



EXPERIENCES OF CONSUMERS
WITH MANAGED LONG-TERM
SERVICES AND SUPPORTS
PROGRAMS

*Insights from Dual Eligible Enrollees
in Massachusetts and Ohio*

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The Center for Consumer Engagement in Health Innovation

is a hub devoted to teaching, learning and sharing knowledge to bring the consumer experience to the forefront of health. The Center works directly with consumer advocates to increase the skills and power they have to establish an effective voice at all levels of the health care system. We collaborate with innovative health plans, hospitals and providers to incorporate the consumer experience into the design of their systems of care. We work with state and federal policymakers to spur change that makes the health system more responsive to consumers, particularly those who are most vulnerable. We have been working to improve Medicaid and Medicare for consumers for more than a decade, producing tools for consumer advocates to use in state-based advocacy as well as tools for use by other stakeholders.

The Center is part of Community Catalyst, a national non-profit advocacy organization dedicated to quality affordable health care for all. Since 1998, Community Catalyst has been working to build the consumer and community leadership required to transform the American health system.

Lake Research Partners *is a nationally recognized qualitative and quantitative research firm with over 24 years of experience in all phases of consumer and public opinion research. It has designed and conducted more than 3,000 opinion surveys for its network of partners, including nonprofit groups, government agencies, elected officials, associations, ballot measures, and political campaigns in every state and region of the country. LRP has especially deep expertise in public health research, working on topics as diverse as hospitals and medical residents, childhood obesity, mental health, chronic diseases, substance abuse, long-term care, and women's health.*

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INTRODUCTION

Long-term services and supports (LTSS) include a broad range of services from nursing home care to community supports such as personal care, transportation, help with chores and maintaining a home. They provide a particularly important lifeline for older adults and individuals with disabilities or multiple chronic conditions. Access to appropriate LTSS can help people live independently, including remaining in their homes, continuing to work, and participating in their families and communities.

State Medicaid programs are primary payors of LTSS for low-income seniors and people with disabilities. Too often, however, these high-need beneficiaries have encountered persistent problems getting consistent access to these supports and having them coordinated with their medical services. In response to these challenges, public payors have developed programs aimed at improving care coordination, expanding access to services, and in some cases, improving integration with medical care.¹ For instance, managed care models for LTSS, once rare, are now increasing in popularity.² Additionally, Financial Alignment Initiative demonstrations (“duals demonstrations”) have allowed several states to integrate Medicare and Medicaid payments and benefits/services by contracting with managed care plans.³ Such integration of financing streams is intended to facilitate the full integration of LTSS and acute care services.

Given the vulnerability of the population relying on LTSS, it is important to understand whether these managed care models are living up to their potential and providing the access to services and coordination that beneficiaries need, including supports that allow them to live independently in the community. With this in mind, Community Catalyst engaged Lake Research Partners to conduct focus groups in 2015 and 2016 in Ohio and Massachusetts with dually eligible consumers enrolled in health plans providing managed LTSS through their state demonstration (and one Senior Care Option program), as well as with their caregivers, to better understand consumer experience with these plans.

This work builds on focus groups conducted by PerryUndem Research/Communication in 2014 and 2015 for the Medicaid and CHIP Payment and Access Commission (MACPAC) that looked at enrollees’ early experiences in three duals demonstrations.⁴ While the 2014 focus groups identified issues affecting consumers related to enrollment, care transitions, care coordination, communication and access to easy-to-understand information, they did not examine LTSS, a service that a significant percentage of enrollees utilize. The Lake Research Partners focus groups explored these consumer issues and, in particular, gathered participants’ experience with the provision and management of LTSS.

¹ MaryBeth Musumeci, *Rebalancing in Capitated Medicaid Managed Long-Term Services and Supports Programs: Key Issues from a Roundtable Discussion on Measuring Performance*. February 2015. Available at <http://kff.org/medicaid/issue-brief/rebalancing-in-capitated-medicaid-managed-long-term-services-and-supports-programs-key-issues-from-a-roundtable-discussion-on-measuring-performance/>.

² National Association of States United for Aging and Disabilities (NASUAD), *State Medicaid Integration Tracker*, November 2016. Available at <http://www.nasuad.org/sites/nasuad/files/State%20Medicaid%20Integration%20Tracker%20%20November%202016.pdf>.

³ Medicare-Medicaid Coordination Office, Financial Alignment Initiative. <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/FinancialModelstoSupportStatesEffortsInCareCoordination.html>.

⁵ PerryUndem Research/Communications, *Experiences with Financial Alignment Initiative Demonstration Projects in Three States: Feedback from Enrollees in California, Massachusetts, and Ohio*. May 2015. Available at <https://www.macpac.gov/publication/results-from-focus-groups-with-enrollees-in-the-financial-alignment-initiative-demonstration-in-california-massachusetts-and-ohio/>.

METHODOLOGY

From December 2015 to August 2016, Lake Research Partners conducted and moderated five phone-based focus groups of managed care plan members receiving LTSS and caregivers with 7-8 participants per group. Participants in Ohio were enrolled in the MyCare Ohio program that began in May 2014, while in Massachusetts, participants were enrolled in either the OneCare program (for dual eligibles under age 65) which began in October 2013, or the Senior Care Options (SCO) program (for dual eligibles 65 and older) which began in 2004.

Table 1: Focus Group Participants

| | Median Age | 50-59 |
|----------------------------|------------|-------|
| Sex | | |
| Female | 21 | 62% |
| Male | 13 | 38% |
| Program Represented | | |
| MyCare Ohio | 11 | 32% |
| OneCare | 16 | 47% |
| Senior Care Options | 7 | 21% |
| Participant Status | | |
| Participant | 30 | 88% |
| Caregiver | 4 | 12% |

The goal of this research was to yield qualitative insights from in-depth exploration of beneficiaries' views on what constitutes quality/person-centered care, their attitudes toward—and experiences with—coordinated care and LTSS, and how these might be made more effective.

KEY INSIGHTS

Insights gathered from this research fall into three main areas:

- (1) What members want from their health care; and
- (2) Members' experiences surrounding access, coverage and coordination (with both medical care and LTSS); and
- (3) Recommendations for improving other beneficiaries' experience with the programs.

1. What Members Want from Their Health Care

Focus group participants were asked several questions to better understand their overall perceptions of the health care system (as opposed to their specific plan) and what they want from it. The following are the key takeaways.

In general, participants are looking for quality health care that is accessible, personal, and based on decisions by providers who truly care. They want to be listened to, especially by their doctor.

And, for most, this meant having a consistent doctor who understands them, listens and meets their needs. Notably, quality was also seen by many, especially those with disabilities, as going beyond typical health care services. For these participants, quality also included quality of life. For instance, some cited support services such as transportation that allows them to live independently and to enjoy life in his/her community.

Members respond well to the phrase “person-centered care,” especially its connotation of being “known” by their providers and not having to repeat their “story” at each appointment. However, most do not feel that their current plans offer this level of attention.

Members express general frustration with the health care/insurance system that allows decisions to be made “by the bean counters, not the doctors.” Physicians are revered by members and having an ongoing relationship with the same doctor, rather than seeing someone different at each appointment, seemed to correlate with greater member satisfaction with their plan.

The recurring theme of provider consistency/continuity was also heard from participants who used personal care attendant (PCA) services. Because of the often-intimate nature of PCA responsibilities (e.g., help with dressing, bathing, toileting), and because of the extensive training that is needed to get a new PCA up to speed, **continuity is paramount for members.**

“My doctor is more apt to be concerned about what I want out of my health care. For instance, I’m a natural person. I don’t like to take a lot of medication so we always talk about alternative medicines.”

- Female, Massachusetts, Member

“If they know who I am and they know what it is that I need just because they’re paying attention, that’s quality.”

- Male, Massachusetts, Member

“I needed a repair to my wheelchair and part of it was the insurance, and the other part was the company that was ordering the part. It took three months...”

- Female, Massachusetts, Member

“Once I found the right [PCA], you know, they’re reliable and they’re more like a family member helping me out as opposed to someone who’s paid to do it.”

- Male, Ohio, Member

2. The Member Experience - Access, Coverage and Coordination: Acute Care and LTSS

Participants’ experiences with their managed care programs were mixed, both across and within the states. Many members view certain aspects of the integrated programs, such as improved access to transportation and coordinated care, quite positively. In particular, they report positive experiences with specific individuals who provided

“I have been approved for a certain number, limited number of nonmedical transportation trips, which are an incredible asset for me to be able to go play sports when it’s too cold for me to wait for The Ride outside.”

- Female, Massachusetts, Member

personal attention, such as drivers and personal care aides. Some praised nonmedical transportation services that allow them to go out into the community and pursue “quality of life” activities.

However, members pointed to many obstacles standing in the way of what they consider quality health care and which makes them feel the system lacks the personal care and attention they deserve. A major obstacle reported by several Ohio participants was not having enough information or guidance from their care team, including follow-up consultations with their care manager. This appeared to be less of an issue for Massachusetts participants. Other participants reported continued difficulties receiving durable medical equipment and maintenance in a timely manner.

One major problem that surfaced in focus groups with members in both states was with the provision of personal care attendant (PCA) services. Members reported the disruption of long-term PCA relationships or the high turnover of PCAs. For instance, in Ohio, delays in paying PCAs, particularly in the first year of the MyCare Ohio program, resulted in many members losing critical, sometime longstanding supports. Others found that agencies providing PCAs served as an impediment to timely and effective communication between the PCA and the care manager.

3. Recommendations for Improving Other Beneficiaries’ Experience with the Programs

At the end of the focus group conversations, participants were asked what advice to give to potential enrollees in the Ohio and Massachusetts programs. Members recommended doing plenty of research and fully understanding the different plans available before enrolling. Additional advice included keeping careful records of people they deal with in the event problems occur; being prepared to be a self-advocate and being persistent to get needed care; actively participating as part of the care team; and not being afraid to ask a lot of questions.

“I know people who have had...10, 20 years of personal care relationships and stability with their attendant care, which is extremely important; just completely disrupted by this transition to MyCare Ohio. ... [I]t’s been devastating on some people as far as getting the day-to-day care that they need in that regard. And for me it’s been a tooth-and-nail fight for a year and a half to maintain as much as I can.”

- Male, Ohio, Member

“I was trusting the teams and unfortunately the right not only doesn’t know what the left hand is doing, sometimes the right hand doesn’t seem to be aware that there is a left hand. (laughter) And so I have to coordinate it.”

- Male, Ohio, Member

“There ought to be communication between the actual person who shows up and my care manager, there isn’t because it’s through an agency...And the care manager has no control over who the agency hires to send to my place...[the PCA] could be reporting back to my care manager, but there isn’t any method of communication between those two people.”

- Male, Massachusetts, Member

DISCUSSION

These focus groups provided several insights that are consistent with other research, evaluations⁵ and previous focus groups of the dual demonstrations, including the earlier MACPAC focus groups as well as a recent survey and focus groups that The SCAN Foundation sponsored on dual eligible enrollees in California.⁶ These focus groups provided several insights that are consistent with other research, evaluations⁵ and previous focus groups of the dual demonstrations, including the earlier MACPAC focus groups as well as a recent survey and focus groups that The SCAN Foundation sponsored on dual eligible enrollees in California.⁶

Four areas are worth noting:

- (1) **Consumers want medical professionals and caregivers to listen to them** and offer personalized solutions, some of which may be medical, some non-medical. This is their definition of quality, or person-centered, health care.
- (2) **Education of members** about what plans are offering and are responsible for providing will help beneficiaries choose the right plan for them and mitigate some of the growing pains of the transition to MLTSS programs.
- (3) **Care coordination is fundamental** to the successful integration of services – particularly LTSS - for consumers enrolled in these health plans. Consumers must know who their care manager is and be able to reach them when needed. The manager must be empowered in that role and have constant contact with the entire care team.
- (4) Given the importance of the member’s personal doctor, s/he also must have **easy access to the care coordinator**.
- (5) For consumers receiving home care support, **reliable, consistent personal care** is fundamental.

“[D]on’t be afraid to ask a lot of questions and... [if there is] anything they don’t completely understand, ask a question about it and constantly ask a question about it and never accept no from someone who has not proven that they have the power to say yes.”

- Male, MyCareOhio, Member

“Quality to me, especially with a person with mobility limitations, needs to be able to get out of the house... [not just] to the clinic or to the hospital. But to get out and really enjoy life...”

- Male, Ohio, Member

⁵ See, e.g., Medicare-Medicaid Coordination Office, Financial Alignment Initiative Annual Report: One Care: MassHealth plus Medicare. September 1, 2016. at p. 19. Available at <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Downloads/MASSFirstAnnualEvalReport.pdf>.

⁶ Bruce Chernof, MD, The Scan Foundation, Good Start, Now Get to Goal — Lessons Learned from California’s Duals Demonstration. August 2016. Available at <http://www.thescanfoundation.org/perspectives-good-start-now-get-goal-lessons-learned-californias-duals-demonstration>.

Based on these themes, we suggest placing focused attention on the following areas in MLTSS programs, including duals' demonstrations:

- (1) **Increase support for robust consumer education** and for assisters to help consumers with enrollment decisions: In order for consumers to make smart choices about the plan they want to enroll in, they need help understanding the provider network, benefits and other services available under each plan in order to compare what is best for them.
- (2) **Closely monitor and measure** the following areas of care: (a) members' experiences with their care coordinators, including communication (b) timely access to needed durable medical equipment and repairs (c) continuity of care of personal care attendant services by reviewing turnover data.

Finally, we encourage policymakers, payers, providers and advocates to seek out and support ongoing consumer input on their experience of care. This includes emphasizing patient-reported outcome measures, community outreach, consumer leadership, and a strong infrastructure for consumer and community engagement. It is only by regularly listening to the consumer voice that programs that serve individuals needing long-term services and supports can meet those needs and create care that is effective and person-centered.



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