioning of Enrollees with disabilities through health promotion and preventive care”. **[10] [11]**

The LTS Coordinator is an advocate for transforming the medical definition of disability from a sickness model to a whole-person-centered model. The inclusion of the LTS coordinator in One Care is the result of robust grassroots advocacy. Advocacy efforts included persistent communication and education of federal/state legislators about self-determination and meaningful community as essential elements of care integration, as well as ongoing negotiation with MassHealth CMS on the final statutory language that was eventually passed by the Massachusetts legislature.

Key Objectives of the LTS Coordinator

1. Act as change agents, promoting the social model of disability in care plan goal setting.

Educate care team members on whole person-centered care that advances health and wellness goals in keeping with IL and recovery principles

2. Provide conflict free supports and services that advance consumer choice, control, dignity of risk, community engagement and hope.

3. Promote equity and reduce disparities in access to LTSS that may result from de facto bias based on diagnosis, race, ethnicity, gender, gender identity, sexual orientation.

4. Strive to provide members with LTS coordinators who have experience-based expertise in independent living philosophy and/or recovery principles e.g. Certified Peer Specialists (CPSs), Certified Recovery Coaches (CRCs).

Reasons put forward by the disability community for inclusion of the LTS coordinator:

- Perceived discrimination within the healthcare delivery system. **[12] [13]**
- Disparities in health outcomes. **[11] [14] [15]**
- The Minimum Data Set-Home Care (MDS-HC) – the initial onboarding and yearly clinical screening system used by plans to determine services needed by enrollees is a mix of standardized and proprietary questions. This poses three immediate challenges:
 - The MDS-HC is conducted by clinical nurses who may lack the cultural competency required make determination of need for people with LTSS, recovery or other social needs.

- Because there are questions in the MDS-HC that are proprietary within each plan, it is a challenge to determine the reliability of the questions used in assessing enrollee needs.
- The algorithms that determine medical necessity of services within the MDS-HC may focus on reduction of preventable emergency department visits, hospitalizations and institutionalization, but not address key upstream needs of enrollees. These include low-level depression and isolation.

The LTS coordinator is expected to work with care teams to advance person-centered LTSS that builds enrollee agency and supports the basic tenants of IL philosophy and recovery model. These basic tenants include consumer choice, control, dignity of risk, purpose, and relationships. The LTS coordinator is:

- a full member of an enrollee’s in care team.
- to serve as a change agent, advocating for LTSS that supports the ability of an enrollee to achieve goals established in the enrollees care plan.
- is to advance care team competency in IL philosophy and the primacy of consumer choice, control and dignity of risk.

Operationalizing the LTS Coordinator: A Mixed Picture

The LTS coordinator role has received wide-ranging support from MassHealth, CMS and One Care plan; however, the role remains a challenge. Key stakeholders, including RTI International (the federal evaluators of One Care), the One Care IC, and consumers attending DAAHR forums have identified a number of themes that continue to act as barriers to the full integration of the LTS coordinator into the One Care model.

Challenges identified by stakeholders include:

- Descriptions of the LTS coordinator contained in enrollee materials do not fully capture the richness of the role.
- One Care plan staff may not understand the critical role the LTS coordinator and community-based organizations have in providing truly integrated care to enrollees.
- Enrollees may not be receiving person-centered LTS coordinator services that advance IL and recovery principles. This may occur due to different understandings of the LTS coordinator role across providers, plans and care teams.
- Enrollees may not be receiving accurate or comprehensive definitions of the LTS coordinator role by care coordinators.

- Limited number of LTS coordinators with CPS certification for Recovery Coach Certification (RCR), substance use disorders, trauma, mental health diagnoses or developmental disabilities. The lack of lived experience or expertise is a risk that may lead to inequities in access to person-centered culturally appropriate LTSS.

Successes

Along with challenges, there are also successes to note. Presentations by One Care plans, Independent Living Centers (ILCs) who were present at One Care IC meetings (as well as testimonies at DAAHR forums by One Care enrollees) sheds light on a number of innovative interventions; several examples of collaboration between the LTS coordinator and care teams drive home the evolving nature of the LTS coordinator role. LTS coordinators are:

- Developing trusting relationships with One Care enrollees by being present with them in their homes and listening to their concerns through an IL lens. The result, the LTS coordinator and enrollee develop unique solutions to address LTSS needs, e.g. treating a pile of laundry on the floor not as a problem to be solved by offering laundry service, but understanding that the enrollee wants to do his own laundry that requires a minor adaptation to his wheelchair or the laundry machine.
- Addressing enrollee needs at the intersection of SDOH needs and LTSS. Disability advocates have long noted the intersection of adequate accessible housing as an unmet need for people with disabilities. LTS coordinators are working with One Care enrollees to help them transition from homelessness, substandard living, and housing with access issues to accessible housing units.
- Overcoming barriers preventing a One Care enrollee from engaging in his care plan. A One Care enrollee, for example, was resisting to being away from home to have a medical procedure conducted. The LTS coordinator identified the enrollee's concern over her pet as the reason for not wanting to leave the house overnight. Working with the enrollee, the LTS coordinator was able to find someone to care for the animal and give the enrollee the ease of mind needed to have the procedure done.
- Facilitating care coordination and collaboration with the plan care coordinator. Plans and LTS coordinators (in addition to enrollees) have provided numerous examples of truly integrated care. For example, One Care plan care coordinators reaching out to the LTS coordinator to work collaboratively on meeting the unmet LTSS needs of an enrollee to support opportunities to meaningfully engage in the community. The LTS coordinator made the arrangements for transportation and other services needed for this enrollee to engage in a community sailing program.

One Care 2.0 Raises the Level of Importance of the LTS Coordinator

MassHealth is in the process of re-procuring One Care under the title “One Care 2.0.” One Care 2.0 will be launched in 2021. MassHealth aims to grow the program to scale by procuring up to five One Care plans and triple current enrollment. Disability advocates endorse extending the One Care demonstration and remain committed to ensuring continued integration of independent living, recovery principles, and One Care 2.0. The LTS coordinator plays a key role in the ongoing advancement of this goal. As such it is suggested that consumer-driven action research be undertaken to:

1. Promote full integration of LTS coordinators on care teams in a conflict free manner that is faithful to the ideals of independent living philosophy and recovery model to support One Care enrollee health and wellness goals.
2. Address workforce capacity and sustainability barriers.
3. Increase cultural competency of workforce by increasing the proportion of LTS coordinators with CPS/ CRC expertise, and cultural identity that is more representative of the populations enrolled in One Care.
4. Establish quality measures specific to the LTS coordinator to monitor the quality of services provided to One Care enrollees across plans and by population.
5. Strengthen the capacity of contracted CBOs to provide LTS coordinators the opportunity to engage in Community-Based Participatory Action Research (CBPAR) as a social justice activity that promotes the civil of human rights of people with disabilities in managed-care.

Conclusion

The LTS coordinator is a unique intervention that came about as a result of robust advocacy by the disability community. The singular nature of the role requires that it be monitored evaluated and changed over time as required. Community-Based Participatory Action Research (CBPAR), grounded in the principle of “nothing about us without us,” provides a framework for advancing the development of the LTS coordinator that is true to the voice of the disability community and IL philosophy. The re-procurement of One Care and potential growth to scale of the plan provides both an opportunity and an obligation to further investigate and pursue best practices in the implementation of the LTS coordinator. YESHealth, **[16]** the research arm of the Disability Policy Consortium has experience conducting research to advance systems transformation in One Care and as such, is well-positioned to continue carrying out grassroots based research on implementation of the LTS coordinator role.

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