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Health plan enrollees with disability informing primary care practices and providers about their quality of care: A randomized trial

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ABSTRACT

Background: In October 2013, Massachusetts initiated the One Care demonstration, which enrolls beneficiaries ages 21 to 64 dually-eligible for Medicare and Medicaid. Local disability advocates argued that persons with disability should assess their own One Care quality.

Objectives: To test the comparative effectiveness for improving patient-reported health care experiences of two informational interventions in a 12-month period: (1) “**YESHealth: Your Experience, Speak up for better health care,**” in which disability advocates developed brief topical surveys and gathered information from One Care enrollees with significant physical disability or serious mental illness; and (2) the Persons with Disability Quality Survey (PDQ-S), developed collaboratively with persons with disability.

Methods: This cluster randomized controlled trial randomly assigned 27 primary care practices with ≥50 One Care members to three study arms differing by information provided to practice directors and primary care providers (PCPs): (1) quarterly YESHealth reports plus results from baseline administration of PDQ-S to 720 enrollees before YESHealth implementation; (2) PDQ-S results only; and (3) no study information. We administered PDQ-S again one year later and used difference-in-differences analyses of results across the two years to assess intervention outcomes.

Results: Disability advocates conducting YESHealth reported substantial difficulties contacting practices and engaging PCPs. With few exceptions, no differences were found across the three study arms in enrollee-reported outcomes.

Conclusions: Providing consumer-designed and generated quality information to PCPs had no measurable effect on enrollees' perceptions of One Care quality. Barriers to PCPs engaging with disability advocates could have contributed to YESHealth's failure to improve care.

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Introduction

Persons who are dually eligible for Medicare and Medicaid generate disproportionately high costs for both public insurance

programs.¹ The 2010 Patient Protection and Affordable Care Act mandated experiments with innovative health care delivery models to serve dually-eligible individuals, and in August 2012, Massachusetts was the first state to win approval from the Financial Alignment Demonstration initiated by the new Center for Medicare and Medicaid Innovation and Medicare-Medicaid Coordination Office.^{2–6} Launched in 2013, the Massachusetts One Care program is unique among Financial Alignment Demonstrations in focusing on fully dually eligible beneficiaries ages 21 through 64 (i.e., all persons qualify for Medicare because of disability).^{4,7} This costly population (approximately 105,000 Massachusetts residents) had

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annually generated \$1.3 billion in fee-for-service Medicaid (MassHealth) costs and \$1.2 billion in Medicare expenditures, with long-term services and supports (LTSS) consuming 35% of total spending compared with 22% for inpatient services.⁸

Massachusetts disability rights advocates consulted regularly with state officials as they designed One Care provisions.^{5,6} The One Care contract – a three-way agreement among the Centers for Medicare & Medicaid Services (CMS), MassHealth, and participating health plans⁹ – includes independent living principles and stipulates person-centered care with consumer direction of core components of care. Furthermore, Massachusetts created an Implementation Council that would oversee One Care throughout the demonstration period and include, as at least half of its members, MassHealth members with disability or family members or guardians of MassHealth members with disability. Specific roles of the Implementation Council include monitoring access to health care and quality of care among One Care members, advising MassHealth leadership on One Care implementation, ensuring transparency and accountability, and tracking compliance with provisions of the Americans with Disabilities Act. The Implementation Council met first in February 2013, seven months in advance of One Care's start, giving persons with disability a formal role in One Care planning and future oversight.

However, One Care's dually capitated payment structure (i.e., both Medicare and MassHealth pay capitated rates to One Care plans) and its potentially powerful financial incentives raised concerns among disability rights advocates about potential threats to care quality, especially skimping on community-based LTSS. Several advocacy groups joined together as the Disability Health Alliance (DHA), which in January 2013 published a Mission Statement. DHA called for persons with disability to assume leading roles in defining and proactively measuring One Care quality. As have others,^{10–13} DHA argued that standard quality metrics do not adequately capture well-being and quality of life concerns of persons with disability.

Guided by DHA Mission Statement principles and in collaboration with the Disability Policy Consortium (DPC, Malden, MA), researchers sought funding from the Patient-Centered Outcomes Research Institute to develop and test the effectiveness of consumer-driven quality information in improving the experiences of One Care enrollees with serious mental illness or significant physical disability. This paper reports results of a cluster randomized controlled trial to compare the effectiveness of two informational interventions in a 12-month period:

- **“YESHealth: Your Experience, Speak up for better health care,”** in which disability advocates designed tools and gathered information from One Care enrollees with serious mental illness or significant physical disability about their care experiences, which they aimed to report to primary care providers (PCPs) and practices and to engage providers in productive discussions about improving care; and
- A report from baseline administration of the Persons with Disability Quality Survey (PDQ-S), developed collaboratively with persons with serious mental illness or significant physical disability.

Our major research question was: compared with baseline, does providing consumer-defined information about their quality of care to primary care practices and their PCPs improve enrollees' subsequent perceptions of their quality of care? For the YESHealth intervention, we hypothesized that practices whose PCPs engaged with consumers in discussing their care would use consumers' views to shape quality improvement activities, thus producing

changes important to and detectable by One Care enrollees.

Methods

The Massachusetts General Hospital (MGH)/Partners Health-Care Human Research Committee Human Research Committee approved all aspects of this study. This project was registered with [ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02390557) (NCT02390557).

Study setting and design

The study setting was the larger of two One Care plans operating at the time of the YESHealth intervention (October 2015–September 2016). This private, non-profit plan covers all regions except westernmost Massachusetts, Cape Cod, Martha's Vineyard, and Nantucket. It operates both as a health insurer and provider, employing interprofessional clinicians within its own practices in certain locations and contracting with providers elsewhere in Massachusetts. The plan informed its clinical staff and contracted practices about the study but asked the researchers not to make potentially time-consuming outreach to these practitioners because of the considerable time demands required in newly implementing the complex One Care program.

The plan gave us One Care enrollment records so that we could select practices for participation. Our unit of randomization was primary care practices caring for ≥ 50 One Care members with serious mental illness or significant physical disability according to MassHealth's “rating category” assignment (which is used to set capitation payment levels for enrollees). Twenty-seven primary care practices met this criterion.

For the cluster randomized trial, we randomly assigned the 27 practices to one of three study arms. The three study arms differed in the nature and quantity of consumer-derived information provided to the practice director and individual PCPs:

- Arm 1 (9 practices): The one-year YESHealth intervention, in which persons with disability developed and produced quarterly reports about aspects of One Care quality important to consumers, mailed these reports to PCPs and practice directors, and attempted to engage practice staff in discussions of these findings; in addition, PCPs and practice directors were mailed results from the baseline PDQ-S conducted before YESHealth implementation;
- Arm 2 (9 practices): PCPs and practice directors received the baseline PDQ-S results only; and
- Arm 3 (9 practices): PCPs and practice directors received no information from the study.

The outcome used to assess the effect of the Arm 1 and 2 interventions was the comparison of results from a second round of surveys with PDQ-S, which occurred after the one-year implementation of YESHealth, with the baseline PDQ-S results.

Below, this Methods section describes the various components of the study. We start with the PDQ-S, its design and baseline administration, use of this baseline PDQ-S to produce reports sent to PCPs and practice directors in Arm 1 and 2 practices, the second round of PDQ-S administration, and PDQ-S administration procedures. We then briefly describe the YESHealth intervention (Arm 1). During its one-year implementation, YESHealth encountered significant difficulties engaging PCPs and practices. For this and other reasons described below, we decided late in the study to survey PCPs to explore possible reasons for PCPs' lack of responsiveness. We therefore next describe the PCP survey. The Methods section concludes by describing our analysis approach.

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