TARGETED COST CHALLENGE INVESTMENTS PROGRAM

CARE COORDINATION CASE STUDY

MASSACHUSETTS
HEALTH POLICY COMMISSION

NOVEMBER 2021

TABLE OF CONTENTS

EXECUTIVE SUMMARY

TCCI CARE COORDINATION CASE STUDY: OVERVIEW

The Massachusetts Health Policy Commission created the Targeted Cost Challenge Investments Program (TCCI Program) to "foster innovation in health care payment and service delivery by supporting promising innovations that address the Commonwealth's most complex health care cost challenges."[1] The TCCI program provided $6.6 million in funding to ten awardees, who partnered with more than 60 community organizations to conduct 18-month programs designed to address challenges related to social determinants of health, behavioral health integration, post-acute care, serious advancing illness and care at the end of life, and site and scope of care. The goal of the TCCI Care Coordination Case Study was to collect and synthesize participant and provider perspectives on strategies for care coordination tested by four TCCI awardees. All four awardees' initiatives served vulnerable populations, including those experiencing housing instability, receiving palliative care, and/or living with serious physical and mental health concerns.

The aim of exploring these awardees' approaches to care coordination was to learn more about successful strategies and barriers for meeting these populations' needs. Overarching study questions were:

- How did the initiative's care coordination approach create resonance for participants?
- How did the initiative's care coordination approach create relevance for providers and partners?

To assess the perspective of the awardees and their partners, the study team conducted focus groups with awardee and partner organization staff. Perspectives of participants in awardees' initiatives were gathered through individual, face-to-face interviews. This case study was designed and written as a complement to the HPC's comprehensive, mixed-methods evaluation of the TCCI initiatives. Findings from the Targeted Cost Challenge Investments Program Evaluation Report can be found here.

POTENTIAL OF CARE COORDINATION

Care coordination can have a variety of benefits, including improving patient outcomes,[2] increasing continuity of care,[2] and reducing utilization.[2-4] It is also valuable for vulnerable populations,[5-9] who experience higher health and social needs[10-15] and more fragmented care.[11,12,14-16] Defined as "the deliberate organization of patient care activities between two or more participants,"[2] care coordination typically involves communicating and exchanging information[2,17] and specifying providers' roles.[2,18] It also often includes care planning,[2,18] a process in which providers and patients proactively discuss care.[18-20] Including social needs in these efforts is essential, as they play an important role in driving both medical outcomes and costs.[21-26]

AWARDEE INITIATIVES

The study team conducted interviews and focus groups at four TCCI sites to better understand the process of care coordination and its role in creating resonance for participants and relevance for health care and social service providers.

BEHAVIORAL HEALTH NETWORK: PROJECT FIT

Behavioral Health Network (BHN) is a large, community-based organization in Western Massachusetts that provides behavioral health services for adults, children, and families. The goal of its TCCI Program initiative, Families in Transition (Project FIT), was to provide overall stability to participants through a "high-touch" care coordination program that connected behavioral health, primary care, housing supports, and vocational services. Within Project FIT, care planning was rooted in ongoing relationships and communication between project staff and participants, which helped BHN and partner staff respond to participants' high-priority needs in a timely way.

BOSTON HEALTH CARE FOR THE HOMELESS PROGRAM: SOCIAL DETERMINANTS OF HEALTH CONSORTIUM

The Boston Health Care for the Homeless Program provides health care for homeless individuals and families in the Boston area. The goal of BHCHP's TCCI initiative, known as the Social Determinants of Health (SDH) Consortium, was to improve the care and lives of Boston's highest-need patients by serving as a hub for a team of medical providers, shelters, and advocacy organizations. The program focused on providing evolving, participant-centered care that was coordinated through frequent communication both among staff and clinicians and with participants, but that did not necessarily involve ongoing updates of a written care plan document.

BROOKLINE COMMUNITY MENTAL HEALTH CENTER: HEALTHY LIVES

Brookline Community Mental Health Center provides mental health care and community-based social services to Brookline-area residents, regardless of ability to pay. The goal of its TCCI initiative, Healthy Lives, was to deploy a mobile, multidisciplinary care management team to integrate behavioral health, primary care, and community services. Care planning within Healthy Lives focused on integrating the care participants received from a variety of medical, behavioral health, and community providers in order to best support participants' stated goals and needs.

CARE DIMENSIONS: PALLIATIVE CARE+

Care Dimensions provides palliative and hospice care for people in Eastern Massachusetts. The goal of their TCCI initiative, Palliative Care+, was to integrate palliative care staff into North Shore Physicians Group (NSPG) primary care sites in order to increase early identification of patients and bridge the gap between curative and end-of-life care. Because many participants had already received care plans from multiple providers, Palliative Care+ focused less on creating new, independent plans and more on operationalizing existing plans by helping participants synthesize recommendations and identify priorities. Frequent and ongoing communication between the Care Dimensions team and NSPG high-risk nurse care managers facilitated coordination throughout this process.

CARE COORDINATION CONSIDERATIONS

The awardees included in this study worked with complex populations whose behavioral, medical, and social needs required coordination across a wide range of providers. This coordination occurred primarily through communication among awardees, partners, and participants, and was facilitated by trusting relationships between participants and initiative staff. Addressing social needs was an important element of these efforts. However, even with well-planned, strongly implemented, evidence-based initiatives, the four awardees faced shared challenges stemming from community-level, systemic issues that constrained the efficacy of care coordination efforts. While these challenges limited initiatives' impacts, the programs were nevertheless seen as valuable by staff members and appreciated by participants.

COMPLEX NEEDS REQUIRE MULTIFACETED INTERVENTIONS

Awardees worked with some of the most vulnerable individuals living in Massachusetts communities. Addressing these populations' complex needs requires robust interventions that coordinate care across diverse providers,[5,9,27,28] and the four initiatives incorporated many evidence-based care coordination approaches toward this end. In the words of one Healthy Lives team member: **"We try to think holistically: what will contribute most to this patient's well-being and health before it becomes an emergency?"** However, consistent with the literature,[29-31] most initiatives described challenges providing such interventions in the context of limited financial, time, and staffing resources.

ROBUST COMMUNICATION UNDERPINS CARE COORDINATION

For included initiatives, care coordination was a high-touch, human process based on continuous, responsive communication among awardees, their partners, and participants. While written care plans provided a place to start, care coordination within these programs was primarily relationship-based and formal care plans were not emphasized. Participants appreciated the ongoing communication among staff members: as one SDH Consortium participant observed, **"I have five doctors and two, maybe three [case managers] and they all talk to each other."**

Project FIT and Palliative Care+ primarily relied on direct communication with partners to exchange information about participants. Clinicians from both initiatives considered this ongoing contact to be essential. The SDH Consortium and Healthy Lives also used direct communication, but supplemented it with shared access to health and social service records, which has the potential to facilitate coordination.[32-35] Both teams valued this technological integration.

While communication was a key element of all included initiatives, staff also reported challenges in this area. Palliative Care+ staff often did not have access to participants who were admitted to hospitals or rehabilitation facilities, substantially limiting their ability to coordinate care. Palliative Care+ team members and primary care partners also identified lack of electronic data sharing as a challenge. Within Project FIT, medical providers were not involved in the care planning process, and there was no systematic structure for joint planning or regular sharing of information. While BHN staff did reach out to primary care and other providers on an as-needed basis, BHN staff perceived primary care practices as being non-responsive to these requests.

BUILDING TRUST WITH PARTICIPANTS IS A PREREQUISITE FOR SUCCESS

Trusting relationships with participants are essential for successful care coordination,[36-41] particularly for the initiatives' target populations, which included people with trauma histories[42-44] and negative experiences with the health care system.[40,45] Staff members from Project FIT, the SDH Consortium, and Healthy Lives emphasized the importance of building trusting relationships with participants, and participants expressed their appreciation of the strong connections they had with initiative staff. As one Project FIT staff member pointed out, **"Without trust, participants will not be able to work with you."**

Home visits, used by most of the initiatives, offer a valuable opportunity to build relationships, identify needs and barriers, reconcile medications, and provide education and coaching.[46,47] The Healthy Lives team saw home visits as key to the initiative's success, and interviewed participants appreciated them as well. After finding that many participants did not accurately report how they were doing over the phone, the Palliative Care+ team planned to incorporate more home visits in future iterations of the program. This is in contrast to the trend for health and care coordination services to increasingly be delivered telephonically or electronically rather than in person[48] and suggests that these strategies may not be effective with medically and socially complex and vulnerable populations.

ADDRESSING SOCIAL NEEDS IS ESSENTIAL

Addressing health-related social needs is essential to both improving medical outcomes and reducing costs.[26,49-52] All four initiatives incorporated efforts to address social needs, though some emphasized this more than others. The Project FIT, SDH Consortium, and Healthy Lives teams worked with participants to address a wide variety of social needs, an approach that resonated with participants and was valued by staff. Said one SDH Consortium participant, **"These folks don't give up. No matter what I have done, they find me and we start again."** In contrast, robust attention to social needs was outside the scope of the Palliative Care+ model and was a key gap identified by interviewed participants.

COMMUNITY RESOURCE INEQUITIES CONSTRAIN THE EFFICACY OF CARE COORDINATION

Addressing social and other needs was complicated by inequities facing the communities in which initiatives were situated. As one Healthy Lives participant observed, **"The nicest, most caring social workers just cannot fix the system."** For both Project FIT and the SDH Consortium, chronic homelessness and a lack of affordable, appropriate housing affected possibilities for care planning. School systems and childcare also posed difficulties for Project FIT participants, particularly for families whose children had special needs. Across initiatives, participants also reported transportation challenges and barriers to accessing medical and behavioral health services. Several recounted negative experiences with health care providers. These challenges and systemic barriers affected possibilities for care planning and limited the efficacy of some care coordination activities.

CARE COORDINATION HAD POSITIVE IMPACTS

Awardees and their partners viewed care coordination as a relevant and necessary tool that improved participant outcomes and reduced avoidable health care utilization. Awardees' partners also appreciated the services provided by TCCI-supported care coordination initiatives, describing how the programs helped them in their own work. As one Healthy Lives partner observed, **"Healthy Lives allowed us to do what we would not otherwise have been able to."** Awardees' evidence-based care coordination strategies also resonated meaningfully with participants, who appreciated the personal, emotional, and practical support they received from initiative staff.

CONCLUSION

Care coordination encompasses many evidence-based approaches that can improve patient outcomes and prevent avoidable health care utilization. For included initiatives, care coordination efforts resonated with participants, who felt that someone was listening and working with them to address their needs. In addition, initiative and partner organization staff believed that care coordination was relevant and a core aspect of their program's effectiveness. For all awardees, the impact of care coordination came less through a formal, written care plan and more through constant communication among awardees, partners, and participants—making it possible for awardees and partners to put their efforts into addressing participants' urgent, evolving circumstances. While this ongoing communication enabled positive impacts for both participants and providers, this case study also highlighted barriers that care coordination alone cannot address. For medically and socially complex populations, care coordination can help participants address some of their needs but cannot resolve structural deficits in the health care system and communities.

REFERENCES

1 Massachusetts Health Policy Commission. Targeted Cost Challenge Investment: Behavioral Health Network. Retrieved from https://www.mass.gov/files/documents/2019/06/03/Behavioral%20Health%20Network.pdf

2 McDonald, K. M., Sundaram, V., Bravata, D. M., Lewis, R., Lin, N., Kraft, S. A., . . . Owens, D. K. (2007). Care coordination. In K. G. Shojania, K. M. McDonald, R. M. Wachter, & D. K. Owens (Eds.), Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies (Vol. 7). Rockville (MD): Agency for Healthcare Research and Quality. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK44015/

3 Breckenridge, E. D., Kite, B., Wells, R., & Sunbury, T. M. (2019). Effect of patient care coordination on hospital encounters and related costs. Population Health Management, 22(5). https://doi.org/10.1089/pop.2018.0176

4 Tricco, A. C., Antony, J., Ivers, N. M., Ashoor, H. M., Khan, P. A., Blondal, E., . . . Straus, S. E. (2014). Effectiveness of quality improvement strategies for coordination of care to reduce use of health care services: A systematic review and meta-analysis. CMAJ: Canadian Medical Association Journal, 186(15), E568-578. https://doi.org/10.1503/cmaj.140289

5 Bassuk, E. L., DeCandia, C. J., Tsertsvadze, A., & Richard, M. K. (2014). The effectiveness of housing interventions and housing and service interventions on ending family fomelessness: A systematic review. American Journal of Orthopsychiatry, 84(5), 457-474. https://doi.org/10.1037/ort0000020

6 de Vet, R., van Luijtelaar, M. J., Brilleslijper-Kater, S. N., Vanderplasschen, W., Beijersbergen, M. D., & Wolf, J. R. (2013). Effectiveness of case management for homeless persons: A systematic review. American Journal of Public Health, 103(10), e13-26. https://doi.org/10.2105/ajph.2013.301491

7 Hwang, S. W., & Burns, T. (2014). Health interventions for people who are homeless. Lancet, 384(9953), 1541-1547. https://doi.org/10.1016/s0140-6736(14)61133-8

8 Krahn, J., Caine, V., Chaw-Kant, J., & Singh, A. E. (2018). Housing interventions for homeless, pregnant/parenting women with addictions: A systematic review. Journal of Social Distress and the Homeless, 27(1), 75-88. Retrieved from https://doi.org/10.1080/10530789.2018.1442186

9 National Consensus Project for Quality Palliative Care. (2018). Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Retrieved from https://www.nationalcoalitionhpc.org/ncp/

10 Bahorik, A. L., Satre, D. D., Kline-Simon, A. H., Weisner, C. M., & Campbell, C. I. (2017). Serious mental illness and medical comorbidities: Findings from an integrated health care system. Journal of Psychosomatic Research, 100, 35-45. https://doi.org/10.1016/j.jpsychores.2017.07.004

11 Cagle, J. G., Bunting, M., Kelemen, A., Lee, J., Terry, D., & Harris, R. (2017). Psychosocial needs and interventions for heart failure patients and families receiving palliative care support: A systematic review. Heart Failure Reviews, 22(5), 565-580. Retrieved from https://doi.org/10.1007/s10741-017-9596-5

12 Fazel, S., Geddes, J. R., & Kushel, M. (2014). The health of homeless people in high-income countries: Descriptive epidemiology, health consequences, and clinical and policy recommendations. Lancet, 384(9953), 1529-1540. https://doi.org/10.1016/s0140-6736(14)61132-6

13 Fortuna, K. L., Ferron, J., Pratt, S. I., Muralidharan, A., Aschbrenner, K. A., Williams, A. M., . . . Salzer, M. (2019). Unmet needs of people with serious mental illness: Perspectives from certified peer specialists. Psychiatric Quarterly, 90(3), 579-586. https://doi.org/10.1007/s11126-019-09647-y

14 Grant, R., Gracy, D., Goldsmith, G., Shapiro, A., & Redlener, I. E. (2013). Twenty-five years of child and family homelessness: Where are we now? American Journal of Public Health, 103(Suppl 2), e1-10. https://doi.org/10.2105/ajph.2013.301618

15 Ryan, J., Abrams, M. K., Doty, M. M., Shah, T., & Schneider, E. C. (2016). How High-Need Patients Experience Health Care in the United States: Findings from the 2016 Commonwealth Fund Survey of High-Need Patients. Retrieved from https://www.commonwealthfund.org/publications/issue-briefs/2016/dec/how-high-need-patients-experience-health-care-united-states

16 Lawrence, D., & Kisely, S. (2010). Inequalities in healthcare provision for people with severe mental illness. Journal of Psychopharmacology, 24(4 Suppl), 61-68. https://doi.org/10.1177/1359786810382058

17 Weaver, S. J., Che, X. X., Petersen, L. A., & Hysong, S. J. (2018). Unpacking care coordination through a multiteam system lens: A conceptual framework and systematic review. Medical Care, 56(3), 247-259. Retrieved from https://journals.lww.com/lww-medicalcare/Abstract/2018/03000/Unpacking_Care_Coordination_Through_a_Multiteam.9.aspx

18 Burt, J., Rick, J., Blakeman, T., Protheroe, J., Roland, M., & Bower, P. (2014). Care plans and care planning in long-term conditions: A conceptual model. Primary Health Care Research & Development, 15(4), 342-354. https://doi.org/10.1017/s1463423613000327

19 Coulter, A., Entwistle, V. A., Eccles, A., Ryan, S., Shepperd, S., & Perera, R. (2015). Personalised care planning for adults with chronic or long-term health conditions. Cochrane Database of Systematic Reviews(3), Cd010523. https://doi.org/10.1002/14651858.CD010523.pub2

20 Lhussier, M., Eaton, S., Forster, N., Thomas, M., Roberts, S., & Carr, S. M. (2015). Care planning for long-term conditions–A concept mapping. Health Expectations, 18(5), 605-624. https://doi.org/10.1111/hex.12063

21 Alley, D. E., Asomugha, C. N., Conway, P. H., & Sanghavi, D. M. (2016). Accountable Health Communities — Addressing social needs through Medicare and Medicaid. New England Journal of Medicine, 374(1), 8-11. Retrieved from https://www.nejm.org/doi/full/10.1056/NEJMp1512532

22 Berkowitz, S. A., Basu, S., Meigs, J. B., & Seligman, H. K. (2018). Food insecurity and health care expenditures in the United States, 2011-2013. Health Services Research, 53(3), 1600-1620. https://doi.org/10.1111/1475-6773.12730

23 Billioux, A., Verlander, K., Anthony, S., & Alley, D. (2017). Standardized screening for health-related social needs in clinical settings: The Accountable Health Communities screening tool. NAM Perspectives(Discussion Paper). https://doi.org/10.31478/201705b

24 Fitzpatrick, T., Rosella, L. C., Calzavara, A., Petch, J., Pinto, A. D., Manson, H., . . . Wodchis, W. P. (2015). Looking beyond income and education: Socioeconomic status gradients among future high-cost users of health care. American Journal of Preventive Medicine, 49(2), 161-171. https://doi.org/10.1016/j.amepre.2015.02.018

25 Sterling, S., Chi, F., Weisner, C., Grant, R., Pruzansky, A., Bui, S., . . . Pearl, R. (2018). Association of behavioral health factors and social determinants of health with high and persistently high healthcare costs. Preventive Medicine Reports, 11, 154-159. https://doi.org/10.1016/j.pmedr.2018.06.017

26 Thorpe, K. E., & Joski, P. (2018). Association of social service spending, environmental quality, and health behaviors on health outcomes. Population Health Management, 21(4), 291-295. https://doi.org/10.1089/pop.2017.0136

27 Bradford, D. W., Cunningham, N. T., Slubicki, M. N., McDuffie, J. R., Kilbourne, A. M., Nagi, A., & Williams, J. W., Jr. (2013). An evidence synthesis of care models to improve general medical outcomes for individuals with serious mental illness: A systematic review. Journal of Clinical Psychiatry, 74(8), e754-764. https://doi.org/10.4088/JCP.12r07666

28 Jego, M., Abcaya, J., Stefan, D. E., Calvet-Montredon, C., & Gentile, S. (2018). Improving health care management in primary care for homeless people: A literature review. International Journal of Environmental Research and Public Health, 15(2). https://doi.org/10.3390/ijerph15020309

29 Chen, J., DuGoff, E. H., Novak, P., & Wang, M. Q. (2018). Variation of hospital-based adoption of care coordination services by community-level social determinants of health. Health Care Management Review. Retrieved from https://doi.org/10.1097/hmr.0000000000000232

30 Johnston, B. J., Peppard, L., & Newton, M. (2015). Staying connected: Sustaining collaborative care models with limited funding. Journal of Psychosocial Nursing and Mental Health Services, 53(8), 36-44. https://doi.org/10.3928/02793695-20150720-06

31 McAlearney, A. S., Murray, K., Sieck, C., Lin, J. J., Bellacera, B., & Bickell, N. A. (2016). The challenge of improving breast cancer care coordination in safety-net hospitals: Barriers, facilitators, and opportunities. Medical Care, 54(2), 147-154. https://doi.org/10.1097/mlr.0000000000000458

32 Hersh, W. R., Totten, A. M., Eden, K. B., Devine, B., Gorman, P., Kassakian, S. Z., . . . McDonagh, M. S. (2015). Outcomes from health information exchange: Systematic review and future research needs. JMIR Medical Informatics, 3(4), e39. https://doi.org/10.2196/medinform.5215

33 Nguyen, O. K., Chan, C. V., Makam, A., Stieglitz, H., & Amarasingham, R. (2015). Envisioning a social-health information exchange as a platform to support a patient-centered medical neighborhood: A feasibility study. Journal of General Internal Medicine, 30(1), 60-67. https://doi.org/10.1007/s11606-014-2969-8

34 Ramanuj, P., Ferenchik, E., Docherty, M., Spaeth-Rublee, B., & Pincus, H. A. (2019). Evolving models of integrated behavioral health and primary care. Current Psychiatry Reports, 21, 4. https://doi.org/10.1007/s11920-019-0985-4

35 Rudin, R. S., & Bates, D. W. (2014). Let the left hand know what the right is doing: A vision for care coordination and electronic health records. Journal of the American Medical Informatics Association, 21(1), 13-16. https://doi.org/10.1136/amiajnl-2013-001737

36 Cabassa, L. J., Manrique, Y., Meyreles, Q., Capitelli, L., Younge, R., Dragatsi, D., . . . Lewis-Fernandez, R. (2018). “Treated me ... like I was family”: Qualitative evaluation of a culturally-adapted health care manager intervention for Latinos with serious mental illness and at risk for cardiovascular disease. Transcultural Psychiatry. https://doi.org/10.1177/1363461518808616

37 Gruenewald, D. A., Doan, D., Poppe, A., Jones, J., & Hutt, E. (2018). “Meet me where I am”: Removing barriers to end-of-life care for homeless veterans and veterans without stable housing. American Journal of Hospice and Palliative Care, 35(12), 1483-1489. https://doi.org/10.1177/1049909118784008

38 Milaney, K. (2011). The 6 dimensions of promising practice for case managed supports to end homelessness, part 1: Contextualizing case management for ending homelessness. Professional Case Management, 16(6), 281-287. https://doi.org/10.1097/NCM.0b013e31821ee840

39 O'Campo, P., Kirst, M., Schaefer-McDaniel, N., Firestone, M., Scott, A., & McShane, K. (2009). Community-based services for homeless adults experiencing concurrent mental health and substance use disorders: A realist approach to synthesizing evidence. Journal of Urban Health, 86(6), 965-989. https://doi.org/10.1007/s11524-009-9392-1

40 Sznajder-Murray, B., & Slesnick, N. (2011). 'Don't leave me hanging': Homeless mothers' perceptions of service providers. Journal of Social Service Research, 37(5), 457-468. https://doi.org/10.1080/01488376.2011.585326

41 Vanderboom, C. E., Thackeray, N. L., & Rhudy, L. M. (2015). Key factors in patient-centered care coordination in ambulatory care: Nurse care coordinators' perspectives. Applied Nursing Research, 28(1), 18-24. https://doi.org/10.1016/j.apnr.2014.03.004

42 Dinnen, S., Kane, V., & Cook, J. M. (2014). Trauma-informed care: A paradigm shift needed for services with homeless veterans. Professional Case Management, 19(4), 161-170. https://doi.org/10.1097/ncm.0000000000000038

43 Substance Abuse and Mental Health Services Administration. (2014). SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. (HHS Publication No. [SMA] 14-4884). Rockville, MD: Substance Abuse and Mental Health Services Administration. Retrieved from https://store.samhsa.gov/system/files/sma14-4884.pdf

44 Thompson-Lastad, A., Yen, I. H., Fleming, M. D., Van Natta, M., Rubin, S., Shim, J. K., & Burke, N. J. (2017). Defining trauma in complex care management: Safety-net providers' perspectives on structural vulnerability and time. Social Science and Medicine, 186, 104-112. https://doi.org/10.1016/j.socscimed.2017.06.003

45 Blanchard, J., & Lurie, N. (2004). R-E-S-P-E-C-T: Patient reports of disrespect in the health care setting and its impact on care. Journal of Family Practice, 53(9), 721-730. Retrieved from https://www.mdedge.com/familymedicine/article/65550/r-e-s-p-e-c-t-patient-reports-disrespect-health-care-setting-and-its

46 Fraze, T. K., Beidler, L. B., Briggs, A. D. M., & Colla, C. H. (2019). 'Eyes in the home': ACOs use home visits to improve care management, identify needs, and reduce hospital use. Health Affairs, 38(6), 1021-1027. https://doi.org/10.1377/hlthaff.2019.00003

47 Takahashi, P. Y., Finnie, D. M., Quigg, S. M., Borkenhagen, L. S., Kumbamu, A., Kimeu, A. K., & Griffin, J. M. (2019). Understanding experiences of patients and family caregivers in the Mayo Clinic Care Transitions program: A qualitative study. Clinical Interventions in Aging, 14, 17-25. https://doi.org/10.2147/cia.S183893

48 Dorsey, E. R., & Topol, E. J. (2016). State of telehealth. New England Journal of Medicine, 375(2), 154-161. Retrieved from https://www.nejm.org/doi/full/10.1056/NEJMra1601705

49 Beck, A. F., Henize, A. W., Kahn, R. S., Reiber, K. L., Young, J. J., & Klein, M. D. (2014). Forging a pediatric primary care-community partnership to support food-insecure families. Pediatrics, 134(2), e564-571. https://doi.org/10.1542/peds.2013-3845

50 Mays, G. P., Mamaril, C. B., & Timsina, L. R. (2016). Preventable death rates fell where communities expanded population health activities through multisector networks. Health Affairs, 35(11), 2005-2013. Retrieved from https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2016.0848

51 Rocque, G. B., Pisu, M., Jackson, B. E., Kvale, E. A., Demark-Wahnefried, W., Martin, M. Y., . . . Partridge, E. E. (2017). Resource use and Medicare costs during lay navigation for geriatric patients with cancer. JAMA Oncology, 3(6), 817-825. https://doi.org/10.1001/jamaoncol.2016.6307

52 Shier, G., Ginsburg, M., Howell, J., Volland, P., & Golden, R. (2013). Strong social support services, such as transportation and help for caregivers, can lead to lower health care use and costs. Health Affairs, 32(3), 544-551. https://doi.org/10.1377/hlthaff.2012.0170

1. TCCI CARE COORDINATION CASE STUDY: OVERVIEW

The Massachusetts Health Policy Commission (HPC) is an independent state agency that develops policy to reduce health care cost growth and improve the quality of patient care. The HPC's mission is to advance a more transparent, accountable, and equitable health care system through its independent policy leadership and innovative investment programs. The HPC's goal is better health and better care – at a lower cost – for all residents across the Commonwealth.

The HPC invests in and tests promising and innovative care delivery and payment models that hold promise for supporting achievement of the Commonwealth's goals of reducing health care cost growth and ensuring access to high-quality services. The HPC launched the Targeted Cost Challenge Investments Program (TCCI Program) in 2016 as a pathway of the Health Care Innovation Investment Program to "foster innovation in health care payment and service delivery by supporting promising innovations that address the Commonwealth's most complex health care cost challenges."[1] The TCCI Program provided $6.6 million in funding to ten awardees, who partnered with more than 60 community organizations to conduct 18-month programs designed to address challenges related to social determinants of health, behavioral health integration, post-acute care, serious advancing illness and care at the end of life, and site and scope of care. For a complete description of TCCI and findings from the ten initiatives, please see the Targeted Cost Challenge Investments Program Evaluation Report.

A number of TCCI awardees chose to employ care coordination in their programs. The goal of the TCCI Care Coordination Case Study was to collect and synthesize participant and provider perspectives on strategies for care coordination tested by four TCCI awardees: Behavioral Health Network, Boston Health Care for the Homeless Program, Brookline Community Mental Health Center, and Care Dimensions. The four included initiatives worked to coordinate care for people living in their communities with complex medical, health care, and social needs. This study seeks to understand participant and provider perspectives on these efforts, with the intent to inform further efforts to improve outcomes for some of the Commonwealth's most disadvantaged populations.

2. CARE COORDINATION AND VULNERABLE POPULATIONS

Care coordination refers to "the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services."[2] This typically involves communication and the exchange of information among these parties,[2,3] as well as activities such as specifying providers' roles in care and developing and implementing a care plan.[2,4] Care coordination can have a wide range of benefits, including improving patient outcomes,[2] reducing utilization,[2,5,6] and increasing continuity of care.[2] However, various factors pose barriers to its implementation. These obstacles include a lack of medical record interoperability;[7,8] time, resource, and staffing limitations;[9,10] and a lack of avenues for reimbursement,[9,11] though recent changes have begun to address this last issue for some patient groups.[12]

Care coordination often includes care planning,[2,4] a process in which providers and patients proactively discuss care[4,13,14] and assign specific roles to different parties.[4] The process typically incorporates shared decision-making and focuses on patients' goals,[4,13,14] as well as addressing psychosocial needs[13,14] and providing self-management support.[4,13,14] Care planning can also—but does not always—result in the development of a care plan, which is a written document recording the decisions made during care planning.[4] The specific contents of these documents vary based on patients' circumstances,[4] but often include background information about the patient and their providers;[15,16] a summary of the patient's goals and needs, as well as the team members responsible for addressing them;[15,16] identification of specific tasks to be completed;[15,16] and information about evaluation and follow-up.[16] Evidence suggests that care planning can improve patient outcomes,[13,17] and sharing these plans across providers is thought to be particularly valuable for coordinated care.[16,18]

For medically and socially vulnerable and complex populations, care coordination is particularly vital. These groups often experience worse health[19-21] and higher social needs,[20-24] yet receive more fragmented care[20-22,24,25] and face barriers to health care access.[20,21,24-29] Care coordination has shown promise for improving outcomes for these populations.[30-34] To realize the full potential of this approach, addressing social needs as part of these efforts is essential: social needs play an important role in driving both medical outcomes and costs,[35-40] and addressing them can contribute to improvements in both areas.[40-44] While formal care plans can be helpful for care planning and coordinating medical and social needs they are only one component of care coordination,[3,4,45] and relational elements—building trust with patients and relationships with other providers—are foundational to the process.[3,16,46,47]

3. METHODOLOGY

The primary area of interest in this case study was the process of care coordination and its effectiveness in creating resonance for participants and relevance for health care and social service providers. To investigate these matters, the study team conducted qualitative interviews with participants in awardees' participant-centered care coordination initiatives. In addition, focus groups were conducted with awardee staff and staff of partner organizations. This qualitative methodology was selected because it allowed us to uncover insights and perspectives in a way not possible through a quantitative approach. This case study was designed and written as a complement to the HPC's comprehensive, mixed-methods evaluation of the TCCI initiatives.

Awardee- and partner-specific focus groups began with a general overview of the awardee's initiative, then moved to staff or partner perceptions of the best strategies for serving the target population, as well as how care coordination (or its implementation) did or did not improve outcomes. Focus group participants also shared their perceptions about what was helpful and how the program could improve. Finally, facilitators presented the interviewed participants' worldviews and perspectives on care coordination, facilitating a discussion among the focus group participants. The study team supplemented focus groups with individual phone calls with awardee partner staff who were not able to attend.

Participant interviews were conducted in participants' homes or awardees' offices and took place in either English or Spanish. Family members of Palliative Care+ participants were included in interviews or interviewed instead of participants when appropriate. Across awardees, eligible interview participants were people of all genders, races, and ethnicities who were aged 18 years or older and able and willing to provide consent. Participants were also required to be enrolled in one of the awardees' TCCI initiatives, each of which had its own set of conditions for participation. A subset of interview participants was interviewed again after three months to develop a deeper understanding of the care coordination process over time.

For the full methodology used in this case study, please see **Appendix A: Case Study Methodology** of this report.

4. AWARDEE INITIATIVES

BEHAVIORAL HEALTH NETWORK: PROJECT FIT

Behavioral Health Network (BHN) is a large, community-based organization in Western Massachusetts that provides behavioral health services for adults, children, and families facing challenges related to mental illness, substance abuse, or intellectual and developmental disabilities. The goal of its TCCI-supported initiative, Families in Transition (Project FIT), was to provide overall stability to participants through a "high-touch" care coordination program that connected behavioral health, primary care, housing supports, and vocational services. Project FIT targeted families with a child under age 18 in the household (or a reunification plan in place), housing instability (as identified by referring partners), and at least one member with undertreated substance use disorder and/or an unmet behavioral health need. This focus on the family unit was unique among included initiatives and meant that Project FIT staff provided services to both parents and children, working with all family members to assess, track, and address their individual needs.

Key partners in the Project FIT initiative included the Springfield Housing Authority (SHA) and Way Finders, both housing providers and important sources of referrals for Project FIT. When a new participant was referred, a BHN clinical care manager (CCM) and community health worker (CHW) met with the family for intake and assessment. The CCM then developed a family care plan. The CHW carried out this plan over time, including meeting with the family and coordinating with other service and care providers. CCM and CHW pairs met every other week in case consultation teams to ensure consistency and relevance of their combined efforts with the families. Focusing on the family unit added complexity to this process, as Project FIT staff needed to track each family member and address their individual needs and providers.

PROJECT FIT KEY ELEMENTS

- Collaboration with housing providers
- Integrated health care
- Integrated behavioral health services

Care planning within Project FIT was rooted in ongoing relationships and communication between project staff and participants. Because participants' needs were often urgent and evolving, trusting relationships and continued contact helped BHN and partner staff respond to high-priority issues in a timely way. In addition, Project FIT staff created written care plans at intake and updated them based on subsequent reassessments. These written plans were used primarily within BHN. A hallmark strength of Project FIT was the ongoing communication between BHN and partner staff, which occurred through face-to-face meetings and ad hoc phone contact and was driven by the shared mission of addressing participants' ever-changing circumstances.

Project FIT's approach of listening to participants, helping them respond to urgent needs, devising participant-driven care plans, and working with other social needs organizations is well-established in the literature.[30,33,48-51] In addition, many Project FIT staff members shared characteristics and cultural similarities with the initiative's participants, commonalities that helped them to form trusting and supportive connections. Many Project FIT participants appreciated the personal and emotional support provided by the CCM and the CHW. Nearly every participant interviewed shared an instance when a Project FIT staff member helped them complete a form, assisted them with a phone call, or accompanied them to an important appointment. In the words of one participant: **"'No hay malo que decir,' there is nothing bad to say. The CHW and CCM were like guardian angels for me and my son."**

Additional details about the Project FIT initiative are presented in **Appendix B: Detailed Project FIT Case Study**.

BOSTON HEALTH CARE FOR THE HOMELESS PROGRAM: SDH CONSORTIUM

The mission of the Boston Health Care for the Homeless Program (BHCHP) is to provide high-quality health care for homeless individuals and families in the Boston area. The goal of BHCHP's TCCI initiative, known as the Social Determinants of Health (SDH) Consortium, was to improve the care and lives of Boston's highest-need patients by serving as a hub for a team of medical providers, shelters, and advocacy organizations. This team consisted of primary, acute, and specialty providers and was responsible for identifying participants, tracking utilization, and providing intensive care coordination. BHCHP's partners in this initiative included Bay Cove Human Services, Boston Public Health Commission, Boston Rescue Mission, Casa Esperanza, Massachusetts Housing and Shelter Alliance, New England Center and Home for Veterans, Pine Street Inn, St. Francis House, and Victory Programs. The SDH Consortium targeted the MassHealth patients with the highest health care costs who were attributed to BHCHP with high emergency department (ED) and/or hospital utilization in the most recent six months. Participants were identified for the program using MassHealth claims data. Case managers (CMs), most of whom were employed by partner organizations, then connected with participants when they visited an SDH Consortium organization or through street outreach. After participants were enrolled, CMs met with them weekly, developed care plans, and participated in case conferences with medical/behavioral health providers and participants. Data from CMs, BHCHP, and SDH Consortium partners were stored in the Boston Department of Neighborhood Development data warehouse, an innovative feature of the SDH Consortium that allowed BHCHP and its partners to access and share participant data in a centralized way.

SDH CONSORTIUM KEY ELEMENTS

- Collaboration among primary care, behavioral health, housing, shelter, and social services organizations
- Integrated case management
- Existing connections with target population

While the SDH Consortium created initial care plans for participants, these were point-in-time documents that provided a place to start but were not regularly updated. Instead, the initiative focused on providing evolving, participant-centered care that was coordinated through frequent communication both among staff members and clinicians and with participants. This care responded to participants' changing circumstances and goals as they arose, but was not necessarily reflected through ongoing updates of a formal, written care plan document.

The SDH Consortium's approach of providing case management,[31,32,52] integrating social and medical services,[53-55] and offering tailored medical care[29,32,53-55] through BHCHP clinicians is strongly evidence-based. Interviewed participants were relentless in their praise and genuine respect for the SDH Consortium team and their BHCHP medical and behavioral health providers. They reported that SDH Consortium and BHCHP staff did not judge them. Instead, they listened, knew how hard it was for them to survive, and worked with them to outline a path to meet their basic needs and work towards longer-term solutions. As one participant explained, **"[The CM] helped me see my priorities, helped me find my way."**

Additional details about the SDH Consortium are presented in **Appendix C: Detailed SDH Consortium Case Study**.

BROOKLINE COMMUNITY MENTAL HEALTH CENTER: HEALTHY LIVES

Brookline Community Mental Health Center (BCMHC) provides mental health care and community-based social services to all Brookline-area residents, regardless of ability to pay. The goal of its TCCI initiative, Healthy Lives, was to deploy a mobile, multidisciplinary care management team to integrate behavioral health, primary care, and community services. This team included a nurse care manager, a social worker, and health outreach workers. One of the key partners in the Healthy Lives initiative was Beth Israel Deaconess Care Organization (BIDCO), a physician and hospital network and HPC-certified accountable care organization (ACO). The initiative targeted adult BIDCO patients with expenditures of at least $50,000 in the last year, a behavioral health condition, and two or more chronic medical conditions.

Participants were referred to Healthy Lives by a clinician or BIDCO nurse care manager. The Healthy Lives team then gathered participant information and potential resources, conducted a home visit and initial needs assessment, and continued to meet with participants over time, including accompanying them to medical or community appointments. Participants were discharged from the Healthy Lives program after six to 12 months, once they had been stabilized.

The Healthy Lives multidisciplinary care management team focused on integrating the care participants received from a variety of medical, behavioral health, and community providers. This enabled medical, behavioral, and social care plans to mesh together in a way that best supported participants' stated goals and needs. For the purposes of the Healthy Lives initiative, "care plans" consisted of the strategies deployed to accomplish this participant-centered integration.

The Healthy Lives initiative's approach of using care managers to coordinate between staff and clinicians,[25,56-60] provide coaching and support to participants,[25,56-60] and work with participants on practical skills, illness self-management, and goal setting[56] is well-supported in the literature. Within the Healthy Lives initiative, interviewed participants felt supported and that someone was listening to them, working on their behalf, and helping them advocate for themselves. All interviewed participants valued meeting with Healthy Lives team members to discuss their medical, behavioral, and social needs: **"They know so much. They really help me understand."**

Additional details about Healthy Lives are presented in **Appendix D: Detailed Healthy Lives Case Study**.

HEALTHY LIVES KEY ELEMENTS

- Integration of behavioral health, primary care, and community services
- Mobile, community-based approach
- Extended duration of contact and more frequent contacts
- Transition to less-intensive services after six to 12 months
- Flexibility of services to address a wide range of needs

CARE DIMENSIONS: PALLIATIVE CARE+

Care Dimensions provides palliative and hospice care for people in Eastern Massachusetts. The goal of its TCCI initiative, Palliative Care+, was to integrate palliative care staff into primary care sites in order to increase early identification of patients and bridge the gap between curative and end-of-life care. For this project, Care Dimensions partnered with North Shore Physicians Group (NSPG), a multispecialty practice with more than 20 locations throughout the North Shore. The Palliative Care+ initiative targeted high-risk NSPG patients who were part of the practice's ACO.

Participants were referred to the program by NSPG high-risk nurse care managers (NCMs), physicians, and nurse practitioners (NPs). In addition, as part of the TCCI grant, NSPG employed a Palliative Care+ liaison who visited primary care practices regularly and helped to identify participants and facilitate referrals. Once participants were referred, the Care Dimensions Palliative Care+ team—consisting of NPs, nurses, and a social worker—pulled and entered any participant information that was available through Partners HealthCare's Physician Gateway portal, talked to NSPG high-risk NCMs to see why the participant was referred, and called the participant to schedule an appointment. After that, a Care Dimensions NP conducted a home visit and any new information was communicated back to NSPG. Participants then received ongoing care as needed, including weekly phone calls from a Care Dimensions nurse.

Because many participants had already received care plans from multiple providers, Palliative Care+ focused less on creating new, independent plans and more on operationalizing existing plans in a participant-centered way. This occurred largely through speaking with participants and helping them to synthesize recommendations and identify priorities that aligned with their goals. Frequent and ongoing communication between the Care Dimensions team and NSPG high-risk NCMs facilitated coordination throughout this process.

PALLIATIVE CARE+ KEY ELEMENTS

- Integrating palliative care staff into primary care sites
- Using triggers to identify appropriate patients
- Educating physicians and the community
- Increasing hospice admission and advance care planning

The Palliative Care+ initiative utilized many evidence-based approaches, including delivering palliative care through an interdisciplinary, outpatient palliative care team,[34,61-63] communicating and collaborating with participants' other providers,[34,64,65] and using a systematic process for screening and referral.[61,66] Despite the presence of a social worker on the Care Dimensions team, social needs—a challenge for many palliative care patients[22,62,67] and their families[68,69]—were not a prominent focus of the initiative, and were identified as a gap by interviewed participants and caregivers. However, participants did feel that NSPG and Palliative Care+ helped to assess and address their medical priorities, as well as to make sense of the many recommendations they had received from different providers: **"I know there are things I must do to stay out of that hospital. It's confusing. The [Palliative Care+] nurse helped me sort it out."**

Additional details about Palliative Care+ are presented in **Appendix E: Detailed Palliative Care+ Case Study**.

5. CARE COORDINATION CONSIDERATIONS

The awardees included in this study worked with complex populations whose behavioral, medical, and social needs required coordination across a wide range of providers. This coordination occurred primarily through communication among awardees, partners, and participants, and was facilitated by trusting relationships between participants and initiative staff. Addressing social needs was an important element of these efforts. However, even with well-planned, strongly implemented, evidence-based initiatives, the four awardees faced shared challenges stemming from big-picture issues beyond their reach. While these challenges limited initiatives' impacts, the programs were nevertheless seen as valuable by staff members and appreciated by participants.

COMPLEX NEEDS REQUIRE MULTIFACETED INTERVENTIONS

The four included awardees worked with some of the most medically and socially complex individuals living in Massachusetts communities. BHN's Project FIT targeted families facing housing insecurity, who often have trauma histories,[70,71] higher health care needs and utilization,[21,51] limited social support,[21] and higher rates of mental health concerns, developmental delays, and substance use.[21,51,72] BHCHP's SDH Consortium worked with homeless individuals, who face challenges such as higher mortality,[20,73] worse physical[20,54] and mental health,[20,54,74] histories of trauma,[20,75] and a wide range of barriers to health care.[20,29] Brookline Community Mental Health Center's Healthy Lives initiative targeted people with serious mental and physical health conditions, who tend to have high health care needs and utilization[19,76,77] but face barriers such as stigma,[25,27,28] fragmentation between physical and mental health care[25,28] and symptoms of mental illness that may interfere with seeking treatment.[25,28] Finally, the Care Dimensions Palliative Care+ initiative worked with participants with serious illnesses, who need coordinated, responsive care that centers their goals and priorities[34,78,79] and supports caregivers as they navigate emotional, physical, and financial burdens.[68,69]

Addressing these complex needs requires robust interventions that coordinate across medical, behavioral, and social needs providers. For families with housing insecurity, care coordination approaches are most effective when combined with housing supports,[30,33] as well as when they incorporate other important service providers such as primary care practices[48,51] and schools.[51] People experiencing homelessness benefit from integrated care models combining medical and social services,[53-55] tailored models of care delivery,[29,32,53-55] and case management.[31,32,52] Similarly, people with serious mental and physical illness benefit from integrated care models that coordinate physical and mental health care,[25,56,60,80,81] as well as from care management and coaching.[25,56-60] Palliative care that is delivered through an interdisciplinary team[34,61-63] and that communicates and collaborates with patients' other providers[34,64,65] is valuable for people with serious illnesses and their families.

The four included initiatives incorporated many of these evidence-based approaches. However, providing these comprehensive interventions is challenging, and becomes even more difficult in the context of limited financial, time, and staffing resources.[82-84] Project FIT, SDH Consortium, and Healthy Lives awardees and partners all discussed this issue in focus groups. For example, BHCHP medical and behavioral health providers reported that the volume and high needs of the patients they treated made it challenging to provide concentrated attention to SDH Consortium participants. Healthy Lives partner clinicians regretted the initiative's limited catchment area, feeling that many patients who could have benefited from the program were unable to access it.

> *"It gets overwhelming when the need is greater than can be met."*
>
> **– SHA STAFF MEMBER (PROJECT FIT)**

ROBUST COMMUNICATION UNDERPINS CARE COORDINATION

For included initiatives, care coordination was a high-touch, human process based on continuous, responsive communication among awardees, their partners, and participants. While written care plans provided a place to start, care coordination within these programs was primarily relationship-based and formal care plans were not emphasized.

Project FIT and Palliative Care+ primarily relied on direct communication to exchange information about participants. For Project FIT, this included monthly meetings between BHN and partner organizations and frequent ad hoc communication about participant needs. For Palliative Care+, direct communication consisted of frequent ad hoc contact between the Care Dimensions team and NSPG high-risk nurse care managers, meetings between the two organizations' administrative teams, and the use of a dedicated liaison who helped identify participants and facilitate referrals. From Palliative Care+ participants' perspectives, the Care Dimensions and NSPG teams appeared to be one and the same, and clinicians from both Palliative Care+ and Project FIT considered ongoing communication to be key to the initiatives' success. Care Dimensions and NSPG clinicians also noted the importance of interpersonal relationships among providers, sharing examples of situations in which this facilitated referrals or coordination.

The SDH Consortium and Healthy Lives utilized direct communication as well, but supplemented it with shared access to health and social service records. Such access has the potential to facilitate coordination,[8,81,85,86] making information-sharing faster, more comprehensive, and more convenient. The SDH Consortium employed a sophisticated data-sharing approach, utilizing a data warehouse that was shared across partners and included social and medical information about participants. Healthy Lives used a shared medical record that allowed the BCMHC and BIDCO teams to see each other's notes and communicate easily. In both initiatives, care management teams and medical/behavioral health providers considered electronic integration to be valuable for the success of the program. Interviewed SDH Consortium participants specifically noticed and appreciated this sharing of information.

> *"I have five doctors and two, maybe three CMs and they all talk to each other."*
>
> **– SDH CONSORTIUM PARTICIPANT**

While communication was a key element of all included initiatives, staff also reported challenges in this area. Palliative Care+ staff and primary care partners identified lack of electronic data sharing as a barrier and felt that it would have been beneficial for Care Dimensions to have access to the NSPG electronic medical record. In addition, Palliative Care+ staff reported difficulty following participants across care settings, such as hospitals, rehabilitation facilities, and nursing homes. This caused fragmentation and limited the extent to which the team could participate in discharge planning for these participants, posing obstacles to effective palliative care.[34,65] Within Project FIT, medical providers were not involved in the care planning process, and there was no systematic structure for joint planning or regular sharing of information. While BHN staff reached out to primary care and other providers on an as-needed basis, BHN staff perceived primary care practices as being non-responsive to these requests.

BUILDING TRUST WITH PARTICIPANTS IS A PREREQUISITE FOR SUCCESS

Like communication among providers, trusting relationships with participants are essential for successful care coordination.[50,87-91] This is particularly true for the populations included in this study. For example, target populations with histories of trauma—a description that characterizes many Project FIT and SDH Consortium participants—require special consideration.[92-94] The same is true of people who, like many Healthy Lives and Palliative Care+ participants, have had negative experiences with the health care system.[50,95] Staff members from Project FIT, the SDH Consortium, and Healthy Lives emphasized the importance of building trusting relationships with participants and believed that their work would not have been possible without this trust as a foundation. Participants in these initiatives also expressed their appreciation of the strong connections they built with program staff, sometimes describing them as **"family."** While these relationships facilitated care coordination and were meaningful to participants, they also meant that a staff member's departure was often difficult for affected participants.

> *"Without trust, participants will not be able to work with you."*
>
> **– PROJECT FIT STAFF MEMBER**

Evidence-based strategies for building trust with participants include treating them with respect and compassion,[34,50,88,90,96] being nonjudgmental,[50,88,96] and using strengths-based approaches that focus on participants' abilities and priorities.[49,89,97] Staff members from the four initiatives described similar methods, including treating participants respectfully and compassionately, centering their priorities and concerns, explaining how the program could help, and maintaining contact over time.

Home visits—incorporated by most of the included initiatives—also offer a valuable opportunity to build relationships, identify needs and barriers, reconcile medications, and provide education and coaching.[98,99] The Project FIT, Healthy Lives, and Palliative Care+ initiatives all incorporated home visits, while the SDH Consortium utilized street outreach. Healthy Lives staff and clinicians particularly emphasized the importance of home visits, noting that these visits, which allowed team members to conduct hands-on medication reconciliation, learn more about participants' life circumstances, provide education, and conduct follow-up, were key to the initiative's success. Interviewed participants also valued the personal attention. After finding that many Palliative Care+ participants did not accurately report how they were doing when the nurse called them, Care Dimensions leadership discussed their intention to incorporate more home visits in future iterations of the program. This approach is in contrast to the trend for health and care coordination services to increasingly be delivered telephonically or electronically[100] and suggests that these strategies may not be effective with all medically and socially complex and vulnerable populations.

> *"Being in their home allows us to see and feel how they navigate things."*
>
> **– HEALTHY LIVES TEAM MEMBER**

ADDRESSING SOCIAL NEEDS IS ESSENTIAL

Social needs play an important role in driving both medical outcomes and costs.[35-40] People living in deprived neighborhoods, making low or no incomes, or facing food insecurity are more likely to become high-cost users of health care in the future,[38] and people with higher social needs also tend to have higher current utilization.[39] Addressing social needs is therefore an essential element of efforts to both improve patient outcomes and decrease costs.[40-44] Given the complex social needs of their participants, all four initiatives incorporated efforts to address these issues, though some placed more emphasis on this than others. In instances where these efforts were less central to the initiative's design, social issues arose as a key gap for participants.

HOUSING-RELATED INITIATIVES

Even once a housing-insecure family or individual obtains housing, social and economic factors can interfere with keeping it.[101-103] BHN and partner staff worked with Project FIT participants on a wide range of issues to help them find and maintain stable housing. This included helping them advocate for their children within the school district, work with the Department of Children and Families, and apply for Supplemental Security Income support. Similarly, SDH Consortium team members worked with participants to address their varied social needs, including assisting them with finding food and shelter, arranging transportation, and applying for public assistance programs. Teams worked with participants over time to help them recover from setbacks or address new challenges.

These approaches resonated with participants in both initiatives. Many interviewed Project FIT participants reported calling the Project FIT team when problems arose and getting immediate assistance and several shared milestone accomplishments that they believed the Project FIT team helped them achieve. SDH Consortium participants felt that program staff listened to them nonjudgmentally, understood the obstacles they were facing, and worked with them to find a way forward. They appreciated that the SDH Consortium team's support continued over time, even as new obstacles arose.

> *"These folks don't give up. No matter what I have done they find me and we start again."*
>
> **– SDH CONSORTIUM PARTICIPANT**

INITIATIVES FOR PEOPLE WITH SERIOUS ILLNESSES

For palliative care patients and people with serious mental and physical illnesses, social support needs play a key role in overall health and wellbeing. People receiving palliative care often face emotional, spiritual, and practical concerns,[22,62,67] while their family members and caregivers encounter a range of emotional, physical, and financial challenges.[68,69] People living with serious mental illness often have substantial social, emotional, and practical needs.[23,104] Providing high-quality care for these groups requires addressing these issues.[34,105-107] This was a significant focus of the Healthy Lives initiative, and one that was appreciated by participants and understood by staff members as an important part of the program. The Palliative Care+ initiative also made an effort to address participants' social support needs by incorporating a social worker, but robust attention to social support needs was outside the scope of the model and was a key gap identified by interviewed participants.

Some participants in both the Healthy Lives and Palliative Care+ initiatives needed support in caring for beloved pets that represented a life-sustaining, therapeutic presence. Spending time with animals, such as during animal-assisted therapy, has been shown to help improve emotional wellbeing[111,112]—an important issue for the populations these programs targeted, who often face loneliness and social isolation.[22,23] Many participants in both the Healthy Lives and Palliative Care+ initiatives greatly valued their pets. The Healthy Lives team recognized the pets' therapeutic role and, when needed, was able to help participants find support in caring for their animals. In contrast, this was outside the scope of the Palliative Care+ team's work, and organizations that participants were referred to often told them that they needed to give up their pets. This caused great distress for these participants, many of whom considered their pet to be one of their most important sources of companionship and a reason to live.

> *"I would rather die. I cannot give [my dog] up."*
>
> **– PALLIATIVE CARE+ PARTICIPANT**

The Palliative Care+ and Healthy Lives initiatives faced serious difficulties with the quality and reliability of home health aides. Home health care is known to be of variable quality both in Massachusetts and nationally[108] and to involve safety risks for both patients and providers.[109] In addition, it is a low-wage and a physically and emotionally demanding field to work in.[110] Both Healthy Lives and Palliative Care+ participants experienced recurring issues with personal care aides who did not show up, even after participants made repeated calls to the providing agency. This presented serious difficulties for participants who depended on home health aides to address basic needs and made them feel that they were at the mercy of people who did not care about them.

COMMUNITY RESOURCE INEQUITIES CONSTRAIN THE EFFICACY OF CARE COORDINATION

Addressing social and other needs was complicated by inequities facing the communities in which initiatives were situated. Poverty and community-level economic inequality shape people's health and wellbeing,[113,114] and racism also impacts both individuals and communities.[115-117] The four initiatives worked to help participants navigate these circumstances and barriers, but rectifying these systemic issues was beyond their abilities.

AFFORDABLE, APPROPRIATE HOUSING

For housing-focused initiatives, community-wide equity issues include a lack of affordable housing,[118-120] as well as factors such as poverty and unemployment.[118] Lack of housing that meets the needs of the population, such as by offering a sober living environment[121,122] or being located accessibly to needed services,[122,123] can also present obstacles. In these contexts, focusing on care coordination and initiative goals was not enough to address the root causes of chronic homelessness, which stem from formidable institutional barriers that are beyond the scope of a single initiative to address.

For both Project FIT and the SDH Consortium, chronic homelessness and a lack of appropriate housing meeting participants' needs affected possibilities for care planning. SDH Consortium participants faced a lack of sober housing, as well as an overall lack of affordable housing in Boston.[124] Despite city-wide efforts to provide permanent supportive housing for chronically homeless individuals,[125,126] access to housing remained an intractable issue for many participants, and this was further complicated by the need to be close to service providers on which they relied. One SDH Consortium participant, for example, hesitated to accept a YMCA apartment because of concerns about making it back to BHCHP for appointments. Project FIT participants, similarly, faced an overall lack of affordable housing in Springfield,[124] as well as a shortage of permanent supportive housing for families.[125] In addition, participants reported challenges finding family living with attributes they needed, such as safe playgrounds and features adapted to their children's special needs. This was exacerbated by an overall lack of accessible transportation in the city.[127,128]

> *"The nicest, most caring social workers just cannot fix the system."*
>
> **– HEALTHY LIVES PARTICIPANT**

SCHOOL AND CHILDCARE

School systems and childcare can also be a meaningful source of inequity between and within communities.[129,130] Project FIT families, especially those with children with special needs, described significant gaps in accessing appropriate childcare and school programming. This was particularly challenging during the summer, with participants reporting that school programs did not offer transportation or that their child was unable to enroll because the option had not been selected as part of their Individualized Education Program. In addition, participants often found that community summer programs—even those with sliding-scale fees—were not affordable. Participants and staff members both felt that Project FIT meaningfully supported participants in advocating for their children during the school year; however, these efforts were not enough to fix existing gaps.

> *"[The community program] said I would have to pay $35 weekly for each of my girls. I don't have $70 a week. I have to spend less than that on food each week."*
>
> **– PROJECT FIT PARTICIPANT**

These issues intersected with housing and other challenges, with many participants describing childcare—often for children with special needs—as taking up much of their time and energy. That many Project FIT participants experienced trauma or other adverse events themselves may have exacerbated an already challenging situation for these families.[131-134]

ACCESS TO MEDICAL AND BEHAVIORAL HEALTH CARE

Variations in access to medical care can contribute to community-level inequities.[114,115] Housing-insecure families,[21,26] individuals experiencing homelessness,[20,29] and people with serious mental illness[25,27,28] all face barriers to health care access. While many Project FIT participants did have primary care providers (PCPs) for themselves and their children, they were often unable to get urgent care appointments when necessary and were instead told to go to the ED, which many saw as the easiest and most accessible place even for non-emergency care. Participants were often unaware of other options aside from PCPs and the ED, such as the federally qualified health center. Project FIT and Healthy Lives participants also faced transportation difficulties when trying to access care, often being unable to take public transit and instead having to rely on costly alternatives. In addition, both Healthy Lives and SDH Consortium participants reported negative experiences with health care providers, consistent with literature showing that stigma within health care settings is a challenge for people with serious mental illness[25,27,28] and/or experiencing homelessness.[135,136]

> *"They [medical, behavioral, and insurance providers] just do not care about me. I don't matter to them."*
>
> **– HEALTHY LIVES PARTICIPANT**

Access to behavioral health services—a documented problem within Massachusetts[137]—also presented barriers for participants across included initiatives. While BHN staff worked to address this issue for Project FIT families, such as by connecting them with behavioral health providers and sometimes providing therapy directly, long wait times remained a challenge. BHCHP clinicians described their patients as facing a three-month wait for psychiatric services, while Healthy Lives staff reported that their participants faced a three- to eight-month wait for a therapist. For Healthy Lives participants, finding behavioral health treatment was complicated by many participants' need for in-home therapy and the unwillingness of some providers to accept their cases.

CARE COORDINATION HAD POSITIVE IMPACTS

Care coordination had positive impacts for participants, staff members, and clinicians. All four initiatives used evidence-based care coordination strategies[25,29-34,48-66] to address the needs of their vulnerable target populations. These approaches resonated meaningfully with participants, who appreciated the personal, emotional, and practical support they received from program staff. Participants discussed feeling like someone was listening to them, advocating for them, and helping them determine their priorities and work toward their goals. Awardees' partners also appreciated the services the TCCI-supported initiatives provided, describing ways in which the programs helped them in their own work. Project FIT partners, for example, expressed appreciation for BHN's help in supporting participants and connecting them with needed services. BIDCO clinicians working with Healthy Lives greatly valued the initiative for its ability to uncover information, address participants' needs, and conduct follow-up in a way that would not have been possible without the program.

> *"Healthy Lives allowed us to do what we would not otherwise have been able to. Their team provided a better picture of the true situation and conducted more effective follow-up, especially for complex issues. It's a more effective intervention than anything we could do within our practice."*
>
> **– HEALTHY LIVES CLINICIAN**

6. CONCLUSION

Care coordination encompasses many evidence-based approaches that can improve patient outcomes and prevent avoidable health care utilization. For included initiatives, care coordination efforts resonated with participants, who felt that someone was listening and working with them to address their needs. In addition, initiative and partner organization staff believed that care coordination was relevant and a core aspect of their program's effectiveness. For all awardees, the impact of care coordination came less through a formal, written care plan and more through constant communication among awardees, partners, and participants—making it possible for awardees and partners to put their efforts into addressing participants' urgent, evolving circumstances. While this ongoing communication enabled positive impacts for both participants and providers, this case study also highlighted barriers that care coordination alone cannot address. For medically and socially complex and vulnerable, care coordination can help participants address some of their needs but cannot resolve structural deficits in the health care system and communities.

APPENDIX A: CASE STUDY METHODOLOGY

To investigate the Targeted Cost Challenge Investments Program (TCCI Program) Care Coordination Case Study questions, the study team conducted qualitative interviews with participants in awardees' participant-centered care coordination initiatives. In addition, we conducted focus groups with awardee staff and staff of partner organizations. This qualitative methodology was selected because the primary area of interest was the process of care coordination and its effectiveness in creating resonance for participants and relevance for providers. Qualitative interviews and focus groups with individuals involved in these processes allowed us to uncover such insights in a way not possible through a quantitative approach.

SPECIFICATIONS

The goal of the TCCI Program Care Coordination Case Study was to collect and synthesize participant and provider perspectives on strategies for care coordination as tested by four TCCI Program awardees: Behavioral Health Network (BHN; TCCI Program initiative: Families in Transition (Project FIT)), Boston Health Care for the Homeless Program (BHCHP; TCCI Program initiative: Social Determinants of Health (SDH) Consortium), Brookline Community Mental Health Center (BCMHC; TCCI Program initiative: Healthy Lives), and Care Dimensions (TCCI Program initiative: Palliative Care+). This case study was designed and written as a complement to the HPC's comprehensive, mixed-methods evaluation of the TCCI Program initiatives. Specific study questions included:

HOW DID THE INITIATIVE CREATE RESONANCE FOR PARTICIPANTS?

Specifically, how did care plan development:

- Assess medical, behavioral, and social needs?
- Elicit participant priorities without assumptions?
- Acknowledge the complexity of family and caregiver roles and relationships?
- Facilitate appropriate engagement of family and caregivers?
- Track progress against participant goals?

HOW DID THE INITIATIVE CREATE RELEVANCE FOR PROVIDERS AND PARTNERS?

Specifically, how or to what extent did the care plan:

- Serve as a living road map for care?
- Provide interoperability among users from medical, behavioral, and social services?
- Allow specific components to be disseminated and acted on?
- Respond to changing circumstances and new data?
- Include checks over time to monitor progress against participant goals?

All four awardees' initiatives served medically and socially vulnerable populations, including those experiencing housing instability, receiving palliative care, and/or living with serious physical and mental health concerns. Our aim in exploring these awardees' approaches to care coordination was to learn more about successful strategies to better meet the needs of these populations, as well as to gain insights into the ways that a range of providers can operationalize participant-centered care coordination.

CAPTURING AWARDEES' AND PARTNERS' PERSPECTIVES

The study team conducted awardee- and partner-specific focus groups to gather data on the perspectives of the awardees and their partners. Focus groups occurred after initial participant interviews were completed, which allowed them to utilize participant perspectives. Most focus groups were conducted in person, though two—those for Springfield Housing Authority (SHA) and for partners in the Healthy Lives initiative—took place virtually. The study team worked with awardees and partners to identify times that were likely to work for a majority of the staff members who had been involved with the initiative. Focus group attendance is reflected in Table 1.

Table 1: Focus Group Attendance

TYPE	PROJECT FIT	SDH CONSORTIUM	HEALTHY LIVES	PALLIATIVE CARE+	OVERALL TOTAL
STAFF FOCUS GROUP	16	8	5	9	**38**
PARTNER FOCUS GROUP(S)	3 (Way Finders), 7 (SHA)	13	4	17	**44**
TOTAL	**26**	**21**	**9**	**26**	**82***

*In addition, the team conducted three individual phone calls with partner staff members who could not attend focus groups.

Each focus group began with a general overview of the TCCI Program Care Coordination Case Study and of the awardee's initiative. This included asking participants which elements of the initiative's process they found most influential for care coordination and which outcome measures they found most relevant in assessing care coordination. Then, discussion moved to staff or partner perceptions of the best strategies for serving the target population, as well as how care coordination (or its implementation) did or did not improve outcomes. Focus group participants also shared their perceptions about what was helpful and how the program could improve. Finally, facilitators presented the interviewed participants' worldviews to assess if staff and partners felt that the interview sample was a good representation of the intervention's target population. This was followed by a presentation of interviewees' perspectives on care coordination, which facilitated a discussion among the focus group participants.

In addition, the study team conducted three individual phone calls with awardee partner staff who were not able to attend focus groups. One of these calls was with a leader at a Healthy Lives partner organization, while the other two were with physicians who worked with Palliative Care+ participants. These interviews were structured based on the focus group format. The study team also conducted ad hoc meetings with awardee program managers to clarify questions and validate study findings.

CAPTURING TARGET POPULATIONS' VOICES

The study team conducted qualitative interviews with participants enrolled in awardees' care coordination initiatives. Seasoned interviewers interacted with and observed participants and families during the spring and summer of 2018. Interviews with Project FIT, Healthy Lives, and Palliative Care+ participants took place mainly in their homes, while SDH Consortium participants were interviewed primarily at BHCHP's offices. For Palliative Care+ participants, family members were included in interviews or interviewed instead of participants when appropriate. While the majority of interviews were conducted in English, some were conducted in Spanish.

Across awardees, eligible interview participants were people of all genders, races, and ethnicities who were aged 18 years or older and able and willing to provide consent. Participants were also required to be enrolled in one of the awardees' TCCI initiatives, each of which had its own set of conditions for participation. These conditions are described in the awardee-specific sections. Eligibility was not restricted based on language.

Interview participant selection varied somewhat across awardees. For Project FIT, BHN staff identified eligible participants and scheduled them for interviews using a calendar that the study team provided. Interviewers then finalized recruitment at the scheduled meetings. To recruit SDH Consortium participants, an interviewer spent time on site at BHCHP. Awardee staff introduced the interviewer to eligible participants, who were recruited and interviewed at the time of introduction. For Healthy Lives, BCMHC staff identified eligible participants, requested permission to share their contact information, and provided that information to the study team. The interviewer then contacted potential participants for recruitment and scheduling. Finally, for Palliative Care+, Care Dimensions mailed a letter to eligible participants, informing them about the study and providing a phone number to call if they wished to opt out of being contacted about participation. Awardee staff then provided participant contact information to the study team, who called participants to conduct recruitment and scheduling.

A subset of interview participants was interviewed again after three months, in the fall of 2018. Second interviews mirrored initial interviews but dug deeper on key topics. Based on first interviews, topics were identified that had the greatest role in addressing the study questions. Total interview counts, including both first and second interviews, are reflected in Table 2.

Table 2: Interviews Conducted

TYPE	PROJECT FIT	SDH CONSORTIUM	HEALTHY LIVES	PALLIATIVE CARE+	OVERALL TOTAL
1ST INTERVIEW	21	10	10	13	**54**
2ND INTERVIEW	3	5	4	3	**15**
TOTAL UNIQUE INDIVIDUALS	21	10	10	13	**54**
TOTAL INTERVIEWS	**24**	**15**	**14**	**16**	**69**

LIMITATIONS

Because this is a qualitative analysis, it is not possible to generalize results to all care coordination programs serving included populations.[138,139] However, despite this lack of external validity, the study team took multiple steps to ensure the internal validity[138,139] and overall reliability of the findings. We triangulated data[138,139] by utilizing both participant interviews and awardee/partner focus groups, validating participant worldviews with awardees and partners, and drawing connections to the wider literature. We also performed member checking[138,139] with both participants and awardees. For awardees, this was accomplished by sharing draft reports for feedback and comment. For participants, this occurred through second interviews, which provided an opportunity not only to discuss topics in more depth, but also to confirm our understanding of what was originally shared.

Other study limitations include the fact that key partners for some initiatives were not accessible. Schools and primary care providers were important to Project FIT participants' experiences, but were not formal partners and not included in the data gathering or analysis. Physicians who cared for Palliative Care+ participants did not participate in focus groups, though the study team conducted two individual calls with physicians to supplement focus group data. Attendance at the focus group for partners in the Healthy Lives initiative was low due to the difficulty of reconciling schedules, so an individual call was conducted with a member of this group as well. In addition, while we worked to obtain an unbiased sample of participants, it is possible that our sample was influenced by underlying factors such as participants' level of functioning and willingness to speak with an unknown interviewer. Sharing participant worldviews with awardees and partners allowed us to validate that our sample was representative of the overall initiative population.

APPENDIX B: DETAILED PROJECT FIT CASE STUDY

Behavioral Health Network (BHN) is a large, community-based organization in Western Massachusetts that provides behavioral health services for adults, children, and families facing challenges related to mental illness, substance abuse, or intellectual and developmental disabilities. The goal of its TCCI initiative, Families in Transition (Project FIT), was to provide overall stability to participants through a "high-touch" care coordination program that connected behavioral health, primary care, housing supports, and vocational services. Project FIT targeted families with a child under age 18 in the household (or a reunification plan in place), housing instability (as identified by referring partners), and at least one member with undertreated substance use disorder and/or an unmet behavioral health need. This focus on the family unit was unique among case study programs and meant that Project FIT staff provided services to both parents and children, working with all family members to assess, track, and address their individual needs.

Key partners in the Project FIT program included the Springfield Housing Authority (SHA) and Way Finders, both housing providers. The SHA is a publicly funded housing authority that administers state and federal rental assistance programs and provides public housing within Springfield. Way Finders provides a variety of housing support programs to residents of Western Massachusetts, including emergency housing, emergency financial assistance, and transitional housing for domestic violence survivors. Both the SHA and Way Finders were important sources of referrals for Project FIT, with Way Finders typically referring families who were in shelters and the SHA referring those who were housed but likely to lose their housing soon.

Primary elements of Project FIT included:

- Collaboration with housing providers to house participants and/or stabilize them in their existing housing,
- Integrated health care for participants' primary and secondary care needs, and
- Integrated behavioral health services.

When a new participant was referred, a BHN clinical care manager (CCM) and community health worker (CHW) met with the family for intake and assessment. The CCM then developed a family care plan. The CHW carried out this plan over time, including meeting with the family and coordinating with other providers. CCM and CHW pairs met every other week in case consultation teams to ensure consistency and relevance of their combined efforts with the families. Focusing on the family unit added complexity to this process, as Project FIT staff needed to track each family member and address their individual needs and providers.

Within Project FIT, care planning was rooted in ongoing relationships and communication between staff and participants. Because participants' needs were often urgent and evolving, trusting relationships and continued contact helped staff members and partners respond to high-priority needs in a timely way. In addition, Project FIT staff created written care plans at intake and updated them based on subsequent reassessments. These written plans were used primarily within BHN. While plans were shown to participants, most had little awareness of them; similarly, care plans could be shared with partners if participants gave permission, but this rarely occurred. Instead, coordination between Project FIT and key partners primarily took the form of monthly face-to-face meetings and ongoing phone communication.

Project FIT staff shared a variety of characteristics and cultural similarities with the program's participants. Most staff members were from the Springfield area, and many were bilingual. Some had direct life experiences that mirrored those of Project FIT's target population.

1. CONTEXTUAL FRAMEWORK

Families experiencing housing insecurity—Project FIT's target population—face a wide variety of health needs and negative social determinants of health. Compared with other low-income families, families who are homeless tend to have higher rates of emergency department (ED) use, more unmet care needs, and less social support.[21] Mothers who are homeless or facing housing insecurity have higher rates of substance abuse and mental health concerns,[21] while children are more likely to have physical and mental health challenges,[21,51,70] experience developmental delays,[21,51,72] and struggle in school.[21,51] In addition, both parents and children are more likely to have experienced interpersonal violence or other traumatic experiences.[70,71] These challenges intersect with obstacles facing the city of Springfield as a whole, which has higher rates of poverty, unemployment, crime, and teenage motherhood than the rest of the state, as well as lower rates of high school graduation.[140] Chronic family homelessness is also somewhat higher in Springfield than in the country as a whole: a point-in-time count of people who were unsheltered, living in shelters, or residing in transitional housing on a single night in 2018 found that about 7% of identified families in Hampden County were chronically homeless,[141] compared to a national rate of 5%.[142]

Addressing family housing insecurity requires tackling a number of intersecting issues. Policies and programs that reduce poverty and increase housing access appear to be among the most effective approaches to decreasing housing insecurity itself.[51] In addition, evidence suggests that care and service coordination may help improve housing stability and overall family wellbeing,[30,33] though research on this topic is still developing[30,33] and has at times been inconsistent.[30,51] Such care coordination appears to be most effective when combined with specific housing supports,[30,33] as well as when it incorporates other important service providers such as primary care practices[48,51] and schools.[51] In addition, available evidence highlights the importance of working with housing-insecure families in a way that is empowering, strengths-based, and centered on their specific goals and needs.[51] These best practices in care coordination for housing-insecure families are consistent with Project FIT's approach.

2. RELEVANCE FOR PROJECT FIT, WAY FINDERS, AND SHA PROVIDERS

Project FIT staff members viewed the care plan as a pragmatic and living document, qualities that were supported by its goal-focused design, incorporation into participants' program records, and periodic reassessments of participant status. Underlying these formal elements—and consistent with evidence-based practice[49-51]—was an emphasis on building trusting, open relationships with participants that would allow the care plan to reflect families' true circumstances and priorities. While care plans were not, in practice, shared with partners or other external providers, both BHN and partner staff understood care coordination as essential and viewed Project FIT as helpful in furthering that goal. BHN and partner team members also identified a range of challenges to such coordination, including unresponsiveness of primary care providers, long wait times for mental health services, resource limitations, and other systemic barriers.

CARE PLANNING STRUCTURE AND APPROACH

Project FIT care plans were completed on the family level and structured closely around participants' goals. Created by Project FIT staff after the first intake meeting, care plans stated participants' main goals and specific tasks for achieving them. For example, a participant might have a goal of getting therapy for the whole family; the associated tasks might be for the mother to call for, schedule, and attend an appointment. At a subsequent meeting, Project FIT team members presented the care plan to the head of household for review and signature. Care plans were updated based on participant progress and periodic reassessments.

Both BHN and Way Finders staff named developing the care plan as among the most important parts of Project FIT. In order to keep plans readily accessible, completed documents were linked to participants' program records. Because BHN's database only allowed for the creation of individual, not family, care plans directly within participant charts, care plans were completed as Microsoft Word documents and attached manually. This allowed anyone with access to the BHN database to see the care plan.

> *"It's important to listen to participants. The care plan needs to reflect what they want—otherwise, it's pointless and won't be followed."*
>
> **– PROJECT FIT STAFF MEMBER**

In addition to these formal processes, both BHN and partner staff strongly believed that developing trust and open communication with participants was a prerequisite for meaningful care planning. In the words of one SHA staff member, **"Building relationships is key. Without trust, participants will not be able to work with you."** Only through trusting relationships, they felt, would care plans reflect participants' priorities and secure buy-in. In addition, care plans could only evolve accurately over time if participants were open and honest with staff members about what was going on in their lives.

STRATEGIES FOR BUILDING TRUST

Project FIT staff members believed that approaching participants respectfully was key to building trust, and emphasized the importance of meeting with participants in a considerate way that helped them feel comfortable opening up. This included being humble, listening to participants, and building care plans around their concerns and priorities. It also included structuring program elements in a way that was responsive to participants' needs. In particular, CCMs and CHWs visited participants together to conduct the initial assessment, and believed that visiting separately would have been a barrier: **"It's overwhelming**

if we go in separately—we're yet another agency, and participants are resistant to remembering new names and nervous about having people coming into their home." By approaching participants considerately from the beginning, Project FIT staff believed that they were able to lay the groundwork for future visits and promote trust and open communication.

Way Finders and SHA staff members echoed the importance of engaging respectfully. They also felt that it was essential to show participants how their organizations could help them, and that engaging with the organization was worth the time, effort, and risk of opening up to someone new. As one SHA staff member put it, **"Families need to know what it is they're getting."** Way Finders staff echoed this sentiment, saying, **"We try to make sure we understand our part very well, which helps build trust for participants to come tell us their needs."**

MONITORING AND RESPONDING TO CHANGE

Project FIT staff members used periodic needs reassessments to see if families were making progress and to modify the plan if needed. Team members also responded to specific issues as they arose: if a participant scored high for depression or anxiety, for example, a CCM would visit and assess what services or referrals that person and/or family needed. If referrals were already in place, the CCM would assess what was causing the high scores and what additional options might be available to address those issues. In the words of one BHN team member, **"We try to provide support, tools, and respect."**

Ongoing communication with participants also helped staff stay apprised of new developments and emerging needs. Again, trust was seen as essential to this ongoing communication: as one BHN staff member put it, **"Communication is a big part of it. Without communication and trust, they won't open up."** Project FIT also involved frequent communication between BHN and partner housing providers. SHA and Way Finders staff explained that regular meetings and ongoing phone conversations were essential for the program's success, as they kept both sides informed about participants' statuses and allowed the teams to discover and address urgent issues quickly. Through this sustained contact, both BHN and partner staff were able to maintain a more complete and up-to-date understanding of Project FIT participants.

> *"Sometimes we need to be able to intervene immediately. If we waited for the monthly meeting, it wouldn't work."*
>
> – SHA STAFF MEMBER

CARE COORDINATION

While care plans were not formally shared across organizations, all parties who participated in focus groups recognized that participants' challenges involved many intersecting issues and felt that working together to address these issues was essential. This view was evident in staff perspectives on which program measures were most relevant to the project. Some named maintenance of stable housing as most important, believing that it provided the necessary foundation for improvement in other areas, while others singled out depression and anxiety scores for the same reason. SHA focus group participants also mentioned children's school attendance as an important measure due to its potential to indicate broader problems within the family. On the whole, focus group participants emphasized the interconnectedness of the different measures: **"Sometimes you have a participant where all seven measures intertwine and you must address each in order to move forward,"** said one BHN staff member.

PROJECT FIT OUTCOME MEASURES

- Emergency department visits
- Inpatient admissions
- **Maintenance of stable housing**
- Protective factor scores
- **Children's school attendance**
- Connection with primary care
- **Depression and anxiety scores**

Note: Bolded items were emphasized by focus group participants.

Project FIT's care planning program did not emphasize formal integration of the care plan across users external to BHN. Instead, care coordination activities more often took place through direct communication between BHN and partner staff. BHN did have a release process through which external parties could access the care plan with the permission of participants, and program leaders recalled speaking with partners about this process on multiple occasions. However, sharing rarely occurred, and partners appeared to not be consistently aware of the release process. Way Finders focus group participants expressed surprise at the existence of formal, written plans and felt that having access to the documents would have been helpful.

In addition, medical providers were not involved in care planning, and there was no systematic structure for joint planning or regular sharing of information. While BHN staff did reach out to primary care and other providers on an as-needed basis, the responsibility for this communication fell primarily on participants. Evidence from the literature shows that incorporation of medical providers into care planning is an important component of care coordination;[48,51] however, BHN focus group participants perceived external providers as being resistant to that level of collaboration. In the words of BHN staff, **"They act as though we are evaluating them and they put up barriers."**

ENABLERS OF CARE COORDINATION

BHN and partner staff considered communication between team members to be particularly important in addressing participants' multifaceted needs. For the Project FIT team, this included communication between CCMs and CHWs: the two groups bring different perspectives to their work, and both felt that their partnership and the presence of both groups at initial meetings with participants were important for the program's success. It also included communication between BHN's internal case management team and other branches within the organization, and well as communication with partners and other outside agencies.

For partner focus group participants, ongoing communication with BHN was one of the most important parts of the program. SHA staff stated that monthly meetings with the Project FIT team were helpful and that ongoing, real-time communication was essential to their ability to address participant needs in a timely manner. Way Finders focus group participants also valued their meetings with BHN, particularly once program leaders began involving the full Project FIT team in those meetings. Like SHA staff members, Way Finders staff emphasized the importance of ongoing communication with BHN, believing that this allowed both groups to have more complete information about participants. Way Finders staff described their monthly meetings with BHN as a chance to **"review every case and exchange information: what we know and what we see is needed,"** while SHA team members described them as an opportunity to **"gather together, communicate, and come up with a solution."**

BHN and SHA staff also identified coordination with schools as an impactful element of Project FIT, consistent with findings from the literature.[51] While this coordination applied only during the school year and did not extend to summer programming for children, Project FIT team members felt that efforts to engage schools were generally successful. SHA staff emphasized the importance of such efforts, stating that participating families often needed to work closely with schools due to their children's complex challenges. SHA staff felt that having Project FIT available to help support families in this was valuable, as the task could be overwhelming for an individual service provider. The Project FIT team agreed that navigating the school system was a challenge for many parents and felt that advising and empowering parents in this regard was a meaningful contribution of the program: **"Parents knowing that they can do it is critical in the school system. It's great to see a parent be able to use their voice and be heard."**

BARRIERS TO CARE COORDINATION

Despite these successful areas, BHN and partner staff also identified challenges to care coordination. For BHN, these included external organizations that were unresponsive. Project FIT staff perceived primary care as particularly difficult to communicate with: while the team regularly contacted primary care providers, they reported that they rarely received a response even if there was a release in place. Relatedly, Project FIT staff felt that, while they were trying to foster communication and collaboration, other organizations often seemed to react competitively: **"Even when we explain what we're working on and ask for information to prevent duplication, we get resistance."**

In addition, BHN and partner staff identified long wait times for mental health services as an important barrier. According to Way Finders staff, **"Getting participants what they need when they need it is a major challenge."** They added that this impacts participant trust and continuity of care over time, as participants in crisis often end up seeing an unfamiliar mental health provider who addresses only the issue at hand, rather than developing a long-term plan. In their words, **"When someone finally does come out, it's a stranger with no relationship to the participant, and then next time it's another person. And all the focus is on immediate safety—there's no plan for what comes next, no resolution."** Project FIT worked to address these obstacles by having participants work on coping skills with CCMs while on the waiting list to see a psychiatrist. They also tried to connect participants with other providers, such as primary care offices or BHN clinicians located in Springfield public schools. When necessary, CCMs sometimes provided therapy directly. Way Finders staff, however, emphasized the importance of connecting participants with specialists, particularly since many had experienced significant traumas.

Limited resource availability was another common barrier. SHA focus group participants felt that they never had enough staff to meet the needs of the people they worked with: "**What we can give participants is never enough. It gets overwhelming when the need is greater than can be met."** Given this scarcity, SHA staff felt that BHN's ability to work closely with participants was a particularly valuable aspect of Project FIT, saying, **"Many of these families have a lot of mental health**

issues, which makes the one-on-one element key." In addition, both SHA and Way Finders staff found BHN's help in supporting participants and connecting them with services to be valuable. However, overall resource availability remained a concern. Resource constraints also directly affected Project FIT participants, for whom important items such as summer programs for children were sometimes simply too expensive.

Finally, other systematic issues also posed a challenge. Project FIT team members found that participants' insurance often changed without their knowledge, or that external providers changed the insurance they accepted. In addition, requirements of the multiple systems participants needed to navigate often conflicted with each other. Project FIT staff discussed an example in which a mother believed that she could not regain custody of her children until she secured housing, but was also unable to qualify for housing because she did not have children. In a different circumstance, a family might earn too much to qualify for temporary housing assistance but still be unable to afford market rent. BHN staff found that these issues were often difficult to resolve: **"It's hard to get the attorneys talking to each other."**

3. RESONANCE FOR PARTICIPANTS

Interviewed participants all experienced housing insecurity as the primary presenting problem and shared similar histories of early childhood trauma and abuse. Each had several coexisting medical and mental health concerns and a few also had substance use disorders. Many grew up in foster care, reported having been diagnosed with special needs in school, and began experiencing depression and anxiety early in their lives. They also reported many complex social needs, without a reliable support system for themselves and their children. Most had two or more children who also had special needs with varying degrees of severity. Almost a third reported fleeing domestic violence with their children. A portion of interviewees had lost custody of one or more children, and most were working with the Department of Children and Families (DCF) and the court system to regain custody.

> *"People do not do what they say they will do... Many are just using you or want to hurt you."*
>
> **- PROJECT FIT PARTICIPANT**

Interviewed participants shared a general worldview in which people were disappointing. Some presented a despairing view on their future, seeing themselves as being overwhelmed with stressors and unable to manage their lives. Even when participants experienced a notable accomplishment, they expressed fear that something would happen to diminish their progress. Many had clear goals for themselves and their children. A few presented a pathway to achieve these goals; however, the majority of participants interviewed were focused on finding a way through their immediate crises.

ASSESSING PRIORITIES AND NEEDS

Care planning in Project FIT was less about a concrete, written plan and more about the communication and relationships Project FIT staff cultivated with participants. These ongoing relationships allowed participants to express their needs to staff members and provided opportunities for staff to check in with participants about challenges they were facing. Project FIT staff also communicated with participants about their medical needs, with most interviewees reporting that CHWs called them regularly to see if they had been hospitalized or used the ED.

Some participants recalled developing a care or service plan during their initial visit with the Project FIT CCM and CHW, including revisiting the plan as their situations changed. **"My CHW worked with me to come up with a plan that had three parts—the plan, how to achieve it, and listing my accomplishments."** However, many Project FIT participants had only a distant memory, if any, of a plan. Instead, participants relied on their interactions with Project FIT staff as the plan, since their lives were engulfed in crisis situations involving difficult-to-comprehend systems that several interviewees saw as unjust and discriminatory (e.g., public housing, schools, criminal justice). The Project FIT staff, both CHWs and CCMs, resonated with participants.

> *"We get along very well. I love her [CHW]. She is my family."*
>
> **- PROJECT FIT PARTICIPANT**

ADDRESSING NEEDS AND BARRIERS

When ongoing communication between Project FIT staff and participants revealed medical, behavioral, or social needs, Project FIT staff worked with participants to address them. Many participants reported that when they had a problem, they would call their Project FIT contact and this person would get back to them immediately, then work with them to address the high-priority concerns that had arisen.

All interviewed participants had complex clinical issues that included both chronic and acute serious medical and mental health concerns. With these disabling conditions, their focus was survival for themselves and their children. Many reported that Project FIT staff helped them fill out vital housing, social security, and court forms to pursue these goals. This was particularly emphasized by participants who could not speak English. A few participants who had serious mental health concerns reported that without Project FIT staff helping them fill out the disability application and accompanying them to the eligibility meeting, they **"would have messed it up… I am angry all the time and have a mouth."** With the Project FIT CHW present, however, they were successful in getting Supplemental Security Income support and beginning to work on a path forward. Another participant, with severe mental health and medical issues, recalled being accompanied by her Project FIT CHW to several DCF interviews. She reported that she felt stronger with the CHW by her side, and felt that the focus was on finding resources and services for her children instead of taking them away again and placing them in foster care. Nearly every participant interviewed shared an instance when a Project FIT staff member helped them complete a form, assisted them with a phone call, or accompanied them to an important appointment.

> *"People tend to listen and pay more attention if you have a social worker with you 'cause they are afraid of getting reported or something."*
>
> **- PROJECT FIT PARTICIPANT**

In addition, interviewed participants reported that Project FIT staff assisted them in accessing behavioral health services. Participants reported long waiting lists to see a psychiatrist or mental health clinician. They also expressed concerns about getting needed behavioral health services for their children, as well as family therapy that would support them to, in the words of one mother, **"be the best parent I can be."** To address these needs and shortages, Project FIT CCMs often provided therapeutic support until a behavioral health provider became available. Many Project FIT participants appreciated the personal and emotional support provided by the CCM and CHW.

> *"I appreciate how well she [CCM] listens to me and responds with helpful suggestions or alternative ways of looking at my problems. It's better than just talking to the four walls."*
>
> **- PROJECT FIT PARTICIPANT**

BARRIERS TO ACHIEVING CARE PLAN GOALS

However, despite the best efforts of Project FIT, most participants interviewed conveyed insoluble difficulties with transportation that made it difficult for them to pursue their priorities. The Springfield public transit system has many limitations[127,128] and participants often had to take at least two buses to get places, which could take several hours. One mother with a long history of abuse and trauma would only allow her children to go to schools that were within walking distance, since she could not rely on the transit system to get to them quickly if they needed her. These obstacles had the potential to make even specific care plans infeasible. Sometimes, participants would get transportation vouchers or rides from Project FIT staff; however, with all the appointments participants needed to attend (e.g., clinical, school, courts, DCF), interviewees experienced continual transportation barriers.

In addition, while many interviewees did have primary care providers (PCPs) for themselves and their children, getting urgent appointments with these providers was difficult. While Project FIT staff often succeeded in making such appointments when they called on participants' behalf, participants themselves were often told to go to the ED. Transportation barriers also made getting to PCP appointments difficult. As a result, several participants viewed the ED as the most accessible form of care when they needed to see someone right away, even if it was not an emergency. This was because the ED was easier to get to and open at convenient hours. Although many community health centers, urgent care centers, and primary care practices offer same-day appointments, participants were unsuccessful in getting urgent appointments with their PCPs and unaware of other options except for going to the ED.

Several interviewees also expressed concerns about a change in their relationship with their CHW or CCM. When a new CCM or CHW was assigned, they feared the new person would not be as helpful. Interviewees also occasionally reported that Project FIT staff would not call them back or show up for an appointment. A few believed that Project FIT staff were no longer involved in their lives. When exploring these instances further with the interviewees, it appeared that Project FIT staff had in fact taken them to an appointment, helped them deal with a utility crisis, or assisted with addressing other obstacles. Nevertheless, the interviewee focused on the instance in which the Project FIT staff member was not available to them. Due to Project FIT participants' history of trauma and worldview that people are disappointing, there appeared to be an understandable high sensitivity to instances of staff changes or staff who could not respond quickly to their needs.

FOCUSING ON THE WHOLE FAMILY

> *"My CHW is coaching me and helping me fight to keep my son in a better school."*
>
> **- PROJECT FIT PARTICIPANT**

Project FIT was unique among case study programs in that it focused on the family unit as a whole, working to address the needs of both parents and children. Project FIT participants generally had few other people in their lives they could turn to for support. Interviewees reported histories of childhood trauma or abuse, and a good portion shared that they had fled a domestic violence situation. With their remarkable backgrounds, clinical issues, and overwhelming life stressors, getting their basic needs met in the form of housing, food, utilities, transportation, and interpersonal safety[37] was an insurmountable challenge for many Project FIT participants. Most interviewees did not have a support system and had absolutely no one to call even during an emergency.

In the context of these limited support systems, caring for children was a challenge for many participants. Most interviewees had several children with a variety of special needs. Interviewees reported that during the school year, Project FIT staff helped with a range of complex school issues. However, most of the children were not in summer programs, even though they were certified as having special needs and had individualized education programs (IEPs) during the school year. Project FIT participants, struggling with intense social and emotional challenges, were taking care of special-needs children (e.g., children who with medical conditions or disabilities or had attention-deficit/hyperactivity disorder [ADHD], autism, or emotional disturbance) without a structured environment or resources to keep their children engaged in safe, meaningful, regression-minimizing activities. Even though summer special education programs are accessible and free in other communities,[143] the mothers interviewed reported that the school system could not provide them with transportation for their child or that the programs were filled. In addition, several interviewees reported that they tried to get their child into the summer school program, but that the school refused to allow them to sign up because the extended school year placement box was not checked on the IEP. This can be easily fixed with an IEP modification, but this option was never communicated to the mother.

> *"I completed a YMCA application so my daughters could go to their summer program. They said I would have to pay $35 weekly for each of my girls. I don't have $70 a week. I have to spend less than that on food each week."*
>
> **- PROJECT FIT PARTICIPANT**

Because of these issues, many Project FIT children lacked appropriate environments during the summer. During interviews, many Project FIT participants' children were watching movies on large televisions, and some mothers commented that their children had seen that same movie hundreds of times. On several occasions, children with severe disabilities (e.g., on the autism spectrum) screamed continuously and rocked themselves while isolated in a corner of the living room or in their bedroom. The interviewed mothers reported that they were unable to get their children into non-public-school-based summer programs due to the cost. Many wanted help with engaging and managing their children with severe disabilities. For example, although there was an unfenced park next door to their public housing unit, one mother could not take her son with ADHD out to run and play for fear he would run into the busy adjacent street. Her son is unresponsive to verbal warnings and large enough that she did not believe she could hold him if he decided to run from her.

Many Project FIT participants harbored distrust for organizations like the police, schools, and court system. With the exception of summer placements for their children, interviewees believed that the CHW worked with them to advocate for their rights and the needs of their children. Project FIT staff empowered participants to speak up, hold themselves accountable, and hold powerful bureaucracies like the school system, housing authority, and court system accountable.

> *"'No hay malo que decir,' there is nothing bad to say. The CHW and CCM were like guardian angels for me and my son."*
>
> **- PROJECT FIT PARTICIPANT**

TRACKING PROGRESS

From the perspective of Project FIT participants, progress was tracked by crisis avoidance and personal improvement. An interview participant shared that she stood up at a public meeting to share her story, which is laced with tragedy, loss, and crippling life stressors, even though she had never spoken in front of a group due to anxiety and extremely low self-esteem. She was able to do this with her Project FIT staff member beside her, translating her Spanish to English and holding her through bouts of tearfulness. Several participants shared accomplishments like finally getting into a home after living in their car for three years, getting their three children back from DCF after several years of separation, or starting a firm plan to enroll in an emergency medical technician training program. Interviewed participants felt that they had worked with their Project FIT CHW or CCM on each step to obtain their goal. As some participants shared their progress, stories of success were often followed by a statement of fear that they could lose what they had achieved in one breath or gust of wind.

> *"Having the CHW is nice since I have extreme anxiety. I start not being able to breathe—knowing she is there—I say OK—she breathes me through it."*
>
> **- PROJECT FIT PARTICIPANT**

4. INTERSECTION OF RELEVANCE AND RESONANCE

The two overarching study focus areas addressed how care planning was relevant to providers and partners and how care planning resonated with Project FIT participants. Care planning for providers and partners was solidly aligned with evidence-based practice. Specifically, the program's approach of listening to participants, helping them respond to urgent needs, devising participant-driven care plans, and working with other social needs organizations is well established in the literature.[30,33,48-51]

Project FIT's ongoing communication and coordination with their key partners, Way Finders and the SHA, was a great benefit to the interviewed Project FIT participants. These efforts resulted in immediate responses to crisis situations concerning basic needs, such as loss of housing or utilities. Working with housing partners provided a forum to better understand the needs of the Project FIT families and the best approaches to crisis prevention and resolution.

> *"I can't raise my child the way I was raised—look what has happened to me."*
>
> **- PROJECT FIT PARTICIPANT**

However, coordination in other areas was more limited. Although schools were a focus during the school year, interviewed Project FIT participants did not have adequate summer options for their children. Most of these children had diagnosed special needs and were without services for almost three months during the summer. Some mothers expressed their need for specific guidance on supporting and managing their children. Conversely, some mothers did not want anyone telling them how to raise their children, especially DCF. However, these mothers did express a need to engage in regular supportive interventions, like family therapy, that would provide guidance on parenting. The wait time for mental health services like psychiatry and mental health treatment was reported by interviewed participants as very long (i.e., six months). In addition, medical providers were not partners with Project FIT, despite many attempts to include them. Because social needs are a huge driver of both medical outcomes and cost,[35-40,144] this dissociation between social and medical needs is recognized nationally and in the literature as an area requiring considerable coordination and collaboration.

> *"Don't know where the FIT program came from but I thank God for them. They came into my life when I was overwhelmed and helped me."*
>
> **- PROJECT FIT PARTICIPANT**

Even with these gaps, however, participants reported many gains from Project FIT. Project FIT's approach and staff strongly resonated with the interviewed participants. Many reported that they had learned how to advocate for themselves against organizations and agencies that they feared and believed had treated them disdainfully and unjustly. Project FIT staff, as described by several participants, became role models on how to handle crisis situations. Many interviewed participants had endured a lifetime of trauma and failure. Working with their Project FIT team, several began practicing managing their "failure is inevitable" mindset, and some could reconcile that persistence was a necessary strategy. Many could acknowledge that their circumstances were very complex and difficult to handle. Several recalled periods of their lives when they were consumed with extreme anger and frustration. Even though they continued to face crisis after crisis, many participants now accepted that results take time. These personal achievements were aided by Project FIT's approach of addressing social needs while providing necessary support and life tools to their participants[49,51] in a manner that was well-received by those interviewed.

> *"I just can't give up... have to keep trying until something works."*
>
> **- PROJECT FIT PARTICIPANT**

APPENDIX C: DETAILED SDH CONSORTIUM CASE STUDY

The mission of the Boston Health Care for the Homeless Program (BHCHP) is to provide high-quality health care for individuals and families experiencing homelessness in the Boston area. The goal of BHCHP's TCCI Program initiative, known as the Social Determinants of Health (SDH) Consortium, was to improve the care and lives of Boston's highest-need patients by serving as a hub for a team of medical providers, shelters, and advocacy organizations. This team consisted of primary, acute, and specialty providers and was responsible for identifying clients, tracking utilization, and providing intensive care coordination. BHCHP's partners in this program included Bay Cove Human Services, Boston Public Health Commission, Boston Rescue Mission, Casa Esperanza, Massachusetts Housing and Shelter Alliance, New England Center and Home for Veterans, Pine Street Inn, St. Francis House, and Victory Programs. The SDH Consortium targeted MassHealth patients with the highest health care costs who were attributed to BHCHP with high emergency department (ED) and/or hospital utilization in the most recent six months.

Primary elements of the program included:

- Collaboration between primary care, behavioral health, housing, shelter, and social services organizations;
- Integrated case management; and
- Existing connections with the target population.

Clients were identified for the program using MassHealth claims data. Case managers (CMs), most of whom were employed by partner organizations, then connected with these individuals when they visited an SDH Consortium organization or through street outreach. After clients were enrolled, CMs met with them weekly, developed care plans, and participated in case conferences with providers and clients. Data from CMs, BHCHP, and SDH Consortium partners were stored in the Boston Department of Neighborhood Development data warehouse. Use of this data warehouse was an innovative feature of the SDH Consortium that allowed BHCHP and its partners to access and share client data in a centralized way.

While the SDH Consortium created initial care plans for clients, these were point-in-time documents that provided a place to start but were not regularly updated over time. Instead, the program focused on providing evolving, patient-centered care that was coordinated through frequent communication both among team members and with clients. This care responded to clients' changing circumstances and goals as they arose, but was not necessarily reflected through ongoing updates of a formal care plan document.

1. CONTEXTUAL FRAMEWORK

People experiencing homelessness have higher mortality[20,73] and worse physical[20,54] and mental health[20,54,74] than their housed counterparts, including housed individuals from disadvantaged communities.[20,74] This includes higher rates of both infectious[20,145] and chronic[20] diseases. In terms of mental health, people who are homeless have a high prevalence of psychiatric disorders, drug and alcohol dependence, and comorbidity between mental illness and substance use,[20] as well as higher rates of traumatic brain injury[20] and cognitive impairment.[20,146] Histories of trauma and abuse are common,[20,75] as are continued experiences of victimization and assault.[20,147] A majority report experiences of childhood physical and/or sexual abuse[148-150] and between 25% and 50% report experiencing physical or sexual assault in the past year.[20] In Boston, about 55% of adults experiencing homelessness came to the city from elsewhere in the state or country,[151] and like the homeless population nationally, they face higher mortality rates than the general population.[73]

People who are homeless also face barriers to health care, including being uninsured, lacking transportation, and having competing priorities such as finding food and shelter.[20,29] Housing-specific programs,[32,152,153] such as Housing First,[32,52,154,155] show promise for improving outcomes in this population, as do integrated care models combining medical and social services[53-55] and models of care delivery tailored specifically to homeless populations.[29,32,53-55] The same is true of case management approaches,[31,32] including some forms of high-intensity case management.[31,52] The SDH Consortium utilized many of these evidence-based components, incorporating elements such as case management, integration of social and medical services, and tailored medical care through BHCHP clinicians.

2. RELEVANCE FOR SDH CONSORTIUM AND PARTNER PROVIDERS

The SDH Consortium focused on providing client-centered, coordinated care by building trusting relationships with clients and maintaining frequent communication both with clients and between team members. A robust data-sharing system supported these efforts, with information from a wide array of providers stored in a data warehouse and regularly accessed by the SDH Consortium team. Program capacity, having CMs on the team, and team members' close collaboration and mutual respect were identified as enablers of care coordination. In contrast, technological and logistical constraints, BHCHP clinicians' heavy caseload of non-SDH Consortium clients, limitations in the availability of psychiatric services, and changes in the program model over time were identified as barriers.

CARE PLANNING STRUCTURE AND APPROACH

SDH Consortium care plans were intended as point-in-time documents rather than as living road maps for care. The program's focus was on providing patient-centered care that responded to clients' circumstances and goals but was not necessarily contained in formal, written care plans. CMs believed that client-centered approaches—engaging with clients nonjudgmentally and assessing with them what their goals might be[88-90]—were crucial to providing meaningful care and services over the long term. They also emphasized that clients needed to be ready before substantive change could happen. CMs described the initial care plans they developed as answering questions such as **"What do you want to work on?"** and **"What do you want to improve?"** One member of the medical and behavioral health team described this stage of the care management process, saying: **"We can meet them anywhere they want to meet. We ask about their goals, then work with them to achieve those goals and create a client-centered care plan."**

> *"We make sure we're focusing on their goals, not our goals."*
>
> **– SDH CONSORTIUM CASE MANAGER**

Trust was seen as essential in allowing BHCHP's client-centered care planning to take place and was emphasized as a key element by both CMs and BHCHP medical/behavioral health providers. CMs considered street outreach and enrollment to be the most important element of the program, while BHCHP medical/behavioral health providers described CMs' ongoing connection with clients as particularly influential. Trust between clients and BHCHP clinicians was seen as important as well. One member of the BHCHP medical/behavioral health team summed this up for the group, saying, **"Patients need to trust in you and your team. Nothing will happen if you don't have that trust."** When this trust was built, the impact could run deep: several CMs shared stories of finding out that a client had listed them as a family member, an emergency contact, or a health care proxy. Once CMs become aware of any of these situations, they must talk with the client to find appropriate alternatives.

Enablers and Barriers to Building Trust

Ongoing, compassionate relationships with clients were understood as key to building trust, an understanding also reflected in literature.[90,96,156] One CM described the benefits of working with the same clients over multiple years, while others described the challenges of getting to know new clients for the first time. One saw persistence as a helpful strategy: **"I chased them around, literally followed them to Dunkin' Donuts, to build trust, and they appreciated that."** Treating patients compassionately was also important—as a member of the BHCHP medical/behavioral health team pointed out, **"that is not something they get often."** CMs agreed, describing the benefits of treating clients **"more like a neighbor"** and stating that **"clients can feel that difference."** The BHCHP medical/behavioral health team also had a deep understanding that a nonjudgmental approach was essential, as affirmed in the literature.[88,96]

However, CMs and BHCHP clinicians also identified barriers to building trust. Many SDH Consortium clients, like populations experiencing homelessness at large,[20,75] have histories of trauma and betrayal. CMs explained that clients had a hard time trusting new people. BHCHP clinicians agreed: **"This is a high-trauma population, and when you get close to the center of that trauma, sometimes they run away."** Others mentioned the impact of clients' disillusion and low self-esteem. One CM reported that clients often asked why she would bother to help someone like them, while a member of the BHCHP medical/behavioral health team described clients who would **"get to the point of asking 'why bother' and disconnecting from regular care."**

Clients were also sometimes hesitant to be honest with CMs, instead giving the answers they thought the CMs wanted to hear. In these cases, CMs believed that **"you need to press on to learn what it is they really want."** One CM connected this tendency to the way SDH Consortium clients are often treated: **"They don't usually get asked what they want—mostly folks are telling them what to do."**

Because of these factors and the importance of familiarity in building trust, staff turnover was a significant challenge for clients and providers.[96] CMs recognized this issue and tried to prepare their clients as well as possible when changing jobs, but found that **"no matter how much you prepare them, it's still hard."** They described **"feeling guilty putting your family and life first"** and discussed ways they kept in touch with clients even after changing positions. **"I'll probably be calling them from the nursing home!"** Staff turnover also had the potential to introduce challenges for other staff members. For instance, medical and behavioral health providers described recently losing three key Spanish-speaking staff members, which put an extra burden on other staff to fill the gap.

Finally, physically locating clients could sometimes be a challenge, particularly if the person was not someone the CMs were familiar with. While the data warehouse sometimes included pictures, these were not always available, and CMs described alternative strategies for finding clients. One relied heavily on BHCHP, since many clients visited BHCHP's clinic for medical appointments, while another relied on a shelter "House Mom" who had worked the front desk for many years and knew many clients by name. These challenges were exacerbated by the inclusion of many clients who were not well-connected with BHCHP: in those cases, as one member of the medical/behavioral health team explained, **"the CM has to go out, figure out who they are, find them, and get to know them."**

Monitoring and Responding to Change

While care plans themselves were not regularly updated, ongoing connections with clients allowed care to respond to changing circumstances. CMs met with clients at least weekly and also found clients when they visited for other appointments. These meetings were an opportunity to address any new information that had come up through the data warehouse or in conversations with medical providers, as well as to make sure clients had a plan to get to upcoming specialist, housing, or social needs appointments. Having regular contact also allowed CMs to respond to changes in clients' states of mind: CMs explained that clients had to be ready to make a change and that certain circumstances could encourage this.

> *"Case management is key. They're constantly in contact. Sometimes I'll learn more about patients from a CM then from the patients themselves."*
>
> **– BHCHP MEDICAL/BEHAVIORAL HEALTH PROVIDER**

In addition to regular meetings with clients, ongoing communication between SDH Consortium team members was a key element in allowing the plan of care to respond to changes over time. Medical/behavioral health providers emphasized the importance of ongoing communication within the SDH Consortium team, and saw CMs' participation in case conferences as among the most helpful elements of the program. Regular team meetings and as-needed communication about clients were also considered valuable. In addition, CMs tracked clients daily, including conducting regular searches of the data warehouse and physically looking for them if they missed an appointment. Finally, the SDH Consortium's Registered Nurse (RN) Clinical Navigator played a key role by leading the CM team, helping to enroll clients, monitoring clients' transitions of care, and interfacing between the CM and BHCHP medical teams. CMs valued the RN Clinical Navigator and appreciated her leadership and responsiveness.

CARE COORDINATION

CMs and BHCHP clinicians emphasized the importance of coordination and teamwork for effectively serving clients. In addition, their perspectives on program metrics highlighted the interconnectedness of the many issues clients faced. While most CMs agreed that housing was among the most important elements, they also felt that substance use and issues such as trauma or head injuries could sometimes take precedence and might need to be addressed first. Some BHCHP clinicians felt that all measures were important, while others emphasized access to services to address social needs.

The SDH Consortium promoted care integration through a number of avenues. BHCHP primary care providers (PCPs) signed

SELECTED SDH CONSORTIUM OUTCOME MEASURES

- Emergency department visits
- Inpatient admissions
- **Housing status**
- **Access to SDH-related services**
- **Access to and engagement with substance use disorder treatment**
- Self-sufficiency score
- Receipt of preventative care
- Client recruitment and retention

Note: Bolded items were emphasized by focus group participants.

off on most care plans, and the plans and CMs' notes were shared in the data warehouse. The data warehouse also included information from both BHCHP and partner staff with whom clients interacted, as well as information from patients' electronic medical record (EMR) records. CMs regularly searched the data warehouse for new information such as new appointments or test results. In addition, the RN Clinical Navigator had access to patients' full EMR records and shared this data with CMs or BHCHP clinicians as needed. Both the CMs and the BHCHP medical/behavioral health team considered this access to and sharing of data to be vital: it kept everyone informed and enabled CMs to aid clients in getting to key appointments. In addition, case conferences provided an opportunity to coordinate care among the street team, CMs, and BHCHP primary care clinic, including ensuring that all involved were on the lookout for clients who had missed important appointments.

This data sharing, however, was not able to reach all providers who worked with SDH Consortium clients. Specialist and social service providers outside of BHCHP, the SDH Consortium, and partners were not part of the data warehouse, and case conferencing primarily involved medical providers internal to BHCHP.

Enablers of Care Coordination

BHCHP clinicians considered CMs to be an important enabler of coordination, consistent with evidence from the literature.[31,32] CMs were able to find clients, accompany them to appointments, and follow up afterward, which helped to increase appointment attendance rates. For BHCHP clinicians, **"having someone who can step outside the clinic and follow up, or find the patient in the first place, or accompany them to specialty appointments really helps."** CMs also sometimes uncovered and addressed specific barriers, such as for a client who missed all obstetrician-gynecologist appointments until the CM discovered she had a history of trauma and began accompanying her to visits. For members of the BHCHP medical/behavioral health team who focused on behavioral health, **"having CMs work with clients outside gives us another set of eyes."** This additional insight allowed clinicians to know more about questions such as whether clients were taking their medications regularly or if they were actively using substances.

BHCHP clinicians also highlighted the impact that having a robust and highly collaborative team had on clients and coordination. The team met weekly and communicated even more often regarding clients who needed additional attention. Members of the BHCHP medical/behavioral health team praised all team members' consistency in following up as needed, and also emphasized **"our ability to work as a team and our respect for each other, no matter what our role is,"** as an important strength. This dedication and frequent communication was supplemented by shared access to data, which was also seen as vital by both SDH Consortium team members and BHCHP clinicians.

Barriers to Care Coordination

CMs and BHCHP clinicians saw technological constraints as barriers to effective coordination. While the data warehouse provided a valuable source of information, some details—such as information about clients' doctor appointments and their outcomes—were only available in the EMR itself. Because EMR access was limited to the BHCHP-based RN Clinical Navigator, this created additional work for the RN Clinical Navigator and meant that partner-organization CMs depended on her for information not stored in the data warehouse. In addition, client information from providers outside of BHCHP, the SDH Consortium, and partners was not easily available. BHCHP clinicians, for example, reported that they were able to see some Boston Medical Center chart notes through ChartLink but did not have access to the full record.

Logistical difficulties also posed challenges for coordination. Competing demands on CMs' time were sometimes an issue: for example, a CM explained that while part of her role was to collaborate with other providers, she spent most of her time working to engage clients. Another CM found the process of getting physicians to sign care plans to be cumbersome: **"Going over goals with the client is easy—it's getting the PCP to sign off that's the tough part!"** Even when she attended appointments with clients and **"put the plan under the doctor's nose,"** physicians were often busy with other medical issues for the visit. The CM found that it was often easier to have this discussion with physicians during a case conference, but mentioned that while some coordination took place with clinicians from other organizations, these meetings primarily involved BHCHP providers.

BHCHP medical and behavioral health providers also felt that BHCHP's status as the default provider for a wide swath of people without access to medical services, and the resulting heavy caseloads, presented a challenge for care coordination and resource availability for SDH Consortium clients. The high demand for BHCHP's services, often by clients with very high needs, meant that clinicians had less attention to dedicate to the relatively small number of SDH Consortium clients. This was a source of some frustration as clinicians tried to balance the need to care for additional patients with the desire provide more concentrated care for others.

BHCHP clinicians also mentioned service availability limitations that affected their ability to deliver coordinated care. One explained that there is a three-month wait for psychiatric services. They also felt that some of the people who come to BHCHP are looking for medications that perpetuate their substance use disorders, and that this can be burdensome for nursing staff and can cause confrontations when requests are denied.

Finally, BHCHP clinicians felt that program changes and variations can pose a challenge for coordination activities. While iterations of the SDH Consortium have existed for some time, the model has changed frequently, often due to differing requirements from a series of funders. **"It has been confusing for doctors because the model keeps changing."** In addition, medical/behavioral health team members reported that reimbursements are different for different clients. As a result, clients may have different levels of access to benefits and services even if they live in the same building or have otherwise similar circumstances.

Many of these identified challenges relate to larger systemic issues, such as BHCHP's role as a statewide resource and limited access to records beyond the data warehouse and BHCHP EMR. The SDH Consortium focused on providing care coordination and outreach to the Commonwealth's highest social, emotional, and medical needs population. Notwithstanding the many challenges, focus group participants expressed their overwhelming appreciation of the SDH Consortium initiative. Those participants who had been at BHCHP for years believed that it was the very best iteration of a specialized patient outreach and case management approach to date. They were genuinely concerned about the transition to the MassHealth Community Partner initiative that would replace the SDH Consortium. However, all agreed that the SDH Consortium staff and BHCHP medical and behavioral health providers were an incredibly strong team with a solid commitment to BHCHP patients.

3. RESONANCE FOR CLIENTS

Interviewed SDH Consortium clients all experienced housing insecurity as their central social need area, followed by food insecurity, interpersonal safety, and basic daily survival. Their histories included multiple incidents of trauma and abuse. **"I have trauma. I take high-dose Klonopin for severe nightmares. My PCP counts the pills and I don't care 'cause it works."** All had several coexisting conditions in the medical, substance use disorder, and mental health categories. Many of those interviewed had lived on the streets for decades with periods of temporary housing. Most reported continual, intense struggles with substance use disorders. Several were on medication for addiction treatment for these conditions and some were receiving treatment and medication for mental illnesses.

Interviewed clients shared a general worldview of fighting to survive every day while being consumed by innumerable sources of distress. Most began their substance use as preteens and had been addicted to a range of non-prescribed drugs and alcohol for many years. Several shared opportunities missed in high school and early adulthood due to the consequences of substance use disorde.r Many had spent time in jail for misdemeanors or felony charges or convictions. A number reported having special needs as children (e.g., attention-deficit/hyperactivity disorder or reading/writing disabilities). Most discussed the necessity of enduring pervasive physical and psychological pain with palpable emotionality of shame, self-loathing, terror, and anger.

"My plan is to figure out how to survive today."

– SDH CONSORTIUM PARTICIPANT

ASSESSING AND ADDRESSING NEEDS

The SDH Consortium team kept in regular touch with clients to stay apprised of and help them meet their medical, behavioral, and social needs. Interviewed clients were relentless in their praise and genuine respect for the SDH Consortium team and their BHCHP medical and behavioral health providers. They reported that SDH Consortium and BHCHP staff did not judge them. Instead, they listened and knew how hard it was for them to survive. **"I am hungry all the time. I have no food. Have needed to steal to get food."** Many clients reported that their CM worked with them to outline a path to get their basic needs met, with sober housing being a priority. Interviewed clients reported that the SDH Consortium team, especially the CMs, helped them figure out the best way to meet immediate needs such as food and shelter and also worked with them on longer-term solutions such as filling out and submitting the necessary paperwork for Supplemental Nutrition Assistance Program and Supplemental Security Income benefits.

"Nothing is easy on the streets. I woke up this morning and didn't have a toilet."

– SDH CONSORTIUM PARTICIPANT

CMs assisted clients with making it to medical and social needs appointments by reminding them or finding them on the streets or wherever they might be to make sure they attended. One client shared his extreme reluctance to accept an apartment at the YMCA because he was so concerned about making it back to BHCHP every day for his multiple appointments. The CM showed him how to take the bus from the YMCA to BHCHP and arranged for bus passes. This client radiated pride when describing his YMCA **"penthouse"** and his success in taking the bus every day.

Interviewed clients reported that accessing substance use treatment and mental health care was central to their ability to get off the streets and keep housing. Many expressed the importance of having the CM and their BHCHP practitioners working with them to access effective treatment. **"I had a difficult time finding an antidepressant that works. Tried many and still could not function. I am on a very high dose now and feel better."** According to interviewed clients, CMs worked with BHCHP behavioral health clinicians and clients' PCPs to ensure persistence in finding what clients needed to address their specific substance use and mental health needs. **"Got to keep trying. Takes time to find what will work."**

Interviewed clients consistently described the outreach efforts of their CMs and the street team. They reported a relentless approach of seeking them out—**"finding me when I don't even know where I am"**—to inquire about how they were doing, what their immediate needs were, and what was a doable next step. **"These folks don't give up. No matter what I have done they find me and we start again."**

In addition, interviewed clients expressed great appreciation for the BHCHP pharmacy location and zero co-pay, which made it easier for them to get their medications refilled when they were done with an appointment at one of the clinics. They could also leave their supply of medication and come daily for their dosage. They did not need to carry their medications around or remember where they left them. Coming to BHCHP daily also increased their opportunity to check in with their CM or other providers.

> *"I have OD'ed 17 times. Suboxone saved my life."*
>
> – SDH CONSORTIUM PARTICIPANT

ELICITING PRIORITIES NONJUDGMENTALLY

Interviewed clients described a process where the CM specifically asked them what they believed was important. Even though some clients gained housing and then lost it because they were unable to comply with the rules, most of those interviewed did not feel that their missteps would drive away their BHCHP team. Many clients talked about the despair and self-loathing they experienced when they failed. Nevertheless, the CM or street team would find them and ask them again what they needed to be successful in their next home.

> *"[BHCHP] staff make me want to get help."*
>
> – SDH CONSORTIUM PARTICIPANT

Clients shared that, working with the CM and the BHCHP team, they could sort through what happened and figure out what steps and additional elements were necessary to keep a home. Many expressed a strong desire to be in a home where others were sober. Several expressed the need for an alcohol- and drug-free zone and many reported having frequent/daily urinalysis to ensure their adherence. **"Fifteen clean urines. Best I have ever had. My PCP ordered them."** Clients identified priorities as well as environments and processes that could support their success in keeping their housing.

ADDRESSING SOCIAL ISOLATION AND STIGMA

Interviewed clients were generally estranged from their biological families. Many perceived BHCHP staff as their family and, in most instances, believed that BHCHP staff were the best family they ever had. These positive relationships were achieved by BHCHP staff members' nonjudgmental approach and commitment to never giving up on a client. Relationships with BHCHP staff were lifelines for SDH Consortium clients. Because of the great importance of these connections, interviewed clients were highly sensitive to changes in their BHCHP team. They reported experiencing severe loss, grief, and anxiety when someone they had worked with moved on. They feared that they would not be able to connect with the new person and that the new individual would not understand them in the same way their previous SDH Consortium or BHCHP team member did.

> *"I took it hard when [the CM] left. She helped me see my priorities. Helped me find my way."*
>
> – SDH CONSORTIUM PARTICIPANT

Outside of BHCHP, some medical providers had a difficult time connecting with and understanding the suffering and challenges experienced by interviewed clients. Interviewed clients shared incidents of micro-aggressions from non-BHCHP providers, particularly in the ED. Many of those interviewed would agree with how one interviewee summed it up: he did not want to go to the emergency room because **"they treat me like crap."** Clients shared stories of many ED experiences in which they experienced staff disdain, intolerance, and contempt. As several pointed out, going to the ED is their last resort—a desperate cry for help. Several interviewed clients had similar experiences with non-BHCHP specialists; however, many also felt that having their CM go with them or having their BHCHP practitioner talk with the specialist beforehand helped the specialist understand their needs and life struggles. This created an environment where some level of empathy existed, as opposed to the ED, where interviewed clients did not feel they received any empathy.

In contrast to their perception of the medical provider community, interviewed clients had strong positive feelings for non-BHCHP social needs providers (e.g., St. Francis House). Many interviewed clients remarked that it made them feel cared about when the SDH Consortium, BHCHP, and others talked about them to help coordinate their care and services. **"I have five doctors and two, maybe three CMs and they all talk to each other."** Some seemed surprised that anyone would take time to talk about how they were doing or coordinate services. They questioned if their lives were worthy of others' time and effort.

TRACKING PROGRESS

"The street team. They really care—saved my life."

– SDH CONSORTIUM PARTICIPANT

Continual contact, no matter the circumstances, is the best way to describe how interviewed clients experienced SDH Consortium and BHCHP staff's efforts to track how they were doing. Most of those interviewed described how their CM would pull them aside at the clinic to check in and remind them about an important next step, hunt them down on the streets if they missed an appointment, or reach out to other social needs providers to find them. Interviewed clients viewed this tracking process very positively. With the complexity of clients' social, substance use disorder, and mental health needs, tracking was a key engagement strategy that interviewed clients reported. Many of those interviewed experienced countless setbacks and having ongoing CM contact enabled clients and CMs to address the issues and incorporate new approaches. **"I really hit a new low. The respite program [Barbara McInnis House] is amazing. Helped me get back in touch with my doctors, sort out my medical issues, and reconnected me with housing and resources that I needed to recover."** Tracking created a perpetual client and CM process of assessing, adjusting, and modifying the pathway to addressing social and clinical needs.

4. INTERSECTION OF RELEVANCE AND RESONANCE

The two overarching study focus areas addressed how care planning was relevant to SDH Consortium and BHCHP teams and how it resonated with SDH Consortium clients. Care planning within the SDH Consortium was solidly aligned with evidence-based practice. Specifically, the program's approach of providing case management,[31,32,52] integrating social and medical services,[53-55] and offering tailored medical care[29,32,53-55] through BHCHP clinicians is well-supported in the literature.

Frequent communication, both with clients and among the SDH Consortium and BHCHP teams, was highlighted by both staff and clients. For staff members, it was these ongoing interactions—not regular updates of a formal care plan document—that allowed client-centered care to be directed, modified, and carried out in real-time tailored to the client's needs. Weekly meetings with clients, regular team meetings, and case conferences with BHCHP medical providers facilitated this process, as did the data warehouse that functioned as a central repository of client information. Interviewed clients noticed and remarked on these coordination activities, appreciating their regular contact with CMs and the ongoing efforts to coordinate their care and services.

For years, the SDH Consortium team and BHCHP practitioners have been devising and perfecting their approach to caring for individuals experiencing housing insecurity and a wide range of other social and medical needs, substance use disorders, and mental health concerns. SDH Consortium staff, BHCHP practitioners, and interviewed clients all recognized the extreme difficulty of staying sober on the streets or in a house where others were not sober. SDH Consortium staff and BHCHP practitioners understood that they might be the only people in clients' lives who cared about what happened to them. From the perspective of interviewed clients, SDH Consortium staff and BHCHP practi-

"I am the best me when I am at BHCHP. They don't judge me. They look at me and say 'good morning.'"

– SDH CONSORTIUM PARTICIPANT

tioners were heroes. On the other hand, several clients, despite great admiration for their CMs, expressed doubt that even heroes could heal their extremely disabling conditions and address their overwhelming social needs. Some in this latter group despaired of their current situation and had no hope that circumstances would improve: **"I have been to the emergency room eight times. People keep finding me on the streets out cold—I don't want to go to the emergency room. Just let me be."**

However, the majority of interviewed clients were not ready to give up. With their SDH Consortium and BHCHP teams, they had hope that at some point something would work—that they would find a way to alleviate their pain; find permanent, safe, sober shelter with adequate food; renew hope for personal safety; and obtain a level of health that would allow them to work and take care of themselves.

APPENDIX D: DETAILED HEALTHY LIVES CASE STUDY

Brookline Community Mental Health Center provides mental health care and community-based social services to all Brookline-area residents, regardless of ability to pay. The goal of its TCCI Program initiative, Healthy Lives, was to deploy a mobile, multidisciplinary care management team to integrate behavioral health, primary care, and community services. This team included a nurse care manager, a social worker, and health outreach workers. One of the key partners in the Healthy Lives program was Beth Israel Deaconess Care Organization (BIDCO), a physician and hospital network and HPC-certified accountable care organization. The program targeted adult BIDCO patients with expenditures of at least $50,000 in the last year, a behavioral health condition, and two or more chronic medical conditions.

Primary elements of the Healthy Lives program included:

- Integration of behavioral health, primary care, and community services;
- A mobile, community-based approach;
- Extended duration of contact and more frequent contacts;
- Transition to less-intensive services after six to 12 months; and
- Flexibility of services to address a wide range of needs.

Patients were referred to Healthy Lives by a medical or behavioral health provider or BIDCO nurse care manager. The Healthy Lives team then gathered patient information and potential resources, conducted a home visit and initial needs assessment, and continued to meet with patients over time, including accompanying them to medical or community appointments. Patients were discharged from the Healthy Lives program after six to 12 months, once they had been stabilized.

The Healthy Lives multidisciplinary care management team focused on integrating the care patients received from a variety of medical, behavioral health, and community providers. This enabled medical, behavioral, and social care plans to mesh together in a way that best supported patients' stated goals and needs. For the purposes of the Healthy Lives program, "care plans" consisted of the strategies deployed to accomplish this patient-centered integration.

1. CONTEXTUAL FRAMEWORK

Serious mental illness and chronic physical conditions are closely linked. People with serious mental illness have lower life expectancies and worse physical health than the general population, due largely to higher incidence of and poorer outcomes from a variety of physical illnesses.[19,28,157,158] Cardiovascular disease in particular is a key factor in these disparities;[28,159,160] however, people with serious mental illness are also at higher risk for a range of conditions,[19,157,161] including chronic obstructive pulmonary disease (COPD), diabetes, and chronic kidney disease.[19,161] Compounding the higher prevalence of these issues is the fact that people with serious mental illness are likely to receive lower-quality physical health care[28,157,162-165] and face stigma from medical providers.[25,27,28] People with serious mental illness and physical comorbidities also have higher health care utilization than the general population.[19,76,77]

People with serious mental illness face a variety of barriers to effective health care, including fragmentation and lack of continuity between physical and mental health care,[25,28] stigma on the part of individual providers,[25,27,28] and patient-level factors such as symptoms of mental illness that may interfere with seeking treatment.[25,28] Integrated care models,[25,56,60,80,81] including the use of care managers to coordinate between physical and mental health providers and provide coaching and support to patients,[25,56-60] have shown promise for reducing these barriers and improving patient outcomes. Models that work with patients on practical skills, illness self-management, and goal setting have also had positive effects.[56] The Healthy Lives program incorporated these evidence-based approaches, using care managers to coordinate care and provide patient education and coaching while increasing system-level integration through data-sharing and regular provider communication.

2. RELEVANCE FOR HEALTHY LIVES AND PARTNER PROVIDERS

Healthy Lives approached care planning as a process of integrating care between medical, behavioral, and social needs providers in a way that centered patient goals and priorities. This effort was supported by building relationships with and engaging patients, meeting regularly with patients over time, and maintaining contact with patients' other providers. Coordination with medical, behavioral, and social needs organizations was seen as an important element of the program and was supported by access to medical records, the ability of Healthy Lives team members to accompany patients to appointments and help with follow-up, and the Healthy Lives health outreach workers' role as dedicated point-people who could address a variety of patient needs. In contrast, barriers included challenges inherent in meeting patients' high needs, resource limitations of the program, and systemic barriers to accessing behavioral health services.

CARE PLANNING STRUCTURE AND APPROACH

Care planning within Healthy Lives focused on integrating existing medical/behavioral health care plans, prioritizing patient goals, and discovering new information about patients to make care plans more effective. The Healthy Lives team and partner medical and behavioral health providers both saw building strong relationships with and engaging patients as key to a meaningful care planning process, an understanding confirmed in the literature.[56,87] Both groups reported that this experience was new for many patients and believed that such relationships could translate into better clinical and utilization outcomes.

SELECTED HEALTHY LIVES OUTCOME MEASURES

- Expenditures & utilization
- Clinical outcomes & adherence
- Access
- **Patient & provider experience**
- Health confidence
- **Social determinants**
- **Referral & engagement rates**

Note: Bolded items were emphasized by focus group participants.

Reflecting the importance of these issues, both Healthy Lives team members and partner medical/behavioral health providers cited patient and provider experience measures and patient engagement rates as key metrics of success. In the words of one Healthy Lives team member, **"The strength of the relationship leads to a lot of success that's difficult to measure."** Medical/behavioral health providers felt that getting patients involved with their care was essential and that the Healthy Lives team made a big difference in this. Healthy Lives team members agreed, saying, **"We serve a population that is very hard to engage, and we do it very well."**

Home Visits and Building Trust

Both Healthy Lives team members and partner medical/behavioral health providers believed that home visits were key to the program, with the Healthy Lives team citing these visits as one of the most important parts of the process. At the first home visit, the health outreach worker introduced the nurse care manager to the patient. The nurse care manager then conducted a thorough medication review: **"We look at everything, even over-the-counter herbals we may see in their home."** Healthy Lives team members also asked patients about what they would do in specific situations, which could turn up new information that was not previously shared. However, for Healthy Lives team members, home visits were **"more than just asking questions." "Being in their home allows us to see and feel how they navigate things."** Partner medical/behavioral health providers agreed: **"Going into the home enabled us to see the big picture."** These partner providers also identified other advantages of home visits, including that going to patients' homes allowed Healthy Lives team members to **"show patients directly how to take care of themselves"** and expanded options for patient contact that were sometimes quite limited. **"Many numbers were incorrect, so we couldn't even call them."** Even if phone numbers were reliably available, staff felt that telephonic case management did not work well for all patients.

Healthy Lives team members used a variety of strategies to build trust with patients and be allowed into their homes. One of the most important factors was maintaining a relationship over time: as the Healthy Lives team reported, **"Patients know us over time and that builds trust."** When first contacting patients, Healthy Lives team members took an approach of explaining the program and how it could help. Team members began by cold-calling patients and explaining that they could help when primary care was busy or if it was not meeting their needs. These benefits were discussed again during the first home visit. At that time, Healthy Lives team members also explained other program elements, including **"[presenting] the concept of reviewing their medications, in a way that is clear and shows we are doing it together."** They also discussed the care plan as part of the program and **"a way to make sure everyone [medical/behavioral providers and patient] is on the same page."**

Focusing on Patients' Goals and Needs

Focusing on patients' goals and needs was also a key element of making the Healthy Lives approach to care planning successful. Healthy Lives team members spoke of the importance of flexibility: **"We never go into a home with an agenda. Instead, we encourage patients to talk about whatever concerns them most."** This could include social or financial needs and helped Healthy Lives team members to understand patients' priorities. **"We ask them, 'What is most important to you right now?'"** As part of this process, the Healthy Lives team used an intake form that included an outline of patient goals. This document provided a starting point that then evolved over time. While the form was not given to patients, Healthy Lives team members used it to identify immediate and long-term goals, then explained to the patient what they would work on together at their next meeting. **"We try to think holistically: what will contribute most to this patient's well-being and health before it becomes an emergency?"**

Focusing on patients' needs also included taking these needs into account when considering patients' interactions with other health providers. Healthy Lives team members gave the example of not scheduling a morning appointment for someone who never attended appointments at that time. If patients were not following providers' plans for them, Healthy Lives team members felt that the first step was to clarify what the patient saw as important and identify any barriers or competing priorities they might be facing: **"Is it what the patient wants? What do we need to help them do first?"** In these situations, they felt that **"communication is important."** Partner medical and behavioral health providers appreciated this approach, saying, **"They had a lot of creative solutions and took the time to find out what patients wanted and needed."** This included highlighting needs of which partner providers had been unaware.

Monitoring and Responding to Change

In order to respond to changing circumstances and new data, the Healthy Lives team continued to meet with patients over time, gather patient information and helpful resources, and assess barriers with patients as they arose. Team members saw these as important components of the Healthy Lives process. Through home visits, Healthy Lives team members were able to assess which strategies were working and which required more consideration: **"Sometimes things did not work out initially. We had to work with the patient to understand the obvious [e.g., transportation] and less obvious [e.g., extreme fear of going to the medical appointment] factors."** Similarly, sometimes the Healthy Lives team would review a medical note and discover a statement that **"the patient is non-compliant—she is not following her diabetes management plan."** Healthy Lives team members would then meet with the patient and wonder with them about the plan, gathering their thoughts and perspectives and working with them to find a way to address whatever fears and barriers were preventing them from taking care of themselves. Understanding the patient's barriers to care was a critical step in addressing changing circumstances and new information.

> *"'Non-compliant' never means a patient is refusing to do what a medical provider wants. It means there is an underlying issue stopping them from following a plan."*
>
> **– HEALTHY LIVES TEAM MEMBER**

CARE COORDINATION

Both Healthy Lives team members and partner providers believed, consistent with evidence from the literature,[25,56,60,80,81] that coordinating care across medical, behavioral, and social needs providers was important. One Healthy Lives team member discussed their goal of acting as **"an extension of primary care planning."** In addition, the Healthy Lives team agreed that measures of social determinants of health were highly relevant for the program, and that understanding those needs was essential for effective care planning: **"We need to understand what is influencing the care plan."** For partner medical/behavioral health providers, the Healthy Lives team's engagement with these issues and ability to leave patients with resources and connections after discharge from the program were key.

Healthy Lives team members focused primarily on operationalizing the care plans that patients' other medical and behavioral health providers developed. However, as one partner administrator explained, the Healthy Lives team often knew more about the patient than did primary care providers, who only saw patients briefly. Healthy Lives team members also noted this issue, saying that partner providers' time was often too limited for them to learn about the patient and that, as a result, the Healthy Lives team had to engage both the patient and the provider. Care planning in practice was therefore an **"iterative process"** in which different parties wrote notes that were then incorporated into the plan. One partner administrator explained that the end result often combined health-related outcomes that primary care providers emphasized with a focus on social needs.

Enablers of Care Coordination

To support this exchange of information and joint care plan development, Healthy Lives team members and BIDCO providers utilized a shared medical record that allowed both groups to see each other's notes, an element of care integration supported in the literature.[81] The partner administrator who discussed this saw it as very helpful. Healthy Lives team members also emphasized the value of this system and felt that being able to read and write notes improved communication. In addition, Healthy Lives team members shared that they had access to a protected email account with BIDCO providers that allowed staff from multiple organizations to be included on the same email. They also had BIDCO identification badges to wear when attending appointments with patients, which they saw as improving fluidity and access.

> *"Access to the medical records made such a huge difference."*
>
> **– HEALTHY LIVES TEAM MEMBER**

In addition, Healthy Lives team members continued to meet with patients over time, a process that both Healthy Lives team members and partner medical/behavioral health providers saw as key to the program. For partner providers, having the Healthy Lives team available to follow up with patients **"allowed us to do what we would not otherwise be able to."** They believed that the Healthy Lives team was able to uncover patients' circumstances and conduct effective follow-up in a way they could not, particularly for complex issues: **"It's a more effective intervention than anything I could do over the phone."** This follow-up, according to partner providers, took a variety of forms. Healthy Lives team members helped patients follow through on recommendations, including assisting with specialist visits, showing them how to take care of themselves, and checking that they kept appointments and took their medicine. They also connected patients to a variety of community resources and showed them how to use these services, even accompanying them if necessary. In addition, Healthy Lives team members identified the best way to communicate with patients, such as through text message. Partner medical and behavioral health providers also felt that having Healthy Lives team members attend appointments with patients was valuable: with the Healthy Lives member there, partners felt that they could explain patients' health needs more clearly and be more confident that those issues would be addressed.

Finally, partner medical/behavioral health providers valued having one point-person who was able to address a wide range of patient needs—in their words, one person **"who can move on things and get it done"** and who **"knows the whole picture."** These providers felt that Healthy Lives not only uncovered many patient needs that they would otherwise have been unaware of—**"Before Healthy Lives and home visits, we would miss many needs"**—but that they also made addressing these needs easier because they could discover the source of patients' problems and work to address them across a wide range of areas. One partner administrator also felt that it was very helpful that the Healthy Lives nurse care manager was well-versed in both physical and mental health conditions and therefore better able to address both sets of issues.

Barriers to Care Coordination

Despite these strengths, Healthy Lives team members felt that addressing patients' needs, particularly given that most did not have family to help them, was a challenge and could make care provision time-intensive. Helping patients **"make ends meet"** was sometimes difficult, and Healthy Lives team members felt that housing in particular could be frustrating to address. Partner medical/behavioral health providers believed that for these reasons, helping connect patients with community partners was key. Healthy Lives team members agreed but found that getting a patient enrolled in, to attend, or to follow up with a program that they needed could be difficult. Similarly, they emphasized that maintaining this connection over time could be challenging: **"Boston has a lot of resources, but it is hard to keep them engaged."** One partner administrator shared that the volume of needs that Healthy Lives team members uncovered could be overwhelming for primary care providers, at least until they understood that the Healthy Lives team was there to work with them to address the identified issues.

Partner medical and behavioral health providers also wished that the Healthy Lives program had a greater reach. Access to the program, they felt, could be a challenge: **"Teams are small and we need more of them."** They wished that their patients who were outside the Healthy Lives catchment area were able to access the program, and felt that the catchment area excluded some of the places with the highest need. Both Healthy Lives team members and partner providers brought up sustainability and spread as important considerations for the program. In addition, some partner providers suggested that the six- to 12-month time limit be removed so that patients could stay in the program for longer periods.

Finally, Healthy Lives team members found that gaps in available behavioral health services posed challenges. They reported that availability of in-home therapy was limited and that behavioral health supports were hard to find outside of Brookline, even though most patients did not live in that area. Finding providers who would accept patients' cases could be difficult, and needing to travel longer distances could make it harder for patients to access these services. In addition, Healthy Lives team members reported that the waitlist for a therapist was three to eight months, and that many primary care providers were not comfortable monitoring psychiatric medications. In addition, patients faced barriers that also made it harder to access these services: for example, depression might make it harder for patients to access a therapist.

Despite these challenges, however, Healthy Lives team members were committed to working with patients to connect them with the community and mental health resources they needed. As one summed it up: **"Institutional systems are so difficult to maneuverer, and it can make you think no one cares. Once you give patients the key to unlock the system, they are very grateful."**

3. RESONANCE FOR PATIENTS

Interviewed Healthy Lives patients all experienced mental illnesses along with chronic and acute medical conditions. Due to their mental illnesses, several interviewed patients lived in specialized housing (group homes). Most interviewed patients were under the care of a psychiatrist for medication management, several had individual therapists, and others were awaiting a therapist. Some patients interviewed were actively managing severe depression, anxiety, delusions, grandiose thinking, and paranoia. Many presented a lifetime of trying to manage disabling emotions. Most could recall losses and regrets; however, many acknowledged their accomplishments, skills, and hopes for the future.

> *"Each therapist taught me so many helpful things. Little steps add up each day."*
>
> **– HEALTHY LIVES PARTICIPANT**

Interviewed patients also faced a variety of medical and social needs. Some had limited mobility and were using or waiting for a wheelchair. Interviewed patients also shared their difficulties with **"making ends meet."** They struggled with decisions such as buying food versus covering the copay for their medications. Many expressed extreme frustration with the health care system: **"They just don't understand my circumstance."** Many perceived the health care system as an enemy, deliberately making their lives harder. Transportation was an additional area of concern, as public transit was overwhelming for most interviewed patients. They did their best to come up with alternatives, including rideshare services that are costly on limited budgets. A few had family or friends in their lives, **"someone to talk to when things go bad."** However, most relied on their own resources to manage their complex medical, behavioral, and social needs.

Many patients took great pride in their home. They cleaned and decorated the best that they could to create a safe and calming environment. Having a pet had a significant therapeutic role in many patients' lives. Each beloved pet had strong therapeutic value, such as decreasing anxiety, enabling the patient to step outdoors to walk the dog; defusing depression by providing unlimited expression of unconditional love; and giving patients someone else to care about, which forced them to do more and see beyond their illness. **"If it wasn't for [my dog] Fluffy, I would not have a reason to get up in the morning."** Many interviewed patients expressed gratitude despite their difficult medical, behavioral, and social needs circumstances.

ASSESSING AND ADDRESSING NEEDS AND PRIORITIES

From the perspective of interviewed patients, care plan development consisted of Healthy Lives team members meeting with them and figuring out what was working well and what was not. All interviewed patients valued meeting with Healthy Lives team members to discuss their medical, behavioral, and social needs. They felt that the Healthy Lives team listened to them and put their concerns and needs first. Interviewed patients also expressed how much they respected Healthy Lives' work and advocacy to get their health care issues understood and addressed by providers. Several patients expressed comfort knowing that the Healthy Lives team was communicating with their medical providers: **"They do a lot of the legwork that I just cannot do."** Interviewed patients appreciated when Healthy Lives team members explained the importance of a specific medical appointment or treatment and then listened to their concerns. **"They know so much. They really help me understand."**

> *"Couldn't do it without [the health outreach worker]."*
>
> **– HEALTHY LIVES PARTICIPANT**

Interviewed patients also reported that Healthy Lives team members asked them specifically about their priorities. When a patient could not follow through with a request from a provider, patients recalled sharing their perspective with Healthy Lives team members and problem-solving with them about the issues that prevented them from moving forward with a treatment or appointment. **"I didn't fully understand the purpose of the medication and the [Healthy Lives] nurse helped me see the importance and how to address the side effects."**

Healthy Lives team members also understood the high value of their patients' dogs and cats. Having a dog or cat provided high therapeutic value for the patients interviewed. **"[My dog] Ava is my greatest support. We are inseparable."** Interviewed patients who had a dog or cat appreciated the support of Healthy Lives team members, who, if needed, helped them keep and care for their beloved companion.

> *"[My dog] Goldie and I talk together all the time. She helps me with my anxiety, staying near me all day and sleeping with me at night."*
>
> **– HEALTHY LIVES PARTICIPANT**

Care planning engaged family as necessary, but this was not the focus of the Healthy Lives initiative as presented by interviewed patients. Some interviewed patients were caring for loved ones who were also facing medical, behavioral, or social needs concerns. In these instances, interviewed patients felt that they could talk with the Healthy Lives team and get guidance and support.

TRACKING PROGRESS AND ADDRESSING BARRIERS

From the perspective of interviewed patients, progress was tracked by ongoing contact with the Healthy Lives team. Interviewed patients reported that Healthy Lives team members consistently followed up with them, meeting with them regularly and when circumstances changed. The team also worked with patients' medical, behavioral, and social needs providers to ensure that patients were able to manage their clinical and socioeconomic needs. Most patients interviewed could identify their progress on goals that they had set. They also recognized and were grateful for the Healthy Lives team and believed that they made progress due to the team's efforts and advocacy. **"They understand me, fight for me, and enable me to fight for myself."**

Despite this support, however, many Healthy Lives patients faced continual barriers and challenges as they pursued their goals. Many had serious mobility limitations due to needing a walker or wheelchair, being legally blind, etc. These patients faced isolation and barriers to basic care and treatment due to difficulties with transportation, miscommunication with providers, and long waits for mental health services. Many patients interviewed also reported numerous incidences of perceived unresponsiveness and disrespect from their health insurance and medical providers. **"They [health insurance] don't listen to me."** When asked for more details, patients shared that their providers and insurers did not return calls and did not do what they said they would: **"You just cannot count on them."**

> *"They [medical, behavioral, and insurance providers] just do not care about me. I don't matter to them."*
>
> **– HEALTHY LIVES PARTICIPANT**

Interviewed patients also endured continual difficulties with personal health aide providers, which made pursuing their identified goals more difficult. **"Several times a week, my aide does not show up. I called the agency and they do nothing. I filed a complaint—still nothing."** Several interviewed patients depended on home care aides to address basic needs. **"When I get home from dialysis, I need a shower. Even though I keep explaining this to each care provider, they don't listen."** Without dependable personal care aides, interviewed patients felt that they were at the mercy of providers who did not care about them. Many patients reported complaining to the home aide provider agency; however, they did not see these efforts as improving the reliability or quality of the care they received from home health aides.

These experiences with insurers and providers are a contrast to patients' experience with the Healthy Lives team. Within the Healthy Lives initiative, interviewed patients felt supported and that someone was listening to them, working on their behalf, and helping them advocate for themselves. Most understood that the Healthy Lives team had limitations: **"The nicest, most caring social workers just cannot fix the system."** Nevertheless, interviewed patients were very thankful for what the Healthy Lives team helped them accomplish.

4. INTERSECTION OF RELEVANCE AND RESONANCE

The two overarching study focus areas addressed how care planning was relevant to Healthy Lives and partner teams and how care planning resonated with Healthy Lives patients. The Healthy Lives approach to care planning—using care managers to coordinate between providers, provide coaching and support to patients,[25,56-60] and work with patients on practical skills, illness self-management, and goal setting[56]—was solidly aligned with evidence-based practice.

Meeting regularly with patients over time and focusing on their needs and priorities were seen as key elements of the Healthy Lives program. A central part of this continued contact was being in patients' homes to listen, assess, and figure out the next best steps for care plan integration, based on patient priorities. This focus had high resonance for patients and strong relevance for staff. Patients expressed their appreciation for having Healthy Lives team members come to their homes and viewed this as highly valuable, considering it to be the strongest asset of the initiative. The importance these visits had for patients was clear in the interviews: one of the most symbolic occurrences during the Healthy Lives interviews was when a patient's Golden Retriever stole the interviewer's car keys and hid them. The patient and interviewer believed that the dog did not want the interviewer to leave, somehow sensing their person's comfort, calmness, and the benefit derived from having a therapeutic visit. Having Healthy Lives team members make such therapeutic visits, learn about patients' priorities and concerns, and build trust over time was very important for interviewed patients.

Visiting patients at home also had high relevance for Healthy Lives team members and partner medical/behavioral health providers, who appreciated the insight and opportunities for follow-up it provided. Both groups saw these visits as a way of detecting unspoken needs: **"A picture is worth a thousand words."** It was also a powerful opportunity for relationship-building and key to a meaningful care planning process. Partner medical/behavioral health providers expressed that although they valued home visits, they were unable to provide this level of care themselves and appreciated having the Healthy Lives team available to do so.

> *"[Healthy Lives]. They are truly my life line."*
>
> **– HEALTHY LIVES PARTICIPANT**

Interviewed patients, Healthy Lives team members, and partner medical/behavioral health providers also identified similar barriers, with both groups seeing systemic issues as a challenge to care planning and meeting patients' needs. Interviewed patients recounted difficulties with external providers, insurance, and home health aides, as well as with broader social issues such as transportation and financial constraints. Similarly, Healthy Lives team members and partner providers felt that patients' high needs, resource limitations of the Healthy Lives program, and barriers to accessing behavioral health services could pose challenges. However, while interviewed patients often had a negative view of the health care system, most felt that the Healthy Lives team was an exception to this rule and valued their help in navigating the system, even as they recognized that the team could not solve all of the issues they faced. The Healthy Lives team were true liaisons, communicators, and problem solvers with their patients.

APPENDIX E: DETAILED PALLIATIVE CARE+ CASE STUDY

Care Dimensions provides palliative and hospice care for people in Eastern Massachusetts. The goal of their TCCI Program initiative, Palliative Care+, was to integrate palliative care staff into primary care sites in order to increase early identification of patients and bridge the gap between curative and end-of-life care. For this project, Care Dimensions partnered with North Shore Physicians Group (NSPG), a multispecialty practice with more than 20 locations throughout the North Shore. The Palliative Care+ program targeted high-risk NSPG patients who were part of the practice's accountable care organization.

Primary elements of the program included:

- Integrating palliative care staff into primary care sites,
- Identifying appropriate patients using triggers,
- Educating physicians and the community, and
- Increasing hospice admission and Medical Orders for Life-Sustaining Treatment (MOLST) completion.

Patients were referred to the program by NSPG high-risk nurse care managers (NCMs), physicians, and nurse practitioners (NPs). In addition, as part of the TCCI grant, NSPG employed a Palliative Care+ liaison who visited primary care practices regularly and helped to identify participants and facilitate referrals. Once a patient was referred, the Care Dimensions Palliative Care+ team—consisting of NPs, nurses, and a social worker—pulled and entered any patient information that was available through Partners HealthCare's Physician Gateway portal, talked to NSPG high-risk NCMs to see why the patient was referred, and called the patient to schedule an appointment. After that, a Care Dimensions NP conducted a home visit and any new information was communicated back to NSPG. Patients then received ongoing care as needed, including weekly phone calls from a Care Dimensions nurse.

Because many patients had already received care plans from multiple providers, Palliative Care+ focused less on creating new, independent plans and more on operationalizing existing plans in a patient-centered way. This occurred largely through speaking with participants and helping them to synthesize recommendations and identify priorities that aligned with their goals. Frequent and ongoing communication between the Palliative Care+ team and NSPG high-risk NCMs facilitated coordination throughout this process.

1. CONTEXTUAL FRAMEWORK

Patients with serious illnesses need coordinated, responsive care that centers their goals and priorities.[34,78,79] However, in practice, many receive care that is misaligned with their preferences, inadequately manages their symptoms, and that they or their families perceive as low quality.[166,167] In addition to decreasing quality of life, these shortcomings can increase hospitalizations and emergency department (ED) visits.[34,168,169] They can also leave caregivers without support as they face a variety of emotional, physical, and financial burdens,[68,69] including challenges related to out-of-pocket expenses and lost employment hours or opportunities.[69] Palliative care works to address these needs by providing care coordination, holistic symptom management, and caregiver support, including addressing practical, emotional, spiritual, and mental health needs in addition to physical symptoms.[34,105-107] A key element of palliative care is its patient- and family-centered approach and emphasis on patient autonomy and choice.[34,62,105,107] While palliative care is often confused with hospice or end-of-life care,[105,170] it can be provided at any stage of illness and in fact is often most effective when implemented early.[34,62,63,65,171] It can have a wide range of benefits for patients and families, including higher quality of life, decreased physical and emotional symptoms, and higher satisfaction with care.[63,65,172,173] In addition, evidence suggests that palliative care can improve caregiver wellbeing[63,173] and decrease resource utilization.[172,173]

While approaches to providing palliative care vary, certain elements help to make it more effective. Delivering care through an interdisciplinary, outpatient palliative care team is a key strategy,[34,61-63] and is preferable to utilizing an uncoordinated network of individual providers. Communication and collaboration with patients' other medical providers[34,64,65] and a systematic process for screening and referral[61,66,174,175] are also important. Palliative Care+ incorporated all three of these evidence-based components.

2. RELEVANCE FOR PALLIATIVE CARE+ AND PARTNER PROVIDERS

Palliative Care+ focused on operationalizing patient-centered care plans that prioritized patients' goals and priorities and helped them to synthesize recommendations from a wide range of providers. These efforts were supported by frequent and ongoing communication between the Care Dimensions team and NSPG high-risk NCMs, which facilitated patient identification and provided both sides with additional information about patients' needs and circumstances. This ongoing communication emerged as a key enabler of care coordination, as did the presence of a Palliative Care+ liaison and NSPG high-risk NCMs. In contrast, electronic medical record (EMR) access limitations, difficulty following patients across care settings, and physicians' and patients' discomfort with palliative care were viewed as the primary barriers.

CARE PLANNING STRUCTURE AND APPROACH

Palliative Care+ team members worked with patients to provide meaningful care that updated as patients' situations and needs evolved. Consistent with literature and best-practice recommendations,[34,62,105,107] Palliative Care+ team members believed that centering patients' goals and priorities was essential. The team helped patients synthesize and prioritize recommendations from many different providers, and reported that taking a step back to look at the big picture could bring patients and families a sense of relief: **"We help them stop feeling so distressed about not knowing what to do and having so many providers giving them recommendations."** After having these conversations with patients, Palliative Care+ team members shared patients' perspectives with NSPG high-risk NCMs. If patients' priorities conflicted with providers' goals for the patient, Palliative Care+ team members met with the patient to explain the importance of the issue from providers' perspectives and come to a shared understanding and resolution. **"We meet with the patient, explain why the doctor wanted them to do something, and then take the information back to the high-risk NCM."**

> *"We take all the little pieces from different providers and help patients put their finger on what's really in line with their goals of care."*
>
> **– PALLIATIVE CARE+ TEAM MEMBER**

To facilitate this process, Palliative Care+ team members found it helpful to go into initial patient meetings with some background information and a sense of why patients were referred. This information came primarily from speaking with the patient's NSPG high-risk NCM, a step that Palliative Care+ team members named as one of the most important parts of the process. **"I would call the high-risk NCM ahead of time and ask, what are you trying to accomplish and how can I help you?"** Having this background information allowed NPs to begin meeting patients' needs right away, rather than having to start from the beginning and ask questions the patient had already answered to other providers. **"Doctors are always asking the same questions. Patients appreciate not running through the whole thing again."** Palliative Care+ team members felt that this ability to get to the point, focus on the bigger picture, and make the patient feel they were there to help was important for successful care planning.

Staff perceptions of the most important program measures reflected the centrality of this patient-centered approach. Palliative Care+ team members considered patient and family satisfaction, though difficult to measure, to be one of the most important metrics: **"You really need to know about the patient and caregiver experience, including how they understand things and what their opinions are."** MOLST form completion was also identified as a particularly relevant metric for care planning, as this can speak to goals of care discussions and is one possible outcome of those conversations.

PALLIATIVE CARE+ OUTCOME MEASURES

- All-cause readmissions
- Emergency department visits
- Hospice length of stay/days of service
- **MOLST form completion**
- Palliative care conversion rate
- Palliative care referrals by NSPG providers
- Hospice admissions and referrals

Note: Bolded items were emphasized by focus group participants.

Responding to and Monitoring Change

In order to respond to changes over time, Care Dimensions held internal coordination of care meetings at which NPs, nurses, and the physician, social worker, and Director of Clinical Services discussed complex patients. They also stayed in regular contact with patients and NSPG high-risk NCMs, including sharing any new patient information with NSPG. High-risk NCMs, in turn, found it helpful to be able to reach out to the palliative care team about Palliative Care+

patients, particularly if they identified patients who seemed to need more care than they were receiving. This team-based approach, combined with communication with other providers, is consistent with evidence-based practice.[34,61-65]

Palliative Care+ nurses and NPs played a key role in monitoring progress against patient goals, including through home visits and weekly phone calls. These team members were responsible for staying connected with patients and following through on items discussed during patients' intake meetings. As Palliative Care+ team members explained, **"The nurses follow through on recommendations and make sure the patient and family do too."** In addition, nurses communicated with NSPG, including reviewing NSPG documentation and sharing any new patient information that arose.

However, while weekly phone calls to patients provided a means of regular contact that allowed the Palliative Care+ team to respond to changes or new concerns, staff found that patients did not always inform the nurse about symptoms they were experiencing or problems they were having reaching their specialists. As a result, Care Dimensions leadership shared that they might include more home visits in future iterations of the program, and also mentioned telehealth as a possible strategy to help address these issues. One NSPG physician expressed the benefits of having both home visits and phone calls available, stating that the two approaches complemented each other: **"Some patients don't want someone coming to their house, and phone calls help with that. But when patients are very symptomatic, having someone in the house can be valuable."**

> *"Communicating back to NSPG helps make sure the physician is aware of and on board with any new decisions."*
>
> **– PALLIATIVE CARE+ TEAM MEMBER**

CARE COORDINATION

While the Palliative Care+ program primarily focused on patients' medical needs, staff members—consistent with evidence from the literature[34,61-65]—emphasized the importance of coordination between the multiple teams working with patients. Much of this information-sharing took place through frequent ad hoc contact between Palliative Care+ team members and NSPG high-risk NCMs, as well as meetings between the two organizations' administrative teams. Palliative Care+ nurses and NSPG high-risk NCMs played important roles in ensuring continuity, since both groups regularly shared and reviewed patient information. In addition, high-risk NCMs and the Palliative Care+ liaison helped to identify patients and facilitate referrals to Palliative Care+.

Despite these multiple coordination structures, however, Palliative Care+ had limitations in the extent to which it was able to coordinate with non-NSPG sites, such as hospitals or rehabilitation facilities. In addition, while palliative care typically addresses a wide range of patient needs,[34] behavioral and social services were not a primary focus of the program, particularly in its early stages. To help with this, a social worker was added to the Palliative Care+ team partway through the grant period. Each patient received a call from this person and had the option of meeting with her if desired, and other members of the Palliative Care+ team reported that **"having access to a social worker is absolutely a plus."** However, high-risk NCMs felt that the social worker's availability was sometimes inconsistent. They noted that it would have been helpful if the Palliative Care+ program was more holistic, similar to how a hospice team might be arranged.

> *"We spend time feeding back to NSPG and looking at the information they share—that lets us keep continuity."*
>
> **– PALLIATIVE CARE+ TEAM MEMBER**

Enablers of Care Coordination

Communication between the Palliative Care+ and NSPG teams was understood by focus group participants to be a key part of the program and an essential element of delivering coordinated care, consistent with the literature.[34,64,65] This communication took place through a variety of avenues. Palliative Care+ team members communicated frequently with NSPG high-risk NCMs, including touching base about why patients were referred and sharing new patient information after visits or other ongoing contacts. NSPG high-risk NCMs appreciated being able to reach out to Care Dimensions staff about Palliative Care+ patients, particularly those who seemed to need more care than they were receiving. In addition, Care Dimensions and NSPG administrative teams met regularly to review patients and discuss any upcoming issues.

As part of the TCCI Program grant that Care Dimensions received, NSPG also employed a Palliative Care+ liaison who visited primary care practices regularly and was identified by Palliative Care+ team members as key to the program's success. This person reviewed data to identify potential patients to refer, brought those patients to doctors' attention, educated physicians, and sometimes conducted joint visits to help physicians talk to patients about palliative care. Palliative Care+ team members felt that this role was essential: **"We wouldn't have had any patients without her. Physicians just see the patient at the moment; the liaison can look at their history and recommend them."** High-risk NCMs felt that the liaison contributed to a change in physicians' perceptions, saying, **"She made physicians start looking at things in a way they never had before."** In addition, an NSPG physician emphasized the importance of the liaison in identifying patients and bringing them to her attention: **"Sometimes things get so hectic that without that extra set of hands, things fall to the wayside. It felt like a safety net for me."** The physician also appreciated the liaison's assistance in raising palliative care conversations with patients: **"Those are often very difficult conversations, but she was able to answer questions and make the referral easier and smoother."**

NSPG high-risk NCMs were also seen as influential. One NSPG physician cited working with the high-risk NCM, who was part of the practice's care team and interacted with the physician almost daily, as an important enabler. Palliative Care+ team members valued high-risk NCMs' role in providing patient information and context about why they were referred. When a primary care practice did not have a high-risk NCM, Palliative Care+ team members found the coordination process more difficult: **"Who do you call to get in touch about the patient? It's more challenging, and things don't get done as quickly."** In these cases, which became less common as the program went on, the Palliative Care+ team typically spoke with the NSPG Palliative Care+ liaison or the general nurse care manager in the office, but the process was more cumbersome. High-risk NCMs also saw themselves as central to the program's success, sharing that they initiated most referrals, brought patients to doctors' attention, and educated doctors about palliative care. **"I don't think Palliative Care+ would have happened if we weren't pulled in."**

Barriers to Care Coordination

Despite these strengths, staff members also identified challenges to care coordination. Lack of EMR access was a key barrier: Palliative Care+ team members did not have access to NSPG records and explained that this could delay care coordination activities. **"We can't look up provider notes because we don't have access to the records. If we can't find someone in the office, there's a lot we don't know."** NSPG high-risk NCMs also felt the impact of this limitation, explaining that communication with the Palliative Care+ team was harder and more time consuming because of the lack of a shared EMR. In addition, patients had to wait while a member of the Palliative Care+ team talked to the NSPG high-risk NCM, who talked to the primary care provider, who talked to the specialist, and so on. High-risk NCMs felt that this process likely contributed to unmet symptom management needs among patients: **"Without EMR access, a lot of time is wasted running around being the messenger. In the meantime, you know the patient is waiting."**

Following patients across care settings also posed a challenge. Palliative Care+ team members reported that it was hard to follow patients when they were admitted to the hospital or a rehabilitation facility or nursing home, even though **"we play such an important role in these situations."** They believed these barriers to be a result of changing providers and the need to obtain a new order to see the patient in each setting, as well as a reluctance on the part of other providers to issue those orders. NSPG high-risk NCMs reported similar issues, including noting that communication with hospitals outside of NSPG's health system was particularly difficult and often did not happen. High-risk NCMs also reported experiencing pushback from inpatient case managers, who sometimes said a patient or family was not ready for palliative care despite being relatively unfamiliar with them and their situation. In addition, high-risk NCMs noted that many physicians were only aware of part of what was happening with patients. They believed that the Palliative Care+ liaison helped with this by reviewing patient data and working with the inpatient palliative care team: **"People are often in silos. Having someone who sees the big picture lets you say, 'something's not working.'"**

Contributing to these issues was physicians' discomfort with palliative care, something also reflected in the literature.[105,176] NSPG high-risk NCMs noted physicians' association of palliative care with hospice as a barrier, and found that physicians were often reluctant to raise palliative care topics with patients: **"Doctors often looked at it like hospice, whereas we saw it more as a bridge."** An NSPG physician agreed, stating that the hectic pace of the practice, combined with discomfort with palliative care conversions and the temptation to put off the time, planning, effort, and coordination involved, could hinder referrals to Palliative Care+. **"Sometimes it's just human to feel in denial—maybe I don't have to, maybe next time."** Palliative Care+ team members, for their part, speculated that providers in other settings might have been hesitant to refer patients because they did not understand

> *"We need more palliative care, and more providers and patients educated about it. I think it's a very underutilized tool."*
>
> **– NSPG PHYSICIAN**

the need for palliative care or associated Care Dimensions with hospice. They reported that educating these providers about the Palliative Care+ program helped with this issue somewhat, as did having an NP colleague in the practice site who was familiar with the program and **"knew who we were and how beneficial we could be."** This belief that physician training could help overcome these barriers is supported in the literature[105,177,178] and was also mentioned by two NSPG physicians, including one who suggested providing repeated trainings to refresh memories and reach new providers. The value of personal relationships was also echoed by an NSPG physician, who explained that knowing the Palliative Care+ liaison personally made her more confident when referring patients.

Like physicians, many patients also have reservations about palliative care.[170,179,180] As one NPSG physician put it, **"There's a general feeling that when palliative care is involved, it means the end is near."** NSPG high-risk NCMs and physicians both saw this as an important barrier. Other factors, such as cultural norms, poor health, and language barriers, also discouraged patients and families from accepting palliative care. NSPG physicians explained that palliative care discussions often took place over multiple visits, and that they needed to educate patients and dispel concerns and misperceptions. **"I try to explain that palliative care isn't just for people who are dying—there are symptoms that extend beyond what I can treat, and palliative care can help with that."** In addition, one talked about guiding patients or families to come to the realization on their own that they need more support. NSPG high-risk NCMs used similar strategies, including introducing palliative care to patients as a means of symptom management, a way of meeting their goal of staying out of the hospital, another layer of support, and/or a way of helping **"keep them in the driver's seat."** They also saw their relationships with patients as a key element in beginning the conversation: **"Many patients wouldn't have agreed if they didn't have the relationship that they did with us, the level of trust."**

3. RESONANCE FOR PATIENTS

Interviewed Palliative Care+ patients were often isolated and eager for an opportunity to share their life stories. They reminisced about life's ups and downs and reaffirmed or expressed regret about life choices. Most were very thankful to be alive, but were candid about their negative experiences with the health care system. Many shared their encounters with EDs and hospitals, portraying the majority of these encounters as fraught with misunderstandings and provider unresponsiveness. All interviewed patients wanted to avoid the ED and hospital at all costs. **"Just tell me what I need to do to stay away from the emergency room and hospital. I do not want to go there again. It makes things worse."**

> *"I count my blessings every day. Cannot believe I survived that last hospitalization."*
>
> – PALLIATIVE CARE+ PARTICIPANT

Caregivers, who were usually spouses or adult children of Palliative Care+ patients, agreed that they did not want their loved one to endure another hospital or ED encounter. They also added that they did not want their family member to go to a nursing home and that this was the core reason they were caring for them at home. **"My father was in a nursing home. It was horrible. I will not let Mom go to one."** Caregivers perceived nursing homes as **"warehouses"** where patients did not get the care and attention that they required and deserved.

Although the overarching focus of this study was care planning, most interviewed patients and caregivers could not identify a singular, coordinated care plan. There were many plans generated by numerous health care providers and most of those interviewed did not fully understand what their current or overall "plan" might be. Most would instead point to a foot-high stack of papers on the kitchen table, stating that all their plans and instructions were somewhere in the pile. Some pulled out calendars they had made that listed their next medical appointments. They knew the date and time of their next appointment with their primary care doctor and specialists. They also knew when the Palliative Care+ nurse would be calling them. However, patients were overwhelmed with numerous different care plans which left them and their family caregivers confused.

> *"I have many care plans. I get one every time I go to an appointment or the hospital."*
>
> – PALLIATIVE CARE+ PARTICIPANT

Most interviewed patients and family caregivers spoke with great appreciation of NSPG and Palliative Care+. In fact, from the patient and family perspective, these two groups appeared to be part of the same team, not from separate organizations. Interviewed patients and family caregivers called the Palliative Care+ team **"the nurses that came to the house or called them."** What resonated with patients and their families was that NSPG and Palliative Care+ (**"the nurses"**) were working together to address their medical needs.

ASSESSING AND ADDRESSING NEEDS AND PRIORITIES

Medical Needs and Priorities

Interviewed patients reported that NSPG worked closely with them to coordinate care with specialists and to make sure their medical concerns were addressed. There was a general perception that the Palliative Care+ team was trying to help them make sense of their complex medical issues by finding the best ways to address their medical needs (symptom management) at home. Most patients and caregivers recalled a visit from the Palliative Care+ nurse practitioner at which they went over what they needed to do to stay at home (e.g., managing their pain, decreasing their risk of pneumonia, managing their diabetes). All interviewed patients and caregivers reported that this visit was helpful. Some patients and all caregivers reported that the approach outlined at the initial visit required constant tweaking due to the patient's changing clinical needs. These ongoing changes were managed through follow-up home visits by a Palliative Care+ nurse practitioner, NSPG office visits, and/or phone calls from the NSPG care manager or Palliative Care+ nurse.

> *"I know there are things I must do to stay out of that hospital. It's confusing. The nurse [Palliative Care+] helped me sort it out."*
>
> **– PALLIATIVE CARE+ PARTICIPANT**

All patients and caregivers firmly articulated their priority of staying out of the ED and hospital. Although some patients would not provide full details of their ED and hospital stays, many outlined experiences of doctors and nurses not listening to them, getting what they believed was the wrong treatment, and being given confusing and contradictory discharge instructions. Patients and caregivers relied on NSPG and the Palliative Care+ team **"to make sense of it all."** Most interviewed patients and caregivers expressed their thankfulness for NSPG and Palliative Care+ for helping with this important priority.

In addition, all interviewed patients recalled going through the MOLST process and completing the form, either during their last hospitalization or with the Palliative Care+ team. Patients and caregivers reported that learning about and completing the MOLST was very helpful. Many also mentioned that in addition to the MOLST, they had completed their health proxy form. Interviewed patients revealed a deep understanding of the possibility that their complex medical conditions could end their lives. Completing the MOLST and designating a health proxy were sources of comfort and reassurance that their choices and desires would be followed when they could no longer speak for themselves. Some caregivers reported that, despite being health proxies for their loved one, they did not have a MOLST form. These Palliative Care+ patients no longer had the cognitive capacity to make their wishes known, and as a result, some caregivers were uneasy about managing the opinions of other family members who were not involved with the patient's daily care. Most of these caregivers were attempting to follow what they believed to be the wishes of their loved one based on conversations they had before their cognitive decline.

> *"I had not really thought things through. MOLST help me talk to my children about what I wanted. It gave me a way to talk about some difficult things."*
>
> **– PALLIATIVE CARE+ PARTICIPANT**

Psychosocial Needs and Priorities

Patients and caregivers valued the Palliative Care+ team's help with their medical priorities. However, when exploring with interviewed patients about how mental health and social or economic concerns were assessed, all patients and caregivers reported that they were deferred to other organizations such as senior services. Generally, participants did not see mental health, substance use, and social and economic needs as being addressed by NSPG and Palliative Care+. This left significant gaps for patients and caregivers.

> *"I just want to go to church. I can't get there on my own and have been asking everyone for help for two years. Nothing—no one will help me."*
>
> **– PALLIATIVE CARE+ PARTICIPANT**

Many patients had priorities that were not centered on their medical conditions but that their medical conditions prevented them from addressing. Most of these priorities related to social needs. Many interviewed patients were homebound, without a way to go out on their own. Most patients who did not have family members nearby or who had family members with many of their own life demands pointed out that they could not engage in activities that gave meaning to their lives. Not being able to attend church or a meaningful event was very upsetting to interviewed patients. In addition, many patients reported feelings of loneliness. **"Is this it for me? Just medical appointments and feeling sick."** They missed many people in their lives who had died and although they all articulated that they were grateful for being alive and wanted to live, some worried that they would never feel any better and their conditions would worsen over time. **"It's so hard for me now. I just can't imagine how much harder it will be when I get even sicker."**

In addition, several interviewed Palliative Care+ patients had beloved pets with clear therapeutic value. **"I feel calmer when I am petting Obi-Wan. He is better than my blood pressure medicine."** Several shared that they could not properly take care of their dog and wanted help with walking and feeding their **"only companion."** Most of these patients had asked for help and been referred to other organizations. For example, a patient with amputated limbs reported that senior services told her she would need to give up her dog. When she explained that her Shih Tzu was the reason she woke up every morning, she was told that there were not any options. After a few moments of deep sobbing, she stated, **"I would rather die. I cannot give him up."** All patients interviewed were aware that they had a key role in staying well. They also believed that addressing their non-medical needs would aid them in their efforts to stay well and avoid ED and hospital encounters.

> *"My [small dog] Charlie. He's my life. My only friend really."*
>
> **– PALLIATIVE CARE+ PARTICIPANT**

ROLE OF FAMILY AND PROFESSIONAL CAREGIVERS

The importance of family caregivers was a recurrent theme in the interviews. Many interviews included caregivers of the Palliative Care+ patients, and interviewed patients all acknowledged the vital role of their caregiver(s). Each realized that it would be difficult or impossible to manage at home without the ongoing care they received from their family member(s).

Family caregivers often faced significant burdens. Several were taking care of loved ones who could no longer speak for themselves. These caregivers expressed concern over the ongoing stress and hardship they were experiencing. Most could not afford respite or personal care services for their loved one. In several cases, spouses who were themselves older adults dealing with illness were taking care of spouses with even more severe illness. Even with some support from their adult children, the daily burden of caring for their spouse was crushing. **"I have been feeling poorly for a week. I am having a hard time breathing and I think I have a fever. Who will take care of my husband if I end up in the hospital?"** Fearing what would happen to their loved one, several interviewed patients reported that they would not attend to their own illness. Most of the interviewed caregivers reported that no one checks up on them or asks how they are doing. **"I feel isolated and overwhelmed."** Many of these caregivers did not feel comfortable asking for help, even from their families. **"My son has his own issues to deal with. I just can't ask him to help me."**

> *"It's just me taking care of my mom for eight years. I still have to work full time and take care of my sons. Some days it just seems impossible."*
>
> **– PALLIATIVE CARE+ PARTICIPANT**

Several of the interviewed patients depended on agency personal care attendants to move them from their bed to their wheelchair, assist them with bathing and daily hygiene, empty their colostomy bag, and conduct similar tasks. Most of the interviewed patients who depended on personal care attendants reported that this service was highly unreliable. Many times they would spend the day in bed because no one came, even after they called the agency several times. **"I do not have reliable, consistent help. I never know if someone is going to show up or if I will spend days in my chair or bed."** Patients who depended on personal care attendants did not know where to turn or who to call. They were overwhelmed with feelings of fear and helplessness. **"I called 911 last year when no one had come for two days even after I called the agency fifteen times. I ended up in the hospital."**

TRACKING PROGRESS

From the perspective of interviewed patients, progress was tracked through follow-up calls from the NSPG and Palliative Care+ teams. All interviewed patients talked about the weekly call they received from **"that nice nurse"** (Palliative Care+). They also reported follow-up calls from the NSPG nurse concerning a change in medication or a follow-up after a hospital stay or ED visit. Many times,

> *"The nurse calls me every Thursday at 4:00 PM. She is very nice."*
>
> **– PALLIATIVE CARE+ PARTICIPANT**

patients shared that they had reached out to their specialist and were waiting to hear back. However, none of the interviewed patients would contact NSPG if they were having trouble getting a call back from their specialist: **"I don't want to bother the nurses. They are very busy and I can wait for my next [specialist] appointment."** Even though all patients knew when the Palliative Care+ nurse would be calling them, most of those interviewed would not bring up a concern or issue. They reported that they did not want to bother her. Digging deeper into this reasoning, some patients revealed that they feared that if they called NSPG or talked with the Palliative Care+ nurse, they might be told to go to the ED and could end up back in the hospital. Although in principle interviewed patients seemed to understand that getting attention sooner could prevent a hospital visit, they still perceived the risk as too great.

> *"I called Dr. [Specialist] several times last week and this morning. They just don't return my calls."*
>
> **– PALLIATIVE CARE+ PARTICIPANT**

4. INTERSECTION OF RELEVANCE AND RESONANCE

The overarching study focus areas addressed how care planning was relevant to the Palliative Care+ and NSPG teams and how care planning resonated with patients and their caregivers. The Palliative Care+ program utilized many evidence-based approaches, including delivering palliative care through an interdisciplinary, outpatient palliative care team,[34,61-63] communicating and collaborating with patients' other providers,[34,64,65] and using a systematic process for screening and referral.[61,66] Within this program, care planning did not take the form of one care plan document per se—instead, the Palliative Care+ team worked closely with other providers and with patients and their loved ones to understand the care plans that had already been developed, learn patients' perspectives on what was or was not working, and collaborate with NSPG to make changes or modifications as needed.

Palliative Care+ and NSPG focus group participants identified a number of program elements as effective interventions. One of the most essential, in their view, was the frequent and ongoing communication between the Care Dimensions and NSPG teams. Having a Palliative Care+ liaison on site at NSPG to provide consultation and education to physicians, patients, and families was also seen as key, as was the presence of NSPG high-risk NCMs. In addition, having the Palliative Care+ team visit the patient's home was valuable for NSPG staff, providing them with needed insight on what was working for patients as well as an opportunity to intervene and recommended modifications to a plan or approach. In contrast, a main difficulty identified by staff members was the inability to follow patients across all settings. Staff also agreed that patients' and caregivers' unmet social and emotional needs—a key issue that emerged from patient and caregiver interviews—were a challenge. These limitations existed due to inadequacies in the larger delivery system, as well as the fact that the initiative was not specifically designed to address patients' non-medical needs or the needs of family caregivers.

Palliative Care+ patients interviewed genuinely appreciated the efforts of NSPG and the Palliative Care+ team. They found the multitude of care plans, instructions, and information they had received from numerous providers confusing and found it difficult to know what they should do and who they should contact regarding their concerns. They saw the Palliative Care+ team as helping them to sort through this abundance of information. In addition, all patients interviewed recalled, in a positive manner, the MOLST process and documenting their wishes.

> *"My primary care doctor and the nurses [Palliative Care+ implied] are good people. They have tried to help me. I would be dead without them."*
>
> **– PALLIATIVE CARE+ TEAM PARTICIPANT**

However, despite these areas of resonance, many interviewed patients had social needs that fell outside the focus of the Palliative Care+ initiative but meaningfully impacted their wellbeing. Non-medical needs, such as the desire to attend an important activity or care for a beloved pet, could profoundly affect interviewed patients. Interviews also revealed a range of unmet caregiver-related needs, including inconsistency on the part of home health aides and significant burdens on family caregivers. While these issues fell outside the focus of the Palliative Care+ program, they have the potential to deeply impact not only patients' overall well-being, but also their physical health. Keeping a patient well is strongly correlated with addressing social needs, with compelling evidence showing that doing so can lead to substantially improved patient outcomes and decreased health care costs.[40-44] While patients and staff members all had great appreciation and respect for the Palliative Care+ initiative in terms of care coordination and planning, these broader issues posed serious challenges that were outside of the scope of the program to address.

APPENDIX F: REFERENCES

1. Massachusetts Health Policy Commission. Targeted Cost Challenge Investment: Behavioral Health Network. Retrieved from https://www.mass.gov/files/documents/2019/06/03/Behavioral%20Health%20Network.pdf
2. McDonald, K. M., Sundaram, V., Bravata, D. M., Lewis, R., Lin, N., Kraft, S. A., . . . Owens, D. K. (2007). Care coordination. In K. G. Shojania, K. M. McDonald, R. M. Wachter, & D. K. Owens (Eds.), Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies (Vol. 7). Rockville (MD): Agency for Healthcare Research and Quality. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK44015/
3. Weaver, S. J., Che, X. X., Petersen, L. A., & Hysong, S. J. (2018). Unpacking care coordination through a multiteam system lens: A conceptual framework and systematic review. Medical Care, 56(3), 247-259. Retrieved from https://journals.lww.com/lww-medicalcare/Abstract/2018/03000/Unpacking_Care_Coordination_Through_a_Multiteam.9.aspx
4. Burt, J., Rick, J., Blakeman, T., Protheroe, J., Roland, M., & Bower, P. (2014). Care plans and care planning in long-term conditions: A conceptual model. Primary Health Care Research & Development, 15(4), 342-354. https://doi.org/10.1017/s1463423613000327
5. Breckenridge, E. D., Kite, B., Wells, R., & Sunbury, T. M. (2019). Effect of patient care coordination on hospital encounters and related costs. Population Health Management, 22(5). https://doi.org/10.1089/pop.2018.0176
6. Tricco, A. C., Antony, J., Ivers, N. M., Ashoor, H. M., Khan, P. A., Blondal, E., . . . Straus, S. E. (2014). Effectiveness of quality improvement strategies for coordination of care to reduce use of health care services: A systematic review and meta-analysis. CMAJ: Canadian Medical Association Journal, 186(15), E568-578. https://doi.org/10.1503/cmaj.140289
7. Samal, L., Dykes, P. C., Greenberg, J. O., Hasan, O., Venkatesh, A. K., Volk, L. A., & Bates, D. W. (2016). Care coordination gaps due to lack of interoperability in the United States: A qualitative study and literature review. BMC Health Services Research, 16, 143. https://doi.org/10.1186/s12913-016-1373-y
8. Rudin, R. S., & Bates, D. W. (2014). Let the left hand know what the right is doing: A vision for care coordination and electronic health records. Journal of the American Medical Informatics Association, 21(1), 13-16. https://doi.org/10.1136/amiajnl-2013-001737
9. Rich, E., Lipson, D., Libersky, J., & Parchman, M. (2012). Coordinating Care for Adults With Complex Care Needs in the Patient-Centered Medical Home: Challenges and Solutions. Retrieved from https://pcmh.ahrq.gov/page/coordinating-care-adults-complex-care-needs-patient-centered-medical-home-challenges-and
10. Tschudy, M. M., Raphael, J. L., Nehal, U. S., O'Connor, K. G., Kowalkowski, M., & Stille, C. J. (2016). Barriers to care coordination and medical home implementation. Pediatrics, 138(3). https://doi.org/10.1542/peds.2015-3458
11. Ronis, S. D., Grossberg, R., Allen, R., Hertz, A., & Kleinman, L. C. (2019). Estimated nonreimbursed costs for care coordination for children with medical complexity. Pediatrics, 143(1). https://doi.org/10.1542/peds.2017-3562
12. Aronson, L., Bautista, C. A., & Covinsky, K. (2015). Medicare and care coordination: Expanding the clinician's toolbox. JAMA, 313(8), 797-798. https://doi.org/10.1001/jama.2014.18174
13. Coulter, A., Entwistle, V. A., Eccles, A., Ryan, S., Shepperd, S., & Perera, R. (2015). Personalised care planning for adults with chronic or long-term health conditions. Cochrane Database of Systematic Reviews(3), Cd010523. https://doi.org/10.1002/14651858.CD010523.pub2
14. Lhussier, M., Eaton, S., Forster, N., Thomas, M., Roberts, S., & Carr, S. M. (2015). Care planning for long-term conditions–A concept mapping. Health Expectations, 18(5), 605-624. https://doi.org/10.1111/hex.12063
15. Rotenstein, L., Tucker, S., Kakoza, R., Tishler, L., Zai, A., & Wu, C. (2016). The critical components of an electronic care plan tool for primary care: An exploratory qualitative study. Journal of Innovation in Health Informatics, 23(2), 529-533. https://doi.org/10.14236/jhi.v23i2.836
16. van Dongen, J. J. J., van Bokhoven, M. A., Daniëls, R., van der Weijden, T., Emonts, W. W. G. P., & Beurskens, A. (2016). Developing interprofessional care plans in chronic care: A scoping review. BMC Family Practice, 17(1), 137. Retrieved from https://doi.org/10.1186/s12875-016-0535-7
17. Mercer, T., Bae, J., Kipnes, J., Velazquez, M., Thomas, S., & Setji, N. (2015). The highest utilizers of care: Individualized care plans to coordinate care, improve healthcare service utilization, and reduce costs at an academic tertiary care center. Journal of Hospital Medicine, 10(7), 419-424. https://doi.org/10.1002/jhm.2351
18. Baker, A., Cronin, K., Conway, P. H., DeSalvo, K. B., Rajkumar, R., & Press, M. J. (2016). Making the comprehensive shared care plan a reality. NEJM Catalyst. Retrieved from https://catalyst.nejm.org/making-the-comprehensive-shared-care-plan-a-reality/
19. Bahorik, A. L., Satre, D. D., Kline-Simon, A. H., Weisner, C. M., & Campbell, C. I. (2017). Serious mental illness and medical comorbidities: Findings from an integrated health care system. Journal of Psychosomatic Research, 100, 35-45. https://doi.org/10.1016/j.jpsychores.2017.07.004
20. Fazel, S., Geddes, J. R., & Kushel, M. (2014). The health of homeless people in high-income countries: Descriptive epidemiology, health consequences, and clinical and policy recommendations. Lancet, 384(9953), 1529-1540. https://doi.org/10.1016/s0140-6736(14)61132-6
21. Grant, R., Gracy, D., Goldsmith, G., Shapiro, A., & Redlener, I. E. (2013). Twenty-five years of child and family homelessness: Where are we now? American Journal of Public Health, 103(Suppl 2), e1-10. https://doi.org/10.2105/ajph.2013.301618
22. Cagle, J. G., Bunting, M., Kelemen, A., Lee, J., Terry, D., & Harris, R. (2017). Psychosocial needs and interventions for heart failure patients and families receiving palliative care support: A systematic review. Heart Failure Reviews, 22(5), 565-580. Retrieved from https://doi.org/10.1007/s10741-017-9596-5

23 Fortuna, K. L., Ferron, J., Pratt, S. I., Muralidharan, A., Aschbrenner, K. A., Williams, A. M., . . . Salzer, M. (2019). Unmet needs of people with serious mental illness: Perspectives from certified peer specialists. Psychiatric Quarterly, 90(3), 579-586. https://doi.org/10.1007/s11126-019-09647-y

24 Ryan, J., Abrams, M. K., Doty, M. M., Shah, T., & Schneider, E. C. (2016). How High-Need Patients Experience Health Care in the United States: Findings from the 2016 Commonwealth Fund Survey of High-Need Patients. Retrieved from https://www.commonwealthfund.org/publications/issue-briefs/2016/dec/how-high-need-patients-experience-health-care-united-states

25 Lawrence, D., & Kisely, S. (2010). Inequalities in healthcare provision for people with severe mental illness. Journal of Psychopharmacology, 24(4 Suppl), 61-68. https://doi.org/10.1177/1359786810382058

26 Kushel, M. B., Gupta, R., Gee, L., & Haas, J. S. (2006). Housing instability and food insecurity as barriers to health care among low-income Americans. Journal of General Internal Medicine, 21(1), 71-77. https://doi.org/10.1111/j.1525-1497.2005.00278.x

27 Stone, E. M., Chen, L. N., Daumit, G. L., Linden, S., & McGinty, E. E. (2019). General medical clinicians' attitudes toward people with serious mental illness: A scoping review. Journal of Behavioral Health Services and Research, 46(4), 656-679. https://doi.org/10.1007/s11414-019-09652-w

28 Viron, M. J., & Stern, T. A. (2010). The impact of serious mental illness on health and healthcare. Psychosomatics, 51(6), 458-465. https://doi.org/10.1176/appi.psy.51.6.458

29 White, B. M., & Newman, S. D. (2015). Access to primary care services among the homeless: A synthesis of the literature using the equity of access to medical care framework. Journal of Primary Care & Community Health, 6(2), 77-87. https://doi.org/10.1177/2150131914556122

30 Bassuk, E. L., DeCandia, C. J., Tsertsvadze, A., & Richard, M. K. (2014). The effectiveness of housing interventions and housing and service interventions on ending family fomelessness: A systematic review. American Journal of Orthopsychiatry, 84(5), 457-474. https://doi.org/10.1037/ort0000020

31 de Vet, R., van Luijtelaar, M. J., Brilleslijper-Kater, S. N., Vanderplasschen, W., Beijersbergen, M. D., & Wolf, J. R. (2013). Effectiveness of case management for homeless persons: A systematic review. American Journal of Public Health, 103(10), e13-26. https://doi.org/10.2105/ajph.2013.301491

32 Hwang, S. W., & Burns, T. (2014). Health interventions for people who are homeless. Lancet, 384(9953), 1541-1547. https://doi.org/10.1016/s0140-6736(14)61133-8

33 Krahn, J., Caine, V., Chaw-Kant, J., & Singh, A. E. (2018). Housing interventions for homeless, pregnant/parenting women with addictions: A systematic review. Journal of Social Distress and the Homeless, 27(1), 75-88. Retrieved from https://doi.org/10.1080/10530789.2018.1442186

34 National Consensus Project for Quality Palliative Care. (2018). Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Retrieved from https://www.nationalcoalitionhpc.org/ncp/

35 Alley, D. E., Asomugha, C. N., Conway, P. H., & Sanghavi, D. M. (2016). Accountable Health Communities — Addressing social needs through Medicare and Medicaid. New England Journal of Medicine, 374(1), 8-11. Retrieved from https://www.nejm.org/doi/full/10.1056/NEJMp1512532

36 Berkowitz, S. A., Basu, S., Meigs, J. B., & Seligman, H. K. (2018). Food insecurity and health care expenditures in the United States, 2011-2013. Health Services Research, 53(3), 1600-1620. https://doi.org/10.1111/1475-6773.12730

37 Billioux, A., Verlander, K., Anthony, S., & Alley, D. (2017). Standardized screening for health-related social needs in clinical settings: The Accountable Health Communities screening tool. NAM Perspectives(Discussion Paper). https://doi.org/10.31478/201705b

38 Fitzpatrick, T., Rosella, L. C., Calzavara, A., Petch, J., Pinto, A. D., Manson, H., . . . Wodchis, W. P. (2015). Looking beyond income and education: Socioeconomic status gradients among future high-cost users of health care. American Journal of Preventive Medicine, 49(2), 161-171. https://doi.org/10.1016/j.amepre.2015.02.018

39 Sterling, S., Chi, F., Weisner, C., Grant, R., Pruzansky, A., Bui, S., . . . Pearl, R. (2018). Association of behavioral health factors and social determinants of health with high and persistently high healthcare costs. Preventive Medicine Reports, 11, 154-159. https://doi.org/10.1016/j.pmedr.2018.06.017

40 Thorpe, K. E., & Joski, P. (2018). Association of social service spending, environmental quality, and health behaviors on health outcomes. Population Health Management, 21(4), 291-295. https://doi.org/10.1089/pop.2017.0136

41 Beck, A. F., Henize, A. W., Kahn, R. S., Reiber, K. L., Young, J. J., & Klein, M. D. (2014). Forging a pediatric primary care-community partnership to support food-insecure families. Pediatrics, 134(2), e564-571. https://doi.org/10.1542/peds.2013-3845

42 Mays, G. P., Mamaril, C. B., & Timsina, L. R. (2016). Preventable death rates fell where communities expanded population health activities through multisector networks. Health Affairs, 35(11), 2005-2013. Retrieved from https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2016.0848

43 Rocque, G. B., Pisu, M., Jackson, B. E., Kvale, E. A., Demark-Wahnefried, W., Martin, M. Y., . . . Partridge, E. E. (2017). Resource use and Medicare costs during lay navigation for geriatric patients with cancer. JAMA Oncology, 3(6), 817-825. https://doi.org/10.1001/jamaoncol.2016.6307

44 Shier, G., Ginsburg, M., Howell, J., Volland, P., & Golden, R. (2013). Strong social support services, such as transportation and help for caregivers, can lead to lower health care use and costs. Health Affairs, 32(3), 544-551. https://doi.org/10.1377/hlthaff.2012.0170

45 McDonald, K. M., Schultz, E., Albin, L., Pineda, N., Lonhart, J., Sundaram, V., . . . Davies, S. (2014). Care coordination measurement framework. In Care Coordination Measures Atlas Update. Rockville, MD: Agency for Healthcare Research and Quality. Retrieved from https://www.ahrq.gov/ncepcr/care/coordination/atlas/chapter3.html

46 Brown, S., Lhussier, M., Dalkin, S. M., & Eaton, S. (2018). Care planning: What works, for whom, and in what circumstances? A rapid realist review. Qualitative Health Research, 28(14), 2250-2266. https://doi.org/10.1177/1049732318768807

47 Hong, C. S., Siegel, A. L., & Ferris, T. G. (2014). Caring for High-Need, High-Cost Patients: What Makes for a Successful Care Management Program? Retrieved from https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_issue_brief_2014_aug_1764_hong_caring_for_high_need_high_cost_patients_ccm_ib.pdf

48 Council on Community Pediatrics. (2013). Providing care for children and adolescents facing homelessness and housing insecurity. Pediatrics, 131(6), 1206-1210. https://doi.org/10.1542/peds.2013-0645

49 Lindsey, E. W. (2000). Social work with homeless mothers: A strength-based solution-focused model. Journal of Family Social Work, 4(1), 59-78. Retrieved from https://doi.org/10.1300/J039v04n01_06

50 Sznajder-Murray, B., & Slesnick, N. (2011). 'Don't leave me hanging': Homeless mothers' perceptions of service providers. Journal of Social Service Research, 37(5), 457-468. https://doi.org/10.1080/01488376.2011.585326

51 Tobin, K., & Murphy, J. (2013). Addressing the challenges of child and family homelessness. Journal of Applied Research on Children, 4(1), Article 9. Retrieved from https://digitalcommons.library.tmc.edu/childrenatrisk/vol4/iss1/9

52 Munthe-Kaas, H., Berg, R. C., & Blaasvaer, N. (2016). Effectiveness of Interventions to Reduce Homelessness: A Systematic Review. Oslo, Norway: The Norwegian Institute of Public Health. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK482073/

53 Jego, M., Abcaya, J., Stefan, D. E., Calvet-Montredon, C., & Gentile, S. (2018). Improving health care management in primary care for homeless people: A literature review. International Journal of Environmental Research and Public Health, 15(2). https://doi.org/10.3390/ijerph15020309

54 Weber, J., Lee, R. C., & Martsolf, D. (2017). Understanding the health of veterans who are homeless: A review of the literature. Public Health Nursing, 34(5), 505-511. https://doi.org/10.1111/phn.12338

55 White, B. M., Logan, A., & Magwood, G. S. (2016). Access to diabetes care for populations experiencing homelessness: An integrated review. Current Diabetes Reports, 16(11), 112. https://doi.org/10.1007/s11892-016-0810-y

56 Bartels, S. J., DiMilia, P. R., Fortuna, K. L., & Naslund, J. A. (2018). Integrated care for older adults with serious mental illness and medical comorbidity: Evidence-based models and future research directions. Psychiatric Clinics of North America, 41(1), 153-164. https://doi.org/10.1016/j.psc.2017.10.012

57 Cabassa, L. J., Manrique, Y., Meyreles, Q., Camacho, D., Capitelli, L., Younge, R., . . . Lewis-Fernandez, R. (2018). Bridges to better health and wellness: An adapted health care manager intervention for Hispanics with serious mental illness. Administration and Policy in Mental Health, 45(1), 163-173. https://doi.org/10.1007/s10488-016-0781-y

58 Druss, B. G., von Esenwein, S. A., Compton, M. T., Rask, K. J., Zhao, L., & Parker, R. M. (2010). A randomized trial of medical care management for community mental health settings: The Primary Care Access, Referral, and Evaluation (PCARE) study. American Journal of Psychiatry, 167(2), 151-159. https://doi.org/10.1176/appi.ajp.2009.09050691

59 Kim, J. Y., Higgins, T. C., Esposito, D., & Hamblin, A. (2017). Integrating health care for high-need Medicaid beneficiaries with serious mental illness and chronic physical health conditions at managed care, provider, and consumer levels. Psychiatric Rehabilitation Journal, 40(2), 207-215. https://doi.org/10.1037/prj0000231

60 Schuster, J. M., Kinsky, S. M., Kim, J. Y., Kogan, J. N., Hamblin, A., Nikolajski, C., & Lovelace, J. (2016). Connected Care: Improving outcomes for adults with serious mental illness. American Journal of Managed Care, 22(10), 678-682. Retrieved from https://www.ajmc.com/journals/issue/2016/2016-vol22-n10/connected-care-improving-outcomes-for-adults-with-serious-mental-illness

61 Ferrell, B. R., Temel, J. S., Temin, S., Alesi, E. R., Balboni, T. A., Basch, E. M., . . . Smith, T. J. (2017). Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. Journal of Clinical Oncology, 35(1), 96-112. Retrieved from http://ascopubs.org/doi/abs/10.1200/JCO.2016.70.1474

62 Lanken, P. N., Terry, P. B., DeLisser, H. M., Fahy, B. F., Hansen-Flaschen, J., Heffner, J. E., . . . Yankaskas, J. R. (2008). An official American Thoracic Society clinical policy statement: Palliative care for patients with respiratory diseases and critical illnesses. American Journal of Respiratory and Critical Care Medicine, 177(8), 912-927. Retrieved from https://www.atsjournals.org/doi/abs/10.1164/rccm.200605-587ST

63 Oliver, D. J., Borasio, G. D., Caraceni, A., de Visser, M., Grisold, W., Lorenzl, S., . . . Voltz, R. (2016). A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. European Journal of Neurology, 23(1), 30-38. https://doi.org/10.1111/ene.12889

64 Hui, D., & Bruera, E. (2016). Integrating palliative care into the trajectory of cancer care. Nature Reviews Clinical Oncology, 13(3), 159-171. Retrieved from http://dx.doi.org/10.1038/nrclinonc.2015.201

65 Maddocks, M., Lovell, N., Booth, S., Man, W. D., & Higginson, I. J. (2017). Palliative care and management of troublesome symptoms for people with chronic obstructive pulmonary disease. Lancet, 390(10098), 988-1002. https://doi.org/10.1016/s0140-6736(17)32127-x

66 Bickel, K. E., McNiff, K., Buss, M. K., Kamal, A., Lupu, D., Abernethy, A. P., . . . Krzyzanowska, M. K. (2016). Defining high-quality palliative care in oncology practice: An American Society of Clinical Oncology/American Academy of Hospice and Palliative Medicine guidance statement. Journal of Oncology Practice, 12(9), e828-838. Retrieved from http://ascopubs.org/doi/abs/10.1200/JOP.2016.010686

67 Grudzen, C. R., Richardson, L. D., Morrison, M., Cho, E., & Sean Morrison, R. (2010). Palliative care needs of seriously ill, older adults presenting to the emergency department. Academic Emergency Medicine, 17(11), 1253-1257. Retrieved from https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1553-2712.2010.00907.x

68 Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. JAMA, 311(10), 1052-1060. https://doi.org/10.1001/jama.2014.304

69 National Academies of Sciences Engineering and Medicine. (2016). Families Caring for an Aging America. Retrieved from https://www.nap.edu/catalog/23606/families-caring-for-an-aging-america

70 Bassuk, E. L., & Beardslee, W. R. (2014). Depression in homeless mothers: Addressing an unrecognized public health issue. American Journal of Orthopsychiatry, 84(1), 73-81. https://doi.org/10.1037/h0098949

71 Bradley, C., McGowan, J., & Michelson, D. (2018). How does homelessness affect parenting behaviour? A systematic critical review and thematic synthesis of qualitative research. Clinical Child and Family Psychology Review, 21(1), 94-108. https://doi.org/10.1007/s10567-017-0244-3

72 Bassuk, E. L., Richard, M. K., & Tsertsvadze, A. (2015). The prevalence of mental illness in homeless children: A systematic review and meta-analysis. Journal of the American Academy of Child and Adolescent Psychiatry, 54(2), 86-96. https://doi.org/10.1016/j.jaac.2014.11.008

73 Baggett, T. P., Hwang, S. W., O'Connell, J. J., Porneala, B. C., Stringfellow, E. J., Orav, E. J., . . . Rigotti, N. A. (2013). Mortality among homeless adults in Boston: Shifts in causes of death over a 15-year period. JAMA Internal Medicine, 173(3), 189-195. https://doi.org/10.1001/jamainternmed.2013.1604

74 Nayyar, D., & Hwang, S. W. (2015). Cardiovascular health issues in inner city populations. Canadian Journal of Cardiology, 31(9), 1130-1138. https://doi.org/10.1016/j.cjca.2015.04.011

75 Mackelprang, J. L., Klest, B., Najmabadi, S. J., Valley-Gray, S., Gonzalez, E. A., & Cash, R. E. (2014). Betrayal trauma among homeless adults: Associations with revictimization, psychological well-being, and health. Journal of Interpersonal Violence, 29(6), 1028-1049. https://doi.org/10.1177/0886260513506060

76 Germack, H. D., Caron, A., Solomon, R., & Hanrahan, N. P. (2018). Medical-surgical readmissions in patients with co-occurring serious mental illness: A systematic review and meta-analysis. General Hospital Psychiatry, 55, 65-71. https://doi.org/10.1016/j.genhosppsych.2018.09.005

77 Hendrie, H. C., Lindgren, D., Hay, D. P., Lane, K. A., Gao, S., Purnell, C., . . . Callahan, C. M. (2013). Comorbidity profile and healthcare utilization in elderly patients with serious mental illnesses. American Journal of Geriatric Psychiatry, 21(12), 1267-1276. https://doi.org/10.1016/j.jagp.2013.01.056

78 Abu Al Hamayel, N., Isenberg, S. R., Hannum, S. M., Sixon, J., Smith, K. C., & Dy, S. M. (2018). Older patients' perspectives on quality of serious illness care in primary care. American Journal of Hospice and Palliative Care, 35(10), 1330-1336. https://doi.org/10.1177/1049909118771675

79 National Academies of Sciences Engineering and Medicine. (2017). Integrating the Patient and Caregiver Voice into Serious Illness Care: Proceedings of a Workshop. Washington, DC: The National Academies Press. Retrieved from https://www.nap.edu/catalog/24802/integrating-the-patient-and-caregiver-voice-into-serious-illness-care

80 Bradford, D. W., Cunningham, N. T., Slubicki, M. N., McDuffie, J. R., Kilbourne, A. M., Nagi, A., & Williams, J. W., Jr. (2013). An evidence synthesis of care models to improve general medical outcomes for individuals with serious mental illness: A systematic review. Journal of Clinical Psychiatry, 74(8), e754-764. https://doi.org/10.4088/JCP.12r07666

81 Ramanuj, P., Ferenchik, E., Docherty, M., Spaeth-Rublee, B., & Pincus, H. A. (2019). Evolving models of integrated behavioral health and primary care. Current Psychiatry Reports, 21, 4. https://doi.org/10.1007/s11920-019-0985-4

82 Chen, J., DuGoff, E. H., Novak, P., & Wang, M. Q. (2018). Variation of hospital-based adoption of care coordination services by community-level social determinants of health. Health Care Management Review. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6536363/

83 Johnston, B. J., Peppard, L., & Newton, M. (2015). Staying connected: Sustaining collaborative care models with limited funding. Journal of Psychosocial Nursing and Mental Health Services, 53(8), 36-44. https://doi.org/10.3928/02793695-20150720-06

84 McAlearney, A. S., Murray, K., Sieck, C., Lin, J. J., Bellacera, B., & Bickell, N. A. (2016). The challenge of improving breast cancer care coordination in safety-net hospitals: Barriers, facilitators, and opportunities. Medical Care, 54(2), 147-154. https://doi.org/10.1097/mlr.0000000000000458

85 Hersh, W. R., Totten, A. M., Eden, K. B., Devine, B., Gorman, P., Kassakian, S. Z., . . . McDonagh, M. S. (2015). Outcomes from health information exchange: Systematic review and future research needs. JMIR Medical Informatics, 3(4), e39. https://doi.org/10.2196/medinform.5215

86 Nguyen, O. K., Chan, C. V., Makam, A., Stieglitz, H., & Amarasingham, R. (2015). Envisioning a social-health information exchange as a platform to support a patient-centered medical neighborhood: A feasibility study. Journal of General Internal Medicine, 30(1), 60-67. https://doi.org/10.1007/s11606-014-2969-8

87 Cabassa, L. J., Manrique, Y., Meyreles, Q., Capitelli, L., Younge, R., Dragatsi, D., . . . Lewis-Fernandez, R. (2018). "Treated me ... like I was family": Qualitative evaluation of a culturally-adapted health care manager intervention for Latinos with serious mental illness and at risk for cardiovascular disease. Transcultural Psychiatry. https://doi.org/10.1177/1363461518808616

88 Gruenewald, D. A., Doan, D., Poppe, A., Jones, J., & Hutt, E. (2018). "Meet me where I am": Removing barriers to end-of-life care for homeless veterans and veterans without stable housing. American Journal of Hospice and Palliative Care, 35(12), 1483-1489. https://doi.org/10.1177/1049909118784008

89 Milaney, K. (2011). The 6 dimensions of promising practice for case managed supports to end homelessness, part 1: Contextualizing case management for ending homelessness. Professional Case Management, 16(6), 281-287. https://doi.org/10.1097/NCM.0b013e31821ee840

90 O'Campo, P., Kirst, M., Schaefer-McDaniel, N., Firestone, M., Scott, A., & McShane, K. (2009). Community-based services for homeless adults experiencing concurrent mental health and substance use disorders: A realist approach to synthesizing evidence. Journal of Urban Health, 86(6), 965-989. https://doi.org/10.1007/s11524-009-9392-1

91 Vanderboom, C. E., Thackeray, N. L., & Rhudy, L. M. (2015). Key factors in patient-centered care coordination in ambulatory care: Nurse care coordinators' perspectives. Applied Nursing Research, 28(1), 18-24. https://doi.org/10.1016/j.apnr.2014.03.004

92 Dinnen, S., Kane, V., & Cook, J. M. (2014). Trauma-informed care: A paradigm shift needed for services with homeless veterans. Professional Case Management, 19(4), 161-170. https://doi.org/10.1097/ncm.0000000000000038

93 Substance Abuse and Mental Health Services Administration. (2014). SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. (HHS Publication No. [SMA] 14-4884). Rockville, MD: Substance Abuse and Mental Health Services Administration. Retrieved from https://store.samhsa.gov/system/files/sma14-4884.pdf

94 Thompson-Lastad, A., Yen, I. H., Fleming, M. D., Van Natta, M., Rubin, S., Shim, J. K., & Burke, N. J. (2017). Defining trauma in complex care management: Safety-net providers' perspectives on structural vulnerability and time. Social Science and Medicine, 186, 104-112. https://doi.org/10.1016/j.socscimed.2017.06.003

95 Blanchard, J., & Lurie, N. (2004). R-E-S-P-E-C-T: Patient reports of disrespect in the health care setting and its impact on care. Journal of Family Practice, 53(9), 721-730. Retrieved from https://www.mdedge.com/familymedicine/article/65550/r-e-s-p-e-c-t-patient-reports-disrespect-health-care-setting-and-its

96 Davis, E., Tamayo, A., & Fernandez, A. (2012). "Because somebody cared about me. That's how it changed things": Homeless, chronically ill patients' perspectives on case management. PloS One, 7(9), e45980. https://doi.org/10.1371/journal.pone.0045980

97 Tse, S., Tsoi, E. W., Hamilton, B., O'Hagan, M., Shepherd, G., Slade, M., . . . Petrakis, M. (2016). Uses of strength-based interventions for people with serious mental illness: A critical review. International Journal of Social Psychiatry, 62(3), 281-291. Retrieved from https://journals.sagepub.com/doi/abs/10.1177/0020764015623970

98 Fraze, T. K., Beidler, L. B., Briggs, A. D. M., & Colla, C. H. (2019). 'Eyes in the home': ACOs use home visits to improve care management, identify needs, and reduce hospital use. Health Affairs, 38(6), 1021-1027. https://doi.org/10.1377/hlthaff.2019.00003

99 Takahashi, P. Y., Finnie, D. M., Quigg, S. M., Borkenhagen, L. S., Kumbamu, A., Kimeu, A. K., & Griffin, J. M. (2019). Understanding experiences of patients and family caregivers in the Mayo Clinic Care Transitions program: A qualitative study. Clinical Interventions in Aging, 14, 17-25. https://doi.org/10.2147/cia.S183893

100 Dorsey, E. R., & Topol, E. J. (2016). State of telehealth. New England Journal of Medicine, 375(2), 154-161. Retrieved from https://www.nejm.org/doi/full/10.1056/NEJMra1601705

101 Culhane, D. P., Metraux, S., Park, J. M., Schretzman, M., & Valente, J. (2007). Testing a typology of family homelessness based on patterns of public shelter utilization in four U.S. jurisdictions: Implications for policy and program planning. Housing Policy Debate, 18(1), 1-28. Retrieved from https://doi.org/10.1080/10511482.2007.9521591

102 Smith, N., Flores, Z. D., Lin, J., & Markovic, J. (2005). Understanding Family Homelessness in New York City: An In-Depth Study of Families' Experiences Before and After Shelter. Retrieved from Vera Institute of Justice: https://www.vera.org/downloads/Publications/understanding-family-homelessness-in-new-york-city-an-in-depth-study-of-families-experiences-before-and-after-shelter/legacy_downloads/Understanding_family_homelessness.pdf

103 Tsai, J., & Huang, M. (2018). Systematic review of psychosocial factors associated with evictions. Health & Social Care in the Community. https://doi.org/10.1111/hsc.12619

104 Luciano, A., Nicholson, J., & Meara, E. (2014). The economic status of parents with serious mental illness in the United States. Psychiatric Rehabilitation Journal, 37(3), 242-250. https://doi.org/10.1037/prj0000087

105 Kelley, A. S., & Morrison, R. S. (2015). Palliative care for the seriously ill. New England Journal of Medicine, 373(8), 747-755. Retrieved from https://www.nejm.org/doi/full/10.1056/NEJMra1404684

106 Seow, H., & Bainbridge, D. (2018). A review of the essential components of quality palliative care in the home. Journal of Palliative Medicine, 21(S1), S37-44. https://doi.org/10.1089/jpm.2017.0392

107 van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., . . . Volicer, L. (2014). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. Palliative Medicine, 28(3), 197-209. https://doi.org/10.1177/0269216313493685

108 Wang, Y., Spatz, E. S., Tariq, M., Angraal, S., & Krumholz, H. M. (2017). Home health agency performance in the United States: 2011-15. Journal of the American Geriatrics Society, 65(12), 2572-2579. https://doi.org/10.1111/jgs.14987

109 Gandhi, T., Bonner, A., Muething, S., Lorincz, C., & McTiernan, P. (2019). As home care expands, let's make it safer for everyone. Health Affairs Blog. Retrieved from https://www.healthaffairs.org/do/10.1377/hblog20190313.270650/full/

110 Newman, A. (2019, Sept. 2). On the job, 24 hours a day, 27 days a month. The New York Times. Retrieved from https://www.nytimes.com/2019/09/02/nyregion/home-health-aide.html

111 Lundqvist, M., Carlsson, P., Sjodahl, R., Theodorsson, E., & Levin, L. A. (2017). Patient benefit of dog-assisted interventions in health care: A systematic review. BMC Complementary and Alternative Medicine, 17(1), 358. https://doi.org/10.1186/s12906-017-1844-7

112 Wells, D. L. (2009). The effects of animals on human health and well-being. Journal of Social Issues, 65(3), 523-543. Retrieved from https://spssi.onlinelibrary.wiley.com/doi/abs/10.1111/j.1540-4560.2009.01612.x

113 Bor, J., Cohen, G. H., & Galea, S. (2017). Population health in an era of rising income inequality: USA, 1980-2015. Lancet, 389(10077), 1475-1490. https://doi.org/10.1016/s0140-6736(17)30571-8

114 Dickman, S. L., Himmelstein, D. U., & Woolhandler, S. (2017). Inequality and the health-care system in the USA. Lancet, 389(10077), 1431-1441. https://doi.org/10.1016/s0140-6736(17)30398-7

115 Bailey, Z. D., Krieger, N., Agenor, M., Graves, J., Linos, N., & Bassett, M. T. (2017). Structural racism and health inequities in the USA: Evidence and interventions. Lancet, 389(10077), 1453-1463. https://doi.org/10.1016/s0140-6736(17)30569-x

116 Wildeman, C., & Wang, E. A. (2017). Mass incarceration, public health, and widening inequality in the USA. Lancet, 389(10077), 1464-1474. https://doi.org/10.1016/s0140-6736(17)30259-3

117 Williams, D. R., & Mohammed, S. A. (2013). Racism and health I: Pathways and scientific evidence. American Behavioral Scientist, 57(8), 1152-1173. https://doi.org/10.1177/0002764213487340

118 Byrne, T., Munley, E. A., Fargo, J. D., Montgomery, A. E., & Culhane, D. P. (2013). New perspectives on community-level determinants of homelessness. Journal of Urban Affairs, 35(5), 607-625. Retrieved from https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1467-9906.2012.00643.x

119 Fargo, J. D., Munley, E. A., Byrne, T. H., Montgomery, A. E., & Culhane, D. P. (2013). Community-level characteristics associated with variation in rates of homelessness among families and single adults. American Journal of Public Health, 103(Suppl 2), S340-347. https://doi.org/10.2105/ajph.2013.301619

120 Hanratty, M. (2017). Do local economic conditions affect homelessness? Impact of area housing market factors, unemployment, and poverty on community homeless rates. Housing Policy Debate, 27(4), 640-655. Retrieved from https://doi.org/10.1080/10511482.2017.1282885

121 Reif, S., George, P., Braude, L., Dougherty, R. H., Daniels, A. S., Ghose, S. S., & Delphin-Rittmon, M. E. (2014). Recovery housing: Assessing the evidence. Psychiatric Services, 65(3), 295-300. Retrieved from https://ps.psychiatryonline.org/doi/abs/10.1176/appi.ps.201300243

122 Wittman, F. D., Polcin, D. L., & Sheridan, D. (2017). The architecture of recovery: Two kinds of housing assistance for chronic homeless persons with substance use disorders. Drugs and Alcohol Today, 17(3), 157-167. https://doi.org/10.1108/dat-12-2016-0032

123 Chan, D. V., Gopal, S., & Helfrich, C. A. (2014). Accessibility patterns and community integration among previously homeless adults: A Geographic Information Systems (GIS) approach. Social Science and Medicine, 120, 142-152. https://doi.org/10.1016/j.socscimed.2014.09.005

124 Chiumenti, N. (2019). The Growing Shortage of Affordable Housing for the Extremely Low Income in Massachusetts. Retrieved from https://www.bostonfed.org/publications/new-england-public-policy-center-policy-report/2019/growing-shortage-affordable-housing-extremely-low-income-massachusetts.aspx

125 Chiumenti, N. (2018). The Supply of Permanent Supportive Housing in Massachusetts: Comparing Availability to the Chronic Homeless Population. Retrieved from https://www.bostonfed.org/publications/new-england-public-policy-center-policy-report/2018/the-supply-of-permanent-supportive-housing-in-massachusetts.aspx

126 Jolicoeur, L. (2018, Oct. 9). Boston makes big strides, but won't meet goal of ending chronic homelessness in 2018. WBUR. Retrieved from https://www.wbur.org/news/2018/10/09/boston-chronic-homelessness

127 Kinney, J. (2018). PVTA gets boost in state budget, still plans service cuts. MassLive. Retrieved from https://www.masslive.com/business-news/2018/07/pvta_gets_boost_in_state_budget_still_pl.html

128 Pollack, S., Williams, L., Lopez, R., & Luna, I. (2013). The Toll of Transportation: Final Report. Retrieved from https://1vmdesign.com/wp-content/uploads/2015/03/DUK_TOLL_N2N_Report.pdf

129 Logan, J. R., Minca, E., & Adar, S. (2012). The geography of inequality: Why separate means unequal in American public schools. Sociology of Education, 85(3), 287-301. Retrieved from https://journals.sagepub.com/doi/abs/10.1177/0038040711431588

130 Logan, J. R., & Burdick-Will, J. (2017). School segregation and disparities in urban, suburban, and rural areas. The ANNALS of the American Academy of Political and Social Science, 674(1), 199-216. Retrieved from https://journals.sagepub.com/doi/abs/10.1177/0002716217733936

131 Bailey, H. N., DeOliveira, C. A., Wolfe, V. V., Evans, E. M., & Hartwick, C. (2012). The impact of childhood maltreatment history on parenting: A comparison of maltreatment types and assessment methods. Child Abuse and Neglect, 36(3), 236-246. https://doi.org/10.1016/j.chiabu.2011.11.005

132 Belsky, J., Conger, R., & Capaldi, D. M. (2009). The intergenerational transmission of parenting: Introduction to the special section. Developmental Psychology, 45(5), 1201-1204. https://doi.org/10.1037/a0016245

133 Hughes, M., & Cossar, J. (2016). The relationship between maternal childhood emotional abuse/neglect and parenting outcomes: A systematic review. Child Abuse Review, 25(1), 31-45. Retrieved from https://onlinelibrary.wiley.com/doi/abs/10.1002/car.2393

134 Patterson, M. L., Moniruzzaman, A., Frankish, C. J., & Somers, J. M. (2012). Missed opportunities: Childhood learning disabilities as early indicators of risk among homeless adults with mental illness in Vancouver, British Columbia. BMJ Open, 2(6), e001586. Retrieved from https://bmjopen.bmj.com/content/bmjopen/2/6/e001586.full.pdf

135 Hudson, B. F., Flemming, K., Shulman, C., & Candy, B. (2016). Challenges to access and provision of palliative care for people who are homeless: A systematic review of qualitative research. BMC Palliative Care, 15(1), 96. https://doi.org/10.1186/s12904-016-0168-6

136 O'Toole, T. P., Johnson, E. E., Redihan, S., Borgia, M., & Rose, J. (2015). Needing primary care but not getting it: The role of trust, stigma and organizational obstacles reported by homeless veterans. Journal of Health Care for the Poor and Underserved, 26(3), 1019-1031. https://doi.org/10.1353/hpu.2015.0077

137 Long, S. K., & Aarons, J. (2018). Access to Care for Mental Health and Substance Use Disorders is a Challenge for Many in Massachusetts. Retrieved from https://www.bluecrossmafoundation.org/sites/g/files/csphws2101/files/2020-09/MHRS_2018_MH%20SUD%20Summary_final.pdf

138 Creswell, J. W. (2014). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches (4th ed.). Thousand Oaks, CA: SAGE Publications, Inc

139 Merriam, S. B. (2009). Qualitative Research: A Guide to Design and Implementation (2nd ed.). San Francisco, CA: John Wiley & Sons, Inc

140 Pioneer Valley Planning Commission. (2014). Data Atlas by Neighborhood: City of Springfield, MA. Retrieved from http://www.pvpc.org/sites/default/files/Springfield%20Data%20Atlas%209-23-14-web-reduced.pdf

141 City of Springfield. (2018). Housing Study. Retrieved from https://www.springfield-ma.gov/housing/fileadmin/housing/Housing_Study/Housing_Study_June_2018.pdf

142 Henry, M., Mahathey, A., Morrill, T., Robinson, A., Shivji, A., & Watt, R. (2018). The 2018 Annual Homeless Assessment Report (AHAR) to Congress: Part 1: Point-in-Time Estimates of Homelessness. Retrieved from https://files.hudexchange.info/resources/documents/2018-AHAR-Part-1.pdf

143 Massachusetts Department of Elementary and Secondary Education. Question and Answer Guide on Special Education Extended School Year Programs. Retrieved from http://www.doe.mass.edu/prs/ta/esyp-qa.html

144 Bachrach, D., Pfister, H., Wallis, K., & Lipson, M. (2014). Addressing patients' social needs: An emerging business case for provider investment. Retrieved from https://www.commonwealthfund.org/publications/fund-reports/2014/may/addressing-patients-social-needs-emerging-business-case-provider

145 Grief, S. N., & Miller, J. P. (2017). Infectious disease issues in underserved populations. Primary Care: Clinics in Office Practice, 44(1), 67-85. https://doi.org/10.1016/j.pop.2016.09.011

146 Ennis, N., Roy, S., & Topolovec-Vranic, J. (2015). Memory impairment among people who are homeless: A systematic review. Memory, 23(5), 695-713. https://doi.org/10.1080/09658211.2014.921714

147 Grenier, A., Barken, R., Sussman, T., Rothwell, D., Bourgeois-Guerin, V., & Lavoie, J. P. (2016). A literature review of homelessness and aging: Suggestions for a policy and practice-relevant research agenda. Canadian Journal on Aging / La Revue Canadienne Du Vieillissement, 35(1), 28-41. https://doi.org/10.1017/s0714980815000616

148 Kim, M. M., Ford, J. D., Howard, D. L., & Bradford, D. W. (2010). Assessing trauma, substance abuse, and mental health in a sample of homeless men. Health and Social Work, 35(1), 39-48. https://doi.org/10.1093/hsw/35.1.39

149 Torchalla, I., Strehlau, V., Li, K., Schuetz, C., & Krausz, M. (2012). The association between childhood maltreatment subtypes and current suicide risk among homeless men and women. Child Maltreatment, 17(2), 132-143. https://doi.org/10.1177/1077559512439350

150 Young, D. A., Shumway, M., Flentje, A., & Riley, E. D. (2017). The relationship between childhood abuse and violent victimization in homeless and marginally housed women: The role of dissociation as a potential mediator. Psychological Trauma: Theory, Research, Practice and Policy, 9(5), 613-621. https://doi.org/10.1037/tra0000288

151 City of Boston Department of Neighborhood Development. (2019). 39th Annual Homeless Census. Retrieved from https://www.boston.gov/sites/default/files/document-file-05-2019/2019_homeless_census_5-15-19_190515.pdf

152 Benston, E. A. (2015). Housing programs for homeless individuals with mental illness: Effects on housing and mental health outcomes. Psychiatric Services, 66(8), 806-816. https://doi.org/10.1176/appi.ps.201400294

153 Rog, D. J., Marshall, T., Dougherty, R. H., George, P., Daniels, A. S., Ghose, S. S., & Delphin-Rittmon, M. E. (2014). Permanent supportive housing: Assessing the evidence. Psychiatric Services, 65(3), 287-294. https://doi.org/10.1176/appi.ps.201300261

154 Ly, A., & Latimer, E. (2015). Housing First impact on costs and associated cost offsets: A review of the literature. Canadian Journal of Psychiatry / Revue Canadienne de Psychiatrie, 60(11), 475-487. https://doi.org/10.1177/070674371506001103

155 Woodhall-Melnik, J. R., & Dunn, J. R. (2016). A systematic review of outcomes associated with participation in Housing First programs. Housing Studies, 31(3), 287-304. Retrieved from https://doi.org/10.1080/02673037.2015.1080816

156 Tiderington, E., Stanhope, V., & Henwood, B. F. (2013). A qualitative analysis of case managers' use of harm reduction in practice. Journal of Substance Abuse Treatment, 44(1), 71-77. https://doi.org/10.1016/j.jsat.2012.03.007

157 De Hert, M., Correll, C. U., Bobes, J., Cetkovich-Bakmas, M., Cohen, D., Asai, I., . . . Leucht, S. (2011). Physical illness in patients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care. World Psychiatry, 10(1), 52-77. https://doi.org/doi:10.1002/j.2051-5545.2011.tb00014.x

158 Druss, B. G., Zhao, L., Von Esenwein, S., Morrato, E. H., & Marcus, S. C. (2011). Understanding excess mortality in persons with mental illness: 17-year follow up of a nationally representative US survey. Medical Care, 49(6), 599-604. https://doi.org/10.1097/MLR.0b013e31820bf86e

159 De Hert, M., Dekker, J. M., Wood, D., Kahl, K. G., Holt, R. I., & Moller, H. J. (2009). Cardiovascular disease and diabetes in people with severe mental illness position statement from the European Psychiatric Association (EPA), supported by the European Association for the Study of Diabetes (EASD) and the European Society of Cardiology (ESC). European Psychiatry, 24(6), 412-424. https://doi.org/10.1016/j.eurpsy.2009.01.005

160 Mangurian, C., Newcomer, J. W., Modlin, C., & Schillinger, D. (2016). Diabetes and cardiovascular care among people with severe mental illness: A literature review. Journal of General Internal Medicine, 31(9), 1083-1091. https://doi.org/10.1007/s11606-016-3712-4

161 Janssen, E. M., McGinty, E. E., Azrin, S. T., Juliano-Bult, D., & Daumit, G. L. (2015). Review of the evidence: Prevalence of medical conditions in the United States population with serious mental illness. General Hospital Psychiatry, 37(3), 199-222. https://doi.org/10.1016/j.genhosppsych.2015.03.004

162 Goldberg, R. W., Kreyenbuhl, J. A., Medoff, D. R., Dickerson, F. B., Wohlheiter, K., Fang, L. J., . . . Dixon, L. B. (2007). Quality of diabetes care among adults with serious mental illness. Psychiatric Services, 58(4), 536-543. https://doi.org/10.1176/ps.2007.58.4.536

163 Liu, J., Brown, J., Morton, S., Potter, D. E. B., Patton, L., Patel, M., . . . Hudson Scholle, S. (2017). Disparities in diabetes and hypertension care for individuals with serious mental illness. American Journal of Managed Care, 23(5), 304-308. Retrieved from https://www.ajmc.com/journals/issue/2017/2017-vol23-n5/disparities-in-diabetes-and-hypertension-care-for-individuals-with-serious-mental-illness

164 McGinty, E. E., Baller, J., Azrin, S. T., Juliano-Bult, D., & Daumit, G. L. (2015). Quality of medical care for persons with serious mental illness: A comprehensive review. Schizophrenia Research, 165(2), 227-235. Retrieved from http://www.sciencedirect.com/science/article/pii/S0920996415001838

165 Scott, D., Platania-Phung, C., & Happell, B. (2012). Quality of care for cardiovascular disease and diabetes amongst individuals with serious mental illness and those using antipsychotic medications. Journal for Healthcare Quality, 34(5), 15-21. https://doi.org/10.1111/j.1945-1474.2011.00155.x

166 Kelley, A. S., & Bollens-Lund, E. (2018). Identifying the population with serious illness: The “denominator” challenge. Journal of Palliative Medicine, 21(S2), S7-s16. https://doi.org/10.1089/jpm.2017.0548

167 Wachterman, M. W., Pilver, C., Smith, D., Ersek, M., Lipsitz, S. R., & Keating, N. L. (2016). Quality of end-of-life care provided to patients with different serious illnesses. JAMA Internal Medicine, 176(8), 1095-1102. https://doi.org/10.1001/jamainternmed.2016.1200

168 Diop, M. S., Rudolph, J. L., Zimmerman, K. M., Richter, M. A., & Skarf, L. M. (2017). Palliative Care Interventions for Patients with Heart Failure: A Systematic Review and Meta-Analysis. Journal of Palliative Medicine, 20(1), 84-92. https://doi.org/10.1089/jpm.2016.0330

169 O’Connor, N. R., Moyer, M. E., Behta, M., & Casarett, D. J. (2015). The impact of inpatient palliative care consultations on 30-day hospital readmissions. Journal of Palliative Medicine, 18(11), 956-961. https://doi.org/10.1089/jpm.2015.0138

170 Shalev, A., Phongtankuel, V., Kozlov, E., Shen, M. J., Adelman, R. D., & Reid, M. C. (2018). Awareness and misperceptions of hospice and palliative care: A population-based survey study. American Journal of Hospice and Palliative Care, 35(3), 431-439. https://doi.org/10.1177/1049909117715215

171 Beernaert, K., Deliens, L., De Vleminck, A., Devroey, D., Pardon, K., Block, L. V., & Cohen, J. (2016). Is there a need for early palliative care in patients with life-limiting illnesses? Interview study with patients about experienced care needs from diagnosis onward. American Journal of Hospice and Palliative Care, 33(5), 489-497. https://doi.org/10.1177/1049909115577352

172 Kavalieratos, D., Corbelli, J., Zhang, D., Dionne-Odom, J., Ernecoff, N., Hanmer, J., . . . Schenker, Y. (2016). Association between palliative care and patient and caregiver outcomes: A systematic review and meta-analysis. JAMA, 316(20), 2104-2114. Retrieved from http://dx.doi.org/10.1001/jama.2016.16840

173 Singer, A. E., Goebel, J. R., Kim, Y. S., Dy, S. M., Ahluwalia, S. C., Clifford, M., . . . Lorenz, K. A. (2016). Populations and interventions for palliative and end-of-life care: A systematic review. Journal of Palliative Medicine, 19(9), 995-1008. https://doi.org/10.1089/jpm.2015.0367

174 Chai, E. (2017). To trigger or not: That is the question! Journal of Palliative Medicine, 20(2), 112-113. https://doi.org/10.1089/jpm.2016.0526

175 Nelson, J. E., Curtis, J. R., Mulkerin, C., Campbell, M., Lustbader, D. R., Mosenthal, A. C., . . . Weissman, D. E. (2013). Choosing and using screening criteria for palliative care consultation in the ICU: A report from the Improving Palliative Care in the ICU (IPAL-ICU) Advisory Board. Critical Care Medicine, 41(10), 2318-2327. https://doi.org/10.1097/CCM.0b013e31828cf12c

176 Kavalieratos, D., Mitchell, E. M., Carey, T. S., Dev, S., Biddle, A. K., Reeve, B. B., . . . Weinberger, M. (2014). “Not the ‘grim reaper service’”: An assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. Journal of the American Heart Association, 3(1), e000544. https://doi.org/10.1161/jaha.113.000544

177 Institute of Medicine. (2015). Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC: The National Academies Press. Retrieved from https://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near

178 Partridge, A. H., Seah, D. S. E., King, T., Leighl, N. B., Hauke, R., Wollins, D. S., & Roenn, J. H. V. (2014). Developing a service model that integrates palliative care throughout cancer care: The time is now. Journal of Clinical Oncology, 32(29), 3330-3336. Retrieved from http://ascopubs.org/doi/abs/10.1200/JCO.2013.54.8149

179 Huo, J., Hong, Y. R., Grewal, R., Yadav, S., Heller, I. W., Bian, J., & Wilkie, D. J. (2019). Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey. Journal of Pain and Symptom Management, 58(1), 39-47. https://doi.org/10.1016/j.jpainsymman.2019.03.014

180 Zimmermann, C., Swami, N., Krzyzanowska, M., Leighl, N., Rydall, A., Rodin, G., . . . Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. CMAJ: Canadian Medical Association Journal, 188(10), E217-227. https://doi.org/10.1503/cmaj.151171

ACKNOWLEDGMENTS

COMMISSIONERS

Dr. Stuart Altman
Chair

Mr. Martin Cohen
Vice Chair

Dr. Donald Berwick

Ms. Barbara Blakeney

Dr. David Cutler

Mr. Timothy Foley

Mr. Michael Heffernan
Secretary of Administration and Finance

Dr. John Christian Kryder

Mr. Richard Lord

Mr. Renato ″Ron″ Mastrogiovanni

Ms. Marylou Sudders
Secretary of Health and Human Services

EXECUTIVE DIRECTOR

Mr. David Seltz

The HPC acknowledges the members of the study team at Brandeis University—Palmira Santos, Cynthia A. Tschampl, Carol Prost, and Kristen Faughnan—for conducting interviews and focus groups, completing the qualitative analysis, and developing this case study.

HPC staff Fran Hodgins and Catherine MacLean prepared this document for publication with guidance and support from David Seltz, Executive Director; Coleen Elstermeyer, Deputy Executive Director; Lois Johnson, General Counsel; Kelly Hall, Senior Director of Health Care Transformation and Innovation; and Susan Flanagan-Cahill, Deputy General Counsel. The case study was designed by Ashley Johnston.

The HPC extends its sincere gratitude to all of the participating organizations, their clinical and non-clinical staff, and the program participants who were a part of the focus groups and interviews from which this case study's content is derived.

MASSACHUSETTS
HEALTH POLICY COMMISSION
50 MILK STREET, 8TH FLOOR
BOSTON, MA 02109
WWW.MASS.GOV/HPC