

Dennis Heaphy
Policy Analyst, Disability Policy Consortium
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Chairman Casey, Ranking Member Scott, Members of the Senate Special Committee on Aging, thank you for the opportunity to testify about my experiences as a dually eligible enrollee in an integrated plan. To start, I want to give a special thanks to Senator Casey for his support of the disability community and his leadership on the COVID HCBS Relief Act. I also want to thank Senator Warren for her ongoing partnership with dually eligible individuals and the larger disability community in Massachusetts.

The Importance of Consumer Involvement in Integrated Care

I am a person with complex medical needs due to a spinal injury and an unrelated autoimmune condition. In 1985, I became disabled at 23 years old. I am now 60 years old. For the last nine years, I have been a member of the One Care integrated model in Massachusetts since it started in 2013. This model was established to address the needs of people with both Medicare and Medicaid ages 21-64 through a single health plan, to step away from the traditional and medical model of care delivery, and to advance independent living.

To be clear, my life and thousands of others depend on integrated care, whole-person care, and a non-medical model, which is why I am professionally engaged in the direction of integrated care in Massachusetts, and with advocates nationally. I am the Chair of the Massachusetts consumer led One Care Implementation Council (IC), which came about through disability advocacy. The IC is comprised of many stakeholders but largely consumers and their families, who work in

partnership with the Medicaid agency to ensure One Care meets enrollees' needs. The positive impact of the IC on the One Care model cannot be overstated.

Integrated Care and Whole Person Care at Its Best

As a disability rights advocate, I know firsthand what works and what does not work in providing whole-person health care for persons with complex needs. Integrated care, when done well, helps us to live meaningful lives in the community. What does a meaningful life in the community mean? It means understanding and promoting the basic principles of independent living. It means having a care team that not only looks at my medical needs, but also my life goals, my ability to engage with family and friends and participate in the community. In my case, it also means ensuring I have the right wheelchair, medical supplies and environmental controls to work independently from home. It means having a direct line of communication with a member of my care team with decision-making authority. It means having a nurse practitioner or physician assistant whom I trust and can act in real time. That can mean writing a prescription or coming to my home to change my urine catheter so that I can avoid the emergency department.

I have seen integrated care at its best. Several years after my spinal cord injury, I became a member of a Medicaid managed care plan in Massachusetts that provided everything I needed. Everything was done in my home. That included care for a cold or the flu, wound care, urine tests, blood tests, and wheelchair seating and positioning. Even x-rays were sometimes taken in my home. My nurse practitioner knew my family and taught my personal care attendant (PCA), who helps with my activities of daily living, how to do wound care, catheter changes, and more. She and I would discuss my overall health and life goals, often including my PCA.

As a result of consumer advocacy, the One Care model was based on this authentic form of person-centered care. Soon after One Care started, I developed a bone infection that required

surgery, many hospitalizations and over a year of recovery. My Medicaid plan, now also my Medicare plan and part of One Care, was able to leverage Medicare dollars to reduce my hospital days and enable me to do my rehabilitation in my home. Following this intensive period, my care team and I decided to increase my personal care hours and to place much more emphasis on prevention. Acupuncture was provided on a weekly basis to reduce pain and control my spasticity. My autoimmune specialist, even though an out-of-network provider, was regularly consulted. I was provided a ceiling lift to transfer me from my bed to a wheelchair, alternating air mattress, upgraded wheelchair, and seating system. This may not sound like anything special, but many health plans that serve people like me do not provide this type of care.

I cannot tell you how grateful I am for the PCAs I had at the time, all of whom, by the way, were underpaid. If not for them, in addition to my care team respecting my choice to stay at home, I would have gone into a skilled nursing facility for rehab where I was at high risk for a series of complications such as secondary infections and skin breakdown. I am not exaggerating when I say that this integrated care model not only kept me out of a long-term nursing facility, One Care also kept me alive. Thankfully I don't usually need intensive services. What I need most are home and community-based services and supports, which are determined in my care planning process with people I know and trust. This is what lets me stay healthy and independent. Many are not as fortunate as I have been and are required to abide by plans that use a one-size-fits-all approach based on algorithms with no regard to their unique needs and goals.

Designing and implementing an integrated program and making sure that it continues to meet enrollees' needs are two different things. Even in One Care, things have started changing. It is increasingly challenging for me and others to know how to navigate the lines of communication, to know which care team members are responsible for what, or even the composition of the care

team. I went to the emergency department for the first time in years because I could not reach anyone in my care plan other than the on-call service. This is at 10 AM. So, not knowing what to do, I drove my wheelchair to the hospital a mile up the road. My fear was the potential spread of a bacterial skin infection known as cellulitis. In my situation, cellulitis can spread rapidly, resulting in 10 plus days in the hospital on antibiotics if not treated readily. Thankfully, I just had a broken toe. If I had been able to reach someone from my care team to send them a picture or have them stop by, I would not have felt like I needed to be my own doctor. And being my own doctor is not a job I want.

Other One Care members are also raising complaints. Complaints include not having a care plan, not having a clear point person or care team of their choosing and not having access to needed services. I am not exaggerating when I say that, if I have more hoops to jump through to access care, or if my home support services get squeezed, I am a goner.

In response to the level of recent complaints raised by One Care enrollees and advocates, the state is working with the Implementation Council, disability advocates and the One Care plans to get the demonstration back on track. I am confident that, because of this relationship between consumers and the state, we will be heard, and we can make change. **Not every state is like Massachusetts.** And One Care might not work in every state. But every state would benefit from giving consumers a voice in the process to evolve integrated care around person-centered goals.

Thank you again for the opportunity to speak with you today, and I look forward to answering your questions.