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# Spiritual care: an intervention to advance health equity for persons with disabilities in capitated managed care

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BOSTON UNIVERSITY  
SCHOOL OF THEOLOGY

Dissertation

**SPIRITUAL CARE: AN INTERVENTION TO ADVANCE HEALTH EQUITY  
FOR PERSONS WITH DISABILITIES IN CAPITATED MANAGED CARE**

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## DEDICATION

One day Jesus was teaching, and Pharisees and teachers of the law were sitting there. They had come from every village of Galilee and from Judea and Jerusalem. And the power of the Lord was with Jesus to heal the sick. Some men came carrying a paralyzed man on a mat and tried to take him into the house to lay him before Jesus. When they could not find a way to do this because of the crowd, they went up on the roof and lowered him on his mat through the tiles into the middle of the crowd, right in front of Jesus. When Jesus saw their faith, he said, “Friend, your sins are forgiven.” (Luke 5:17-25)

This simple document is dedicated with gratitude to the faculty and staff of Boston University School of Theology, my family, many friends, countless personal care attendants, acquaintances, and strangers who embody the healing love of God even at times I am unaware.

**SPIRITUAL CARE: AN INTERVENTION TO ADVANCE HEALTH EQUITY  
FOR PERSONS WITH DISABILITIES IN CAPITATED MANAGED CARE**

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Boston University School of Theology, 2022

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**ABSTRACT**

This thesis argues for providing spiritual care in primary care for Massachusetts persons with disabilities having Medicare and Medicaid as their primary insurers. It outlines an advocacy strategy to (1) increase awareness of the importance of spiritual care as key to primary care, (2) get buy-in for spiritual care as an optional primary care service to Medicaid beneficiaries needing nonmedical supports and services to live in the community due to mental health diagnosis or physical disability, and (3) put forward a statutory or regulatory proposal requiring One Care plans to provide certified peer chaplains as a covered service starting 2023.

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## LIST OF ABBREVIATIONS

ACPE:	Association for Clinical Pastoral Education
ADAPT:	American Disabled for Attendant Programs Today
ADLs:	Activities of Daily Living
ALS:	Amyotrophic Lateral Sclerosis
ASAP:	Aging Services Access Point
ASD:	Autism Spectrum Disorder
BCCI:	Board of Chaplaincy Certification Inc.
BCIL:	Boston Center for Independent Living
BIPOC:	Black Indigenous People of Color
CAPC:	Center to Advance Palliative Care
CBO:	Community-Based Organization
CBPAR:	Community-Based Participatory Action Research
CDC:	Centers for Disease Control and Prevention
CHC:	College of Healthcare Chaplains
CMMI:	Center for Medicaid and Medicare Innovation
CMS:	Centers for Medicare and Medicaid Services
CPE:	Clinical Pastoral Education
CRPD:	Convention on the Rights of Persons with Disabilities
D-SNP:	Dual Eligible Special Needs Plan
DAAHR:	Disability Advocates Advancing Our Healthcare Rights
DPC:	Disability Policy Consortium
ED:	Emergency Department
EOHHS:	Massachusetts Executive Office of Health and Human Services
FBO:	Faith-Based Organization

FFS: Fee-For-Service

FIDE SNPs: Fully Integrated Dual Eligible Special Needs Plan

FQHCs: Federally Qualified Health Centers

GBIO: Greater Boston Interfaith Organization

GP: General Practitioner

HCBS: Home and Community-Based Services

HCPCS: Healthcare Common Procedure Coding System

HHS: Department of Health and Human Services

HRQOL: Health Related Quality of Life

IADL: Instrumental Activities of Daily Living

ICF: International Classification of Functioning

ICO: Integrated Care Organization

ID/DD: Persons with Intellectual and Developmental Disabilities

IDEA: Individuals with Disabilities Education Act

ILC: Independent Living Center

LTSS: Long-Term Services and Supports

MA: Medicare Advantage

MCO: Managed Care Organization

MS: Multiple Sclerosis

NACC: National Association of Catholic Chaplains

NAJC: Neshama: Association of Jewish Chaplains

NAMI: National Alliance on Mental Illness

NHS: National Health Service

PACE: Program of All-Inclusive Care for the Elderly

PAR: Participatory Action Research

PCA: Personal Care Attendants

PCC: Primary Care Chaplaincy

PCP: Primary Care Physician

PHEPR: Public Health Policymakers Engaged in Emergency Preparedness and Response

PWDs: Persons with Disabilities

QALYs: Quality-Adjusted Life Years

SDOH: Social Determinants of Health

SUD: Substance Use Disorder

UK: United Kingdom

UKBHC: United Kingdom Board of Healthcare Chaplaincy

UMass: University of Massachusetts

WHO: World Health Organization

WMA: World Medical Association

## FIGURES

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## DEFINITIONS

**Board-certified chaplain:** Chaplains who receive a Board of Chaplaincy Certification Inc. (BCCI) Certification “are certified chaplains according to national qualifications, including code of ethics” of the Association of Professional Chaplains.<sup>1</sup>

**Dual Eligible Special Needs Plan (D-SNP):** D-SNPs integrate certain medical services to people entitled to both Medicare and Medicaid. Unless carved out by a state, FIDE SNPs are required to cover and fully integrate all LTSS, behavioral health, medical, and other services covered under Medicare and Medicaid.<sup>2</sup>

**Dual-eligible:** “Dual-eligible beneficiaries are individuals who receive both Medicare and Medicaid benefits. The two programs cover many of the same services, but Medicare pays first for the Medicare-covered services that Medicaid also covers.”<sup>3</sup>

**Health disparity:** “A particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity;

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<sup>1</sup> “BCCI Certification,” Board of Chaplaincy Certification, Inc., accessed October 3, 2022, <https://bcciprofessionalchaplains.org/content.asp?pl=25&contentid=25>.

<sup>2</sup> “Medicare Advantage Dual Eligible Special Needs Plans,” Medicaid and CHIP Payment and Access Commission, accessed October 3, 2022, <https://www.macpac.gov/subtopic/medicare-advantage-dual-eligible-special-needs-plans-aligned-with-medicaid-managed-long-term-services-and-supports/>.

<sup>3</sup> “CMS Guidance: Reporting Expectations for Dual-Eligible Beneficiaries, Updated,” Medicaid.gov, accessed October 3, 2022, <https://www.medicaid.gov/medicaid/data-and-systems/macbis/tmsis/tmsis-blog/entry/51064#:~:text=Dual%2Deligible%20beneficiaries%20are%20individuals,are%20also%20covered%20by%20Medicaid.>

geographic location; or other characteristics historically linked to discrimination or exclusion.”<sup>4</sup>

**Health equity:** “The attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.”<sup>5</sup>

**Hospice:** “Hospice care focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life . . . Like palliative care, hospice provides comprehensive comfort care as well as support for the family, but, in hospice, attempts to cure the person's illness are stopped . . . Hospice care brings together a team of people with special skills—among them nurses, doctors, social workers, spiritual advisors, and trained volunteers. Everyone works together with the person who is dying, the caregiver, and/or the family to provide the medical, emotional, and spiritual support needed.”<sup>6</sup>

**Home and Community-Based Services (HCBS):** “Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. These

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<sup>4</sup> “Health Equity in Healthy People 2030,” U.S. Department of Health & Human Services, accessed May 3, 2022, <https://health.gov/healthypeople/priority-areas/health-equity-healthy-people-2030>.

<sup>5</sup> “Health Equity in Healthy People 2030.”

<sup>6</sup> “What Are Palliative Care and Hospice Care?” National Institutes of Health, May 14, 2021, <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#hospice>.

programs serve various targeted populations, such as people with intellectual or developmental disabilities, physical disabilities, and/or mental illnesses.”<sup>7</sup>

**Long-Term Services and Supports (LTSS):** ““Long-term services and supports’ encompasses the broad range of paid and unpaid medical and personal care assistance that people may need—for several weeks, months, or years—when they experience difficulty completing self-care tasks as a result of aging, chronic illness, or disability. Long-term services and supports provide assistance with activities of daily living (such as eating, bathing, and dressing) and instrumental activities of daily living (such as preparing meals, managing medication, and housekeeping).”<sup>8</sup>

**Medicare:** Medicare is the federal health insurance program for people sixty-five or older, certain younger people with disabilities, and people with End-Stage Renal Disease.<sup>9</sup>

**MassHealth (Medicaid):** Massachusetts Medicaid (MassHealth) pays for health care for certain low- and medium-income people living in Massachusetts. MassHealth offers health-care benefits directly or by paying part or all of your health insurance premiums.<sup>10</sup>

**One Care:** The country’s first and only Medicare Advantage (MA) plan designed to provide dual eligible enrollees aged 21–64 with more comprehensive and coordinated

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<sup>7</sup> “Home & Community Based Services,” Medicaid.gov, accessed October 3, 2022, <https://www.medicaid.gov/medicaid/home-community-based-services/index.html>.

<sup>8</sup> Erica L. Reaves and MaryBeth Musumeci, “Medicaid and Long-Term Services and Supports: A Primer,” the Kaiser Foundation on Medicaid and the Uninsured, December 15, 2015, accessed October 3, 2022, <https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/>.

<sup>9</sup> “What’s Medicare,” Medicare.gov, accessed October 3, 2022, <https://www.medicare.gov/what-medicare-covers/your-medicare-coverage-choices/whats-medicare>.

<sup>10</sup> “Massachusetts MassHealth (Medicaid),” Benefits.gov, accessed October 3, 2022, [https://www.benefits.gov/benefit/1282#:~:text=Massachusetts%20Medicaid%20\(MassHealth\)%20pays%20for,of%20your%20health%2Dinsurance%20premiums](https://www.benefits.gov/benefit/1282#:~:text=Massachusetts%20Medicaid%20(MassHealth)%20pays%20for,of%20your%20health%2Dinsurance%20premiums).

care with expanded services. “[E]nrollees will have the ability to shape and direct the care they receive, including through developing an individualized care plan. Care will be delivered through teams that include a primary care provider, care coordinator, independent long-term services and supports (LTSS) coordinator, and other care providers at the discretion of each beneficiary.”<sup>11</sup>

**Palliative care:** “Palliative care is an approach that improves the quality of life of patients (adults and children) and their families facing problems associated with life-threatening conditions.”<sup>12</sup> Palliative care seeks to prevent or relieve suffering through early identification, correct assessment, and treatment of pain and other physical, psychosocial, or spiritual problems.

**Spirituality:** Spiritual wellness is a dynamic that leads to a realization of wholeness that includes having purpose and meaning in life. It is the experience of meaning and purpose gained through connectedness with self, others, art, music, literature, nature, and/or powers greater than oneself it may or may not include affirmation of one being in relationship with God, self, and community.<sup>13</sup>

**Spiritual Care:** In healthcare, spiritual care contributes to the health and well-being of individuals with serious illness, chronic conditions, disabilities, and behavioral health

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<sup>11</sup> “CMS and Massachusetts Partner to Coordinate Care for Medicare-Medicaid Enrollees,” Centers for Medicare and Medicaid Services, August 23, 2012, accessed October 3, 2022, <https://www.cms.gov/newsroom/fact-sheets/cms-and-massachusetts-partner-coordinate-care-medicare-medicaid-enrollees>.

<sup>12</sup> “Palliative Care,” UT Health Houston, accessed August 16, 2022, <https://www.uth.edu/dotAsset/c77ad8f1-3f85-4bdd-a883-1f9c61903d3c.pdf>.

<sup>13</sup> “What Is Spirituality,” Chaplain Partnership, accessed October 3, 2022, <https://chaplainpartnership.org/what-is-spirituality/>.



needs and people important to them by being present to their spiritual and existential needs. In doing so, spiritual care goes beyond a person's biosocial and social needs to aspects of their inner life that give them meaning and purpose. "Spiritual care is provided by chaplains and other healthcare professionals including nurses and doctors. Ideally spiritual care is carried out within interdisciplinary care teams and in a manner that aligns with a person's spiritual assessment and identified goals that are integrated into their care plan."<sup>14</sup>

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<sup>14</sup> "Addressing the Spiritual Care Needs of Patients with Serious Illness," Center to Advance Palliative Care, June 22, 2020, <https://www.capc.org/toolkits/addressing-spiritual-care-needs-patients-serious-illness/>; Niels Christian Hvidt et al., "What is Spiritual Care? Professional Perspectives on the Concept of Spiritual Care Identified through Group Concept Mapping," *BMJ Open* 28, no. 10 (December 2020), <https://doi.org/10.1136/bmjopen-2020-042142>.

## INTRODUCTION

According to the Centers for Disease Control and Prevention (CDC), 61 million persons in the United States live with a disability, accounting for 26% of the population.<sup>15</sup> Yet, persons with disabilities in the United States and other Western societies are persistently marginalized and subjected to direct and de facto discrimination at the interpersonal and systems levels.<sup>16</sup> Discrimination against persons with disabilities continues at every level of society, from education to employment, housing, and healthcare.<sup>17</sup> International studies have demonstrated a persistent link between disability status and socioeconomic and health disparities.<sup>18</sup> For instance, persons with disabilities are more likely to have lower income, higher unemployment rates, and lower educational attainment levels; they may also face violence and discrimination related to their disability and have difficulties accessing appropriate health care.<sup>19</sup>

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<sup>15</sup> “Disability Impacts All of Us,” Centers for Disease Control and Prevention, accessed on October 1, 2022, <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html#:~:text=61%20million%20adults%20in%20the,is%20highest%20in%20the%20South>.

<sup>16</sup> Rebecca Garden, “Disability and Narrative: New Directions for Medicine and the Medical Humanities,” *Medical Humanities* 36, no. 2 (December 1, 2010): 72, <https://doi.org/10.1136/jmh.2010.004143>; Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids: Brazos Press, 2008), 59.

<sup>17</sup> Sara Rosenbaum, *The Americans with Disabilities Act in a Health Care Context* (Washington, D.C.: National Academies Press, 2007); “Disability Rights Section,” The United States Department of Justice, accessed January 10, 2022, <https://www.justice.gov/crt/disability-rights-section>; “Just the Facts: Americans with Disabilities Act,” United States Courts, July 12, 2018, <https://www.uscourts.gov/news/2018/07/12/just-facts-americans-disabilities-act>.

<sup>18</sup> Center for Medicare and Medicaid Services, “Inventory of Resources for Standardized Demographic and Language Data Collection,” March 2020, 22.

<sup>19</sup> Elham Mahmoudi and Michelle A. Meade, “Disparities in Access to Health Care among Adults with Physical Disabilities: Analysis of a Representative National Sample for a Ten-Year Period,” *Disability and Health Journal* 8, no. 2 (April 2015): 184, <https://doi.org/10.1016/j.dhjo.2014.08.007>; World Health

The population of persons with disabilities is also more likely than the general population to have unmet healthcare needs.<sup>20</sup> Barriers to care, including discrimination, resulting in a higher risk of secondary complications of one's disability, resulting from "thinner margins of health."<sup>21</sup> Despite clear needs resulting from barriers to care and an abundance of data on disparities in mobility and mortality, there is little research on the unmet needs of persons with disabilities at the working ages of 21–64.<sup>22</sup> Available literature reveals that people with disabilities have higher levels of health care utilization and cost.<sup>23</sup> Working-age persons with disabilities who have higher ADL/IADL needs also have higher use of prescription medications, mental health visits, and emergency department utilization.<sup>24</sup> Missing from the research is information needed to develop

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Organization, "World Report on Disability," 2011, 10; Nora Ellen Groce, Jillian London, and Michael Ashley Stein, "Inheritance, Poverty, and Disability," *Disability & Society* 29, no. 10 (November 26, 2014): 1555, <https://doi.org/10.1080/09687599.2014.969831>; Deon Filmer, "Disability, Poverty, and Schooling in Developing Countries: Results from 14 Household Surveys," *The World Bank Economic Review* 22, no. 1 (January 1, 2008): 142, <https://doi.org/10.1093/wber/lhm021>.

<sup>20</sup> Reichard et al., "Prevalence and Reasons for Delaying and Foregoing Necessary Care by the Presence and Type of Disability among Working-Age Adults," *Disability and Health Journal* 10, no. 1 (January 1, 2017): 39, <https://doi.org/10.1016/j.dhjo.2016.08.001>.

<sup>21</sup> Marguerite E Burns, Nilay D Shah, Maureen A Smith. "Living at the Thin Margin of Health: Out-of-Pocket Health Care Spending by Medicaid Beneficiaries with Disabilities," *Health Affairs* 29, no. 8 (2011): 1517–1522, <https://doi.org/10.1377/hlthaff.2009.0147>.

<sup>22</sup> Gerben DeJong et al., "The Organization and Financing of Health Services for Persons with Disabilities," *The Milbank Quarterly* 80, no. 2 (June 2002): 276, <https://doi.org/10.1111/1468-0009.t01-1-00004>; Reichard et al., "Prevalence and Reasons for Delaying and Foregoing Necessary Care," 39.

<sup>23</sup> Stephen P. Gulley, Elizabeth K. Rasch, and Leighton Chan, "The Complex Web of Health: Relationships among Chronic Conditions, Disability, and Health Services," *Public Health Reports* 126, no. 4 (July 1, 2011): 500, <https://doi.org/10.1177/003335491112600406>.

<sup>24</sup> Amanda Reichard et al., "Diagnosis Isn't Enough: Understanding the Connections between High Health Care Utilization, Chronic Conditions and Disabilities among U.S. Working Age Adults," *Disability and Health Journal* 8, no. 4 (October 2015): 544, <https://doi.org/10.1016/j.dhjo.2015.04.006>.

interventions that will reduce barriers to healthcare and improve health outcomes for these populations.<sup>25</sup>

A central premise of this thesis is that the lack of necessary research and quality interventions for persons with disabilities stems to an extent from the theoretical models through which disability is perceived and understood. The predominant model that drives healthcare policy development in the United States is the “medical model,” which views disability as a poor health outcome rather than viewing persons with disabilities as fully valued humans with distinct healthcare needs beyond what the medical model recognizes as necessary. This less-than whole-person care model embeds a sense of “othering” of persons with disabilities into the culture that drives healthcare policy development in the United States and Massachusetts. Othering is a verb that, at its most basic level, means treating people from another group as intrinsically different and inferior to the group to which one belongs. One need only look at the priorities set out by the Department of Health and Human Services (HHS) to see that HHS is silent on health disparities impacting persons with disabilities.<sup>26</sup> Persons with disabilities are only identified in a subsection of the HHS website rather than a population whose needs should be prioritized.<sup>27</sup>

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<sup>25</sup> Willi Horner-Johnson et al., “Disparities in Health Care Access and Receipt of Preventive Services by Disability Type: Analysis of the Medical Expenditure Panel Survey,” *Health Services Research* 49, no. 6 (December 2014): 1995, <https://doi.org/10.1111/1475-6773.12195>.

<sup>26</sup> “Strategic Plan FY 2022 – 2026,” U.S. Department of Health and Human Services, accessed October 3, 2022, <https://www.hhs.gov/about/strategic-plan/2022-2026/index.html>.

<sup>27</sup> “Strategic Goal 3: Strengthen Social Well-being, Equity, and Economic Resilience,” U.S. Department of Health and Human Services, accessed October 3, 2022, <https://www.hhs.gov/about/strategic-plan/2022-2026/goal-3/index.html>.

As a result of this “othering,” persons with disabilities face unique barriers to health and wellness resulting from biases in public health, social, and religious spheres. These barriers exacerbate isolation and loneliness in the disability population, often resulting in disparate health outcomes. Low-income persons with disabilities (PWDs) who have complex cognitive, mental health, or substance use disorders and frail elders are often isolated and lack connection to friends or family, let alone faith communities.

In the past twenty years, the field of public health seems to have slowly begun to recognize persons with disabilities as a population and not as patients with poor health outcomes.<sup>28</sup> At the same time there is growing literature on spirituality as a determinant of health and the important intersection of spirituality and healthcare.<sup>29</sup> In recent years, social determinants, including spiritual wellness have been recognized as playing a prominent role among health determinants impacting an individual’s health and well-being. Determinants of health are not static. Increased efforts are now underway to refine and universalize an instrument to measure spirituality as a determinant of health that is reliable and valid.<sup>30</sup>

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<sup>28</sup> “Improving Health of People with Disabilities,” Centers for Disease Control and Prevention, accessed October 3, 2022, <https://www.cdc.gov/ncbddd/aboutus/report/ar-disabilities.html>.

<sup>29</sup> For example, see Tracy A. Balboni et al., “Spirituality in Serious Illness and Health,” *JAMA* 328, no. 2 (2022): 184–197. Kerstin Stieber Roger and Andrew Hatala, “Religion, Spirituality & Chronic Illness: A Scoping Review and Implications for Health Care Practitioners,” *Journal of Religion & Spirituality in Social Work: Social Thought* 37, no. 1 (2018): 24–44, <https://doi.org/10.1080/15426432.2017.1386151>.

<sup>30</sup> Neera Dhar, SK Chaturvedi, Deoki Nandan, “Spiritual Health Scale 2011: Defining and Measuring 4th Dimension of Health,” *Indian Journal of Community Medicine* 36, no. 4 (2011): 277, <https://doi.org/10.4103/0970-0218.91329>.

This thesis provides evidence that the medical system denies persons with disabilities their full humanity by ignoring their spiritual needs. Therefore, access to spiritual care for working-age persons living in community settings with nursing-home-level care needs is a social justice imperative. The immediate goal of this thesis is to argue that offering spiritual care to this population will address the unmet spiritual or religious needs of enrollees with the thinnest margins of health and at highest risk of isolation, depression, and institutionalization. The larger goal is to advance spiritual care as fundamental to whole-person care and a public health priority. This view is supported by the Oxford Textbook of Spirituality in Healthcare, “[p]ublic health without spirituality is not truly holistic and risks omitting an important determinant and dimension of human health and well-being.”<sup>31</sup> The conceptual framework guiding the thesis project is Catholic social teaching, namely the Catholic theological understanding of humanity as *imago Dei* (image of God). As taught by the United States Conference of Catholic Bishops,

We believe in the triune God whose very nature is communal and social. God the Father sends his only Son Jesus Christ and shares the Holy Spirit as his gift of love. God reveals himself to us as one who is not alone, but rather as one who is relational, one who is Trinity. Therefore, we who are made in God’s image share this communal, social nature. We are called to reach out and to build relationships of love and justice.<sup>32</sup>

Catholic social teaching reminds us that, created in God’s image, we are all called to recognize other persons as “one’s neighbor, ‘another self’ . . . To whom one is

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<sup>31</sup> Mark R. Cobb, Christina M. Puchalski, Bruce Rumbold, *Oxford Textbook of Spirituality in Healthcare* (Oxford: Oxford University Press, 2012), 63.

<sup>32</sup> “Sharing Catholic Social Teaching: Challenges and Directions,” United States Conference of Catholic Bishops, accessed February 9, 2022, <https://www.usccb.org/resources/sharing-catholic-social-teaching-challenges-and-directions>.

intrinsically related and with whom one shares human rights and responsibilities.”<sup>33</sup> Because all humans are called to be in a relationship with God and with one another, there no one is “other.”<sup>34</sup> “We were created to ‘Love the Lord your God with all your heart and with all your soul and with all your strength and with all your mind’ and, ‘Love your neighbor as yourself’” (Luke 10:27 NIV). Catholic social justice teaching calls us to live out our vocations and human relationships governed by truth, justice, charity, and freedom—within civil societies, in relationship with one another as citizens, citizens of a global community seeking global justice and interdependence.<sup>35</sup> Applied to public health, Catholic social justice teaching calls for a return by public health to its original logos by advocating for policies and practices at the local, national, and global level that value the individual as having intrinsic value and place at its center the goal of a just world.

The thesis, therefore, proceeds on the premise that persons with disabilities are manifold beings made in the image and likeness of God. Like all other persons, they have distinct physical, psychological, social, and spiritual gifts and needs. However, unlike persons without disabilities, persons with disabilities are too often denied their status as *imago Dei* and, with that, denied of full personhood. The reasons are complex, but in short, our culture is controlled by an ideological power structure rooted in an

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<sup>33</sup> Second Vatican Council, 1965, #27.

<sup>34</sup> Brenda Appleby and Nuala P. Kenny, “Relational Personhood, Social Justice and the Common Good: Catholic Contributions toward a Public Health Ethics,” *Christian Bioethics* 16, no. 3 (December 2010): 299.

<sup>35</sup> Appleby and Kenny, 302.

individualistic utilitarian model of personhood.<sup>36</sup> This model is antithetical to human identity as relational imago Dei.

There is increasing evidence that the American culture is embracing individualistic self-sufficiency over against the imago Dei understanding of personhood. The values of individualism and self-sufficiency are embodied by the Libertarian Party which formed in 1971 and has quickly grown to become the third largest political party in the United States.<sup>37</sup> The preamble to the Libertarian platform states, “we seek a world of liberty: a world in which all individuals are sovereign over their own lives and are not forced to sacrifice their values for the benefit of others.”<sup>38</sup> The values of the Libertarian party are aligned with the objectivist philosophy of Ayn Rand which reduces human relationship to transactions. As stated by Rand, “[t]he principle of trade is the only rational ethical principle for all human relationships, personal and social, private and public, spiritual and material.”<sup>39</sup> According to Rand, trade, which she defines as “giving value for value,” is the central tenet of justice. Libertarianism and Objectivist systems of justice leave the fate of persons with disabilities to charity.<sup>40</sup> As stated by Rand “Who is more valuable to humanity? Which of the two suffers more acutely: the misfit, who

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<sup>36</sup> Reynolds, *Vulnerable Communion*, 59.

<sup>37</sup> “Platform,” Libertarian: The Party of Principles, accessed August 16, 2022, <https://www.lp.org/platform/>; “Libertarian Party,” Ballotpedia, accessed August 16, 2022, [https://ballotpedia.org/Libertarian\\_Party](https://ballotpedia.org/Libertarian_Party).

<sup>38</sup> “Platform,” Libertarian.

<sup>39</sup> Ayn Rand, *The Virtue of Selfishness* (New York: New American Library, 1964), 31.

<sup>40</sup> “Platform,” Libertarian.



doesn't know what he is missing or the talent in one who knows it only too well?"<sup>41</sup> In other words, better to invest in persons with talent than persons with disabilities "in the spirit of a much higher type of charity."<sup>42</sup> In this model, persons with disabilities are viewed as dependent, having less capital, and, therefore, as persons with less value.<sup>43</sup> Having less utilitarian value, persons with disabilities are a threat to the hegemonic able-bodied status quo and "treated with indifference, suspicion, or revulsion."<sup>44</sup> As a result, persons with disabilities are to be feared as alien "other."

The system of devaluation leads to stigma and reduced self-esteem among persons with disabilities. This can lead to self-othering and engagement in unhealthy activities such as smoking, over-eating, etc.<sup>45</sup> As an instrument of the hegemonic system that shapes perceptions of disability, public health perpetuates an "us" versus "them" worldview that maintains ongoing othering of persons with disabilities in health.<sup>46</sup> Public health purports to work in solidarity with populations and communities. However, it fails

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<sup>41</sup> "Letter 034, pg. 1," AynRand.org, <https://letters.aynrandarchives.org/document/55795>.

<sup>42</sup> "To Marjorie Williams," AynRand.org, accessed August 16, 2022, <https://aynrand.org/archives/letters/letter-34/>.

<sup>43</sup> Reynolds, 59; Melinda Rosenberg. "Harm, Liberty, and Disability," *Disability Studies Quarterly* 29, no. 3 (2009), <https://doi.org/10.18061/dsq.v29i3.937>.

<sup>44</sup> Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids: Brazos Press, 2008), 60.

<sup>45</sup> Iryna Babik and Elena S. Gardner, "Factors Affecting the Perception of Disability: A Developmental Perspective," *Frontiers in Psychology* 12 (2021): 2, <https://doi.org/10.3389/fpsyg.2021.702166>.

<sup>46</sup> Nuala P. Kenny, Susan B. Sherwin, and Francoise E. Baylis, "Re-Visioning Public Health Ethics: A Relational Perspective," *Canadian Journal of Public Health* 101, no. 1 (2010): 10, <https://doi.org/10.1007/bf03405552>; Chanee D. Fabius et al., "Racial disparities in Medicaid home and community-based service utilization and expenditures among persons with multiple sclerosis," *BMC Health Services Research* 18, no. 1 (2018): <https://doi.org/10.1186/s12913-018-3584-x>.

to account for its continued engagement in systemic discrimination and devaluation of the most vulnerable persons and communities: persons with disabilities.<sup>47</sup> One example of this is how it excludes persons with disabilities from priority population status in efforts to reduce health disparities caused by social determinants of health that lead to health inequities.<sup>48</sup>

The othering of persons with disabilities by public health and larger society is evident in the negative interpersonal bias and systemic discrimination experienced by persons with disabilities, leading to disparities in morbidity, mortality, and quality of life. Healthy People 2030 defines health disparities as:

[A] particular type of health difference loosely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.<sup>49</sup>

Social determinants cause health disparities for persons with the disabilities, such as “length of life; quality of life; rates of disease, disability, and death; severity of disease; and access to treatment.”<sup>50</sup>

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<sup>47</sup> Kenny, “Re-Visioning Public Health Ethics,” 10.

<sup>48</sup> “Disability—A Neglected Issue in Public Health,” *The Lancet Public Health* 6, no. 6 (June 2021): E346, [https://doi.org/10.1016/S2468-2667\(21\)00109-2](https://doi.org/10.1016/S2468-2667(21)00109-2).

<sup>49</sup> “How Does Healthy People Define Health Equity and Health Disparities?” *U.S. Department of Health and Human Services: Healthy People 2030*, accessed June 23, 2022, <https://health.gov/healthypeople/priority-areas/health-equity-healthy-people-2030#:~:text=Health%20disparities%20adversely%20affect%20groups,or%20gender%20identity%3B%20geographic%20location%3B>.

<sup>50</sup> “Health Equity,” Centers for Disease Control and Prevention, accessed on January 13, 2022, <https://www.cdc.gov/chronicdisease/healthequity/index.htm>.

Efforts to address health equity reflect the hegemonic framework of disability as persons with disabilities face greater barriers to full integration into society regardless of race, ethnicity, or other identity status. Disparities have been identified in persons with disabilities' access to community services or other essential services relative to the general population. It is also important to understand disability in the larger context of society. Persons with disabilities from marginalized ethnic and racial populations face a compounded bias and discrimination.<sup>51</sup> Therefore, it is necessary to apply an intersectional analysis to the problem of health disparities and recognize that other disparities have been identified in racial groups' home and community-based services utilization. For example, recent studies suggest disparities in access to Home and Community Based Services (HCBS) between people who identify as white and those who identify as black.<sup>52</sup> Given the intersectional nature of disability and bias, it is important that spiritual care also address the spiritual needs of people with disabilities, understanding they are not a unidimensional population.

### **The Need for Treating the Whole Person**

Interpersonal and systemic level discrimination negatively impacts the physical, psychological, social, and spiritual dimensions of persons with disabilities that cannot be addressed using reductionistic biomedical approaches to primary care. The primary care

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<sup>51</sup> Willi Horner-Johnson, "Disability, Intersectionality, and Inequity: Life at the Margins," in *Public Health Perspectives on Disability* (New York, NY: Springer, 2021), 91–105.

<sup>52</sup> Chanee D. Fabius et al., "Racial Disparities in Medicaid Home and Community-Based Service Utilization and Expenditures among Persons with Multiple Sclerosis," *BMC Health Services Research* 18, no. 1 (2018): 773.

model needed to promote health and well-being among persons with disabilities must integrate all these aspects of the individual. Providing this type of primary care requires a paradigm shift away from the medical model of disability to a whole person model that incorporates physical, psychological, spiritual, and social elements of health. This paradigm requires spiritual care to be provided for persons with disabilities as part of primary care. Persons with disabilities living in community settings should have access to whole-person-centered primary care that addresses the many facets of their identities-including their religious, spiritual, or existential needs.

Besides being ableist, there remains a stream of anti-religious, anti-spiritual bias in public health and a lack of serious investment of resources to understand the value of spiritual care among policymakers.<sup>53</sup> For example, spirituality is recognized by the Centers for Disease Control and Prevention, and Centers for Medicare and Medicaid Services (CMS) as an essential aspect of human identity. The CDC has identified quality-of-life (Health Related Quality of Life [HRQOL]), including spiritual well-being, as essential to overall health.<sup>54</sup> HRQOL is “an individual’s or group’s perceived physical and mental health over time.”<sup>55</sup> Yet, CMS pays for spiritual care solely for veterans, persons in hospitals, and persons receiving hospice or palliative care services in the

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<sup>53</sup> Linda M. Chatters, “Religion and Health: Public Health Research and Practice,” *Annual Review of Public Health* 21 (2000): 353, 355, <https://doi.org/10.1146/annurev.publhealth.21.1.335>.

<sup>54</sup> “HRQOL Concepts,” Centers for Disease Control and Prevention, accessed on January 9, 2022, <https://www.cdc.gov/hrqol/concept.htm>.

<sup>55</sup> “HRQOL Concepts.”

community. These narrow parameters, persons with unmet spiritual needs are left without care.

The vacuum of unmet need is being addressed for many, but in a very piecemeal manner. For example, the Substance Abuse and Mental Health Services Administration (SAMHSA) puts spiritual wellness at the center of a recovery for persons with substance use disorder. In one of its publications, *Creating a Healthier Life, a Step-By-Step Guide to Wellness*, the question is asked of the reader, "Are you using your spirituality to drive your actions and thoughts and give a better meaning to life?" It goes on to ask, "Are you receptive to your own spirituality even in times of pain and grief?" Noting this is when spirituality can help most.<sup>56</sup> However, SAMHSA does not directly fund spiritual care programs, but engages and supports faith-based and other organizations engaged in substance use and mental health services, providing over 800 faith-based community partners among grantees.<sup>57</sup>

In addition, efforts are being taken to press for imploring of the lines between hospital care and community care. As recognized by the Journal of the Catholic Health Association of the United States, the healthcare delivery system is undergoing incredible transformation in the face of these biases. Care once only provided in hospital settings is increasingly being provided in homes. The definition of healthcare teams is being redefined as the healthcare system moves beyond a narrowly focused physician-patient

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<sup>56</sup> "Creating a Healthier Life," Substance Abuse and Mental Health Services Administration, accessed October 5, 2022, <https://store.samhsa.gov/sites/default/files/d7/priv/sma16-4958.pdf>.

<sup>57</sup> "Faith-Based and Community Initiatives (FBCI)," Substance Abuse and Mental Health Services Administration, accessed October 5, 2022, <https://www.samhsa.gov/faith-based-initiatives>.

relationship to a more dynamic person-centered model of care.<sup>58</sup> If oriented towards the whole person, healthcare should include spiritual care as a clinical practice and as an effective intervention to reduce spiritual and existential suffering as well as physical pain to improve patient quality of care.<sup>59</sup> Therefore, these models should include integration of chaplains into primary care teams. Integrating chaplains requires a paradigm committed to a hermeneutic of “solidarity with and a preferential option for those who are marginalized.”<sup>60</sup> Public Health must, in humility, engage with persons with disabilities to build relationships that lead to action.<sup>61</sup>

Addressing the unmet spiritual needs of persons with disabilities is imperative for health justice and public health.<sup>62</sup> As a person with a disability engaged with the

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<sup>58</sup> Brian P. Smith, “Spiritual Care in the Midst of Health Care Reform: Creating a Framework for Effective Staffing,” *Health Progress* (2014), <https://www.chausa.org/publications/health-progress/article/september-october-2014/spiritual-care-in-the-midst-of-health-care-reform>.

<sup>59</sup> Sangeeta C. Ahluwalia et. al. “A Systematic Review in Support of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, Fourth Edition,” *Journal of Pain and Symptom Management* 56, no. 6 (2018): 831–870, <https://doi.org/10.1016/j.jpainsymman.2018.09.008>.

<sup>60</sup> Mary Jo Iozzio, “God Bends Over Backwards to Accommodate Humankind . . . While the Civil Rights Acts and the Americans with Disability Act Require [Only] the Minimum,” *Journal of Moral Theology* 6, no. 2 (2017): 29. <https://jmt.scholasticahq.com/article/11371-god-bends-over-backwards-to-accommodate-humankind-while-the-civil-rights-acts-and-the-americans-with-disability-act-require-only-the-minimum>.

<sup>61</sup> Iozzio, 29.

<sup>62</sup> Christina M. Puchalski et al., “Overview of Spirituality in Palliative Care,” UpToDate.com, February 3, 2020, [https://www.uptodate.com/contents/overview-of-spirituality-in-palliative-care?source=related\\_link](https://www.uptodate.com/contents/overview-of-spirituality-in-palliative-care?source=related_link); Diane E. Meier and Elizabeth McCormick, “Benefits, services, and models of subspecialty palliative care,” UpToDate.com, June 12, 2020, [https://www.uptodate.com/contents/benefits-services-and-models-of-subspecialty-palliative-care?sectionName=RATIONALE%20FOR%20PALLIATIVE%20CARE&topicRef=86302&anchor=H914734&source=see\\_link#H914734https://www.uptodate.com/contents/palliative-care-for-adults-in-the-ed-concepts-presenting-complaints-and-symptom-management](https://www.uptodate.com/contents/benefits-services-and-models-of-subspecialty-palliative-care?sectionName=RATIONALE%20FOR%20PALLIATIVE%20CARE&topicRef=86302&anchor=H914734&source=see_link#H914734https://www.uptodate.com/contents/palliative-care-for-adults-in-the-ed-concepts-presenting-complaints-and-symptom-management); Judy Kaye and Senthil Kumar Raghavan, “Spirituality in Disability and Illness,” *Journal of Religion and Health* 41, no. 3 (2002): 232. Boni Boswell, et al. “Dance of Disability and Spirituality,” *Journal of Rehabilitation* 72, no. 4 (2007): 34–35; David R Hodge, Conroy Reynolds. “Spirituality among People with Disabilities: A Nationally

independent living movement, I believe that in its quest to free persons with disabilities from the shackles of otherness, the movement has not yet fully realized the intrinsic value of spirituality or the central role spirituality can play in advancing the human dignity and civil rights of persons with disabilities. Jean Vanier was one of the most outspoken critics of individualism of Western society and its impact on persons with disabilities. Vanier recognized that independence requires interior freedom and maturation that can only be achieved by breaking out of the “shell of individualism and self-centeredness that both protects and isolates us.”<sup>63</sup>

Vanier appreciates the tension between connectedness and belonging and the need for creativity that may come from loneliness and drive our creativity to draw us into deeper relationship with God.<sup>64</sup> Though Vanier is primarily referring to able-bodied culture, his words apply to the tensions that exist in the lives of persons with disabilities as they seek connectedness and community having suffered a level of isolation that leads to depression.

Persons with disabilities are more likely to engage in a spiritual practice such as prayer than the general population. They derive a sense of connection, meaning and purpose in their lives from prayer and meditation.<sup>65</sup> Spiritual well-being can have an

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Representative Study of Spiritual and Religious Profiles,” *Health & Social Work* 44, no. 2 (May 2019): 81–82, <https://doi.org/10.1093/hsw/hly035>; Kaye, “Spirituality in Disability and Illness,” 234.

<sup>63</sup> Jean Vanier, *Becoming Human* (Toronto: Paulist Press, 1998), 35.

<sup>64</sup> Vanier, 17.

<sup>65</sup> Harold G. Koenig, “Religion, Spirituality, and Health,” 11.

inverse relationship to loneliness.<sup>66</sup> Spirituality is an important means of support for persons with disabilities in dealing with depression, anxiety and stress associated with the complexity of living with a disability.<sup>67</sup> For persons who are religious, belief in an omnipotent higher power or God can provide a sense of hope and connection. Hope and belonging can be linked with engagement in a faith community, translating spirituality into concrete social support.<sup>68</sup> For atheists, meaning may be found in wonder about the universe or through creative pursuits.<sup>69</sup>

In the secular West, much has been done to improve life expectancy of people with disability and chronic conditions such as persons with cancer. However, improvement in life expectancy often leads to spiritual, religious and existential questions as people struggle to find meaning in their lives.<sup>70</sup> Because of the large amount of literature showing a positive link between spiritual and religious meaning making in the treatment of persons with cancer, professionals working in the field of oncology are increasing their emphasis on enhancing spiritual and religious interventions that strengthen meaning making and coping for persons actively getting treatment and for

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<sup>66</sup> Kaye, “Spirituality in Disability and Illness,” 234.

<sup>67</sup> Kaye, 235.

<sup>68</sup> Kaye, 238–239.

<sup>69</sup> “Where Americans Find Meaning in Life,” Pew Research Center, November 20, 2018, accessed October 3, 2022, <https://www.pewresearch.org/religion/2018/11/20/where-americans-find-meaning-in-life/>. “Atheists,” Pew Research Center, accessed October 3, 2022, <https://www.pewresearch.org/religion/religious-landscape-study/religious-family/atheist/#frequency-of-feeling-wonder-about-the-universe>.

<sup>70</sup> Niels Christian Hvidt et al., “Spiritual, Religious, and Existential Concerns of Survivors in a Secular Country with Focus on Age, Gender, and Emotional Challenges,” *Supportive Care in Cancer* 27, no. 12 (2019): 4713, <https://doi.org/10.1007/s00520-019-04775-4>.



cancer survivors.<sup>71</sup> A study in Denmark, one of the least religious nations in the world, provided clear evidence of the association between emotional disquiet, hopelessness and depression with unaddressed religious or spiritual concerns.<sup>72</sup> Identifying and implementing interventions that enhance an individual's ability to engage in meaning making and spiritual well-being can reduce feelings of despair and depression.<sup>73</sup>

The US Department of Health And Human Services and Office of Disease Prevention and Health Promotion formally recognizes that disability is not synonymous with poor health outcomes. As stated in 2022 It is only through the advocacy of persons with disabilities and their allies that the field of public health has begun to recognize “[p]oorer functional status can, and should not be, equated with poorer quality of life. Quality of life encompasses more than activities of daily living, health states, disease categories, or functional ability, ‘because it directs attention to the more complete social, psychological, and spiritual being.’”<sup>74</sup> With this acknowledgment, HHS has recognized persons with disabilities as a population rather than solely identifying disability as a poor health outcome.

At the same time, however, most public health efforts continue to treat “disability as an individual tragedy or misfortune due to genetic or environmental insult” and focus

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<sup>71</sup> Hvidt, “Spiritual, Religious, and Existential Concerns,” 4714.

<sup>72</sup> Hvidt, “Spiritual, Religious, and Existential Concerns,” 4719.

<sup>73</sup> Kaye, 239.

<sup>74</sup> “Health-Related Quality of Life & Well-Being,” HealthPeople.gov, accessed January 13, 2022, <https://www.healthypeople.gov/2020/topics-objectives/topic/health-related-quality-of-life-well-being>.

on preventing disability.<sup>75</sup> In doing so, they ignore the immediate needs of persons with disabilities which can disproportionately impact the health outcomes of African Americans and other minority populations living with disabilities.<sup>76</sup> This paper provides empirical evidence of spiritual care's positive impact on health and wellness. It discusses the failure of the public health field to advocate for spiritual care among persons with disabilities as a means to reduce health disparities and advance health equity. It then sets out an argument for providing spiritual care as a singular means of assisting persons with complex care needs to grapple with existential questions of meaning and offers ways of addressing experiences of isolation and loneliness.

Despite the evidence of the efficacy of integrating spirituality in patient care, public health practitioners devalue the full humanity of persons with disabilities by ignoring their spiritual needs. The thesis advocates for spiritual care as an optional service for working-age persons (21–64) living in community settings with nursing-home-level care. This paper argues that offering spiritual care to this population will address the unmet spiritual or religious needs of enrollees at the highest risk of isolation, depression, and institutionalization. The larger goal is to advance spiritual care and prove its fundamental place in whole-person care.

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<sup>75</sup> Joel Michael Reynolds, "'I'd Rather be Dead Than Disabled' – the Ableist Conflation and The Meanings of Disability," *Review of Communication* 17, no. 3 (2016): 150, <https://doi.org/10.1080/15358593.2017.1331255>.

<sup>76</sup> Reynolds, 150.

## Problem Statement

Theologian Thomas Berry taught about story—the story of creation, the story of redemption, the story of humanity, and the interior story. Berry described the transmission of values this way: “[e]very being has its own interior, its self, its mystery, its numinous aspect. To deprive any being of this sacred quality is to disrupt the total order of the universe.”<sup>77</sup>

Healthcare as provided today, is disrupting lives by negating the numinous and denying persons with disabilities their identity as *imago Dei*.<sup>78</sup> Healthcare is not fulfilling its obligation to reverence persons with disabilities whose unique voices are vitally important to the redemption story.<sup>79</sup> Persons with disabilities exist in a paradoxical system that provides opportunity within a larger milieu of what Pope John Paul II described as a “culture of death.”<sup>80</sup> It is a culture in which persons, whether because of chronic disease or disability, are perceived as a threat or “intolerable burden” to the “well-being or lifestyle of those who are more favored.”<sup>81</sup> Unprecedented levels of isolation, depression, and loneliness dominate this culture and

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<sup>77</sup> Berry, Thomas. “The New Story: Comments on the Origin, Identification and Transmission of Values,” *CrossCurrents* 37, no. 2/3 (1987): 196, [jstor.org/stable/24459047](https://www.jstor.org/stable/24459047).

<sup>78</sup> Berry, 196.

<sup>79</sup> Berry, 196.

<sup>80</sup> “Evangelium Vitae: To the Bishops Priests and Deacons Men and Women religious lay faithful and all People of Good will on the Value and Inviolability of Human Life,” The Holy See, accessed February 19, 2022, [https://www.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf\\_jp-ii\\_enc\\_25031995\\_evangelium-vitae.html](https://www.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html).

<sup>81</sup> “Evangelium Vitae.”

perhaps impact no single population more than low-income persons with disabilities across the lifespan.<sup>82</sup>

By denying spiritual care, the healthcare system is not only failing to address determinants of health that reduce quality of life and lead to poorer health outcomes for persons with disabilities; it is also denying a service that can aid them in recognizing their identity as human beings created in the image of God. It is therefore important to read the “signs of the times” and take active steps to spiritual care as an affirmation of their dignity and humanity.<sup>83</sup> In cases of persons and family members who do not have a religious tradition but for whom spirituality is important, denial of spiritual care stunts opportunity for existential meaning as they experience personal suffering and social oppression. Healthcare providers, and all those who work in the healthcare system, are also denied validation of their transcendent dignity and the dignity of those they serve.<sup>84</sup>

One Care is a medical plan in Massachusetts funded by both Medicare at the federal level and Medicaid, known in Massachusetts as “MassHealth,” at the state level. One Care was created to provide sustainable whole-person-centered care to low-income dual-eligible persons, insured by both Medicaid and Medicare, between 21–64. This population has a variety of needs including medical, mental health, substance use

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<sup>82</sup> “Evangelium Vitae.”

<sup>83</sup> Claire E. Wolfteich and Thomas Groome, *Invitation to Practical Theology: Catholic Voices and Visions—Chapter 14 Practices of Teaching* (Mahwah, NJ: Paulist Press, 2004), introduction.

<sup>84</sup> “Respect for the Human Person,” The Holy See.

disorder, recovery, and home and community-based service (HCBS). The model of care focuses on addressing unmet long-term services and support (LTSS), recovery, and other health related social needs that can lead to increased cost and poor health outcomes, and One Care plans must conduct an annual care assessment and care planning process to create a comprehensive care plan that includes the member's medical and nonmedical goals.

One Care primary care providers (PCPs) and care teams already offer a number of palliative care level practices into their regular care practices for high need and high-cost populations. These services include addressing an individual's physical, psychological, and social concerns in an integrated manner that is coordinated by a member or members of the care team. In addition to the individual, plans are also required to include family members in care teams at the discretion of the individual and provide respite care. Lacking from One Care is attention to enrollees' religious, spiritual, and existential concerns that impact their overall health and well-being.

The One Care contract does not mention spiritual care or include spiritual care as a covered service. As a result, One Care members experiencing spiritual distress do not have the right to spiritual care provided by chaplains with the training and expertise required to provide competent spiritual care. Comprehensive assessments and care planning processes do not include members' unmet religious and spiritual needs. Integrated care teams, central to the One Care model, are left without uniform practices and procedures needed to screen members or assess potential spiritual care needs of members. Based on a literature review, exclusion of spiritual care as a covered service

in One Care creates a significant barrier to improved quality of life and health outcomes for One Care members experiencing religious, spiritual, or existential stress.

### **Project Purpose**

In contrast to the United Kingdom and other countries, where spiritual care is integrated into primary care, in the United States spiritual care is limited. With limited exceptions, Medicare guidelines only provide coverage of spiritual care for veterans in persons in hospitals or receiving hospice care. Medicaid will cover spiritual care for veterans and persons in hospice.

In response to the evidence for the positive impact of spiritual care on health, researchers are trying to better understand the way spirituality and religion facilitate or impair healthy behavior and health. Spiritual care has been shown to reduce social isolation and loneliness, conditions that can lead to increased morbidity and conditions such as coronary heart disease.<sup>85</sup> Access to interventions that address the spiritual needs of persons with disabilities in primary care is an unmet need. Spiritual care has the potential to reduce isolation, loneliness and other determinants that lead to increased morbidity and mortality in the One Care population.

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<sup>85</sup> Nicole K. Valtorta et al., “Loneliness and Social Isolation as Risk Factors for Coronary Heart Disease and Stroke: Systematic Review and Meta-Analysis of Longitudinal Observational Studies,” *Heart* 102, no. 13 (July 1, 2016): 1015, <https://doi.org/10.1136/heartjnl-2015-308790>; Andrew Steptoe et al., “Social Isolation, Loneliness, and All-Cause Mortality in Older Men and Women,” *Proceedings of the National Academy of Sciences* 110, no. 15 (April 9, 2013): 5797, <https://doi.org/10.1073/pnas.1219686110>.

This project is put forward in response to Pope John XXIII's gospel call to read and respond to "the signs of the times."<sup>86</sup> Spiritual care is a means of addressing the injustice of health inequities that impact persons with disabilities and restoring the imago Dei at the personal and systems levels.<sup>87</sup> Catholic social teaching, in addition to affirming that humans are relational beings and imago Dei, created in the image of the invisible God, also affirms that social justice is attainable by valuing the person's "transcendent dignity."<sup>88</sup> Third, pastoral care is an act of liberation praxis when engaged in active partnership with oppressed people that is transformational at the individual and institutional levels.<sup>89</sup>

### **Project Proposal**

The one-year deliverable for the project is a legislative bill that calls upon the Massachusetts Executive Office of Health and Human Services (EOHHS) to develop regulations requiring MassHealth contracted dual-eligible Medicare Advantage Plans, otherwise known as One Care plans, to offer spiritual care by a board-certified chaplain as an optional service to all enrollees. The bill will require spiritual care be provided as an optional service to One Care members.

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<sup>86</sup> Matt. 16:3, quoted in Pope XXIII, *Humanae Salutis*, Apostolic Constitution, 1961.

<sup>87</sup> Wolfteich, *Practices of Teaching*.

<sup>88</sup> "Respect for the Human Person," The Holy See, subsection 1929.

<sup>89</sup> Gustavo Gutierrez, "Faith as Freedom: Solidarity with the Alienated and Confidence in the Future," *Horizons* 2, no. 01 (1975): 35, <https://doi.org/10.1017/S0360966900011804>.

There are two primary reasons for making spiritual care optional. The first reason is pragmatic. Legislation requiring contracted federal and state dollars might be met with heightened scrutiny and pushback for reasons ranging from separation of church and state as well as misunderstanding about the role of chaplains in healthcare. Second, consumer choice and control of healthcare services is a cornerstone of the disability rights movement. To this point, the bill's structure will mirror language used in an existing law requiring plans offered to One Care members include a Long-Term Services Supports (LTSS) Coordinator on the care team.

The LTSS Coordinators were established in response to advocacy by the disability community. LTSS coordinators are advocates and full participants of a member's care team. They promote access to Home and Community Based Services, LTSS, and other services in keeping with a member's goals and Independent Living and recovery movement principles. The LTSS coordinator is conflict-free. This means the LTSS coordinator is not a direct employee of the health plan. The goal of providing a conflict-free LTSS coordinator is "to limit any conscious or unconscious bias a care manager or agency may have, and ultimately promote the individual's choice and independence."<sup>90</sup>

As with the LTSS coordinator role, the spiritual care provider bill will be developed in partnership with disability advocates, allies, religious leaders, and

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<sup>90</sup> Linda Nakagawa, "Conflict-Free Case Management," *ANCOR.com*, [https://www.ancor.org/article/conflict-free-case-management/#:~:text=Conflict%2Dfree%20case%20management%20\(CFCM,the%20individual's%20choice%20and%20independence.](https://www.ancor.org/article/conflict-free-case-management/#:~:text=Conflict%2Dfree%20case%20management%20(CFCM,the%20individual's%20choice%20and%20independence.)



Massachusetts state house legislators. However, the spiritual care bill will differ from the LTSS coordinator legislation in the scope, function and professional credentials needed to be a spiritual care provider in One Care. The spiritual care provider will have responsibilities and provide services that require a higher level of training and expertise than the LTSS coordinator needs. For example, LTSS coordinators are responsible for advancing independent living principles by promoting community-based services while chaplains are responsible for accompanying people facing life-and-death decisions.

In theory, passage of legislation can be done within 90 days. However, it is uncommon for bills to become law in Massachusetts the first, second, or third year.<sup>91</sup> Understanding the challenges of getting legislation passed in one year, this thesis proposes a multi-year process that includes steps to be taken in the first year to negotiate with the Massachusetts Executive Office of Health and Human Services (EOHHS) to require One Care plans to provide certified chaplains to members as a first step in establishing a broader integrated spiritual care program within One Care. In negotiation with MassHealth, a potential compromise will be piloting a three-year certified chaplain program available to One Care's most complex and costly populations. This group includes One Care members identified as having high level of service needs due to mental health or substance use disorder diagnoses (C2Bs) and members with high level skilled nursing needs and assistance with four or more

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<sup>91</sup> Rupa Shenoy, "Mass. Legislature among States that Pass the Fewest Bills," *WGBH Online*, last modified April 20, 2014, <https://www.wgbh.org/news/2014/04/20/mass-legislature-among-states-that-pass-the-fewest-bills>.

Activities of Daily Living (ADLs) such as bathing, dressing, and eating due to diagnoses such as quadriplegia (C3Bs).<sup>92</sup> Both these populations experience high levels of isolation and depression resulting from stigma and bias and may benefit from spiritual care.<sup>93</sup>

Whether a pilot or codified requirement, One Care plans will be required to conduct a spiritual assessment of all its members as part of their initial and annual comprehensive assessment. The assessment will provide a baseline needs assessment for spiritual care. The assessment needs will be used as part of a longer research project. More information about the research project follows below.

The DMin project is unique in its:

- use of legislative advocacy to ensure access to spiritual care as a right within healthcare;
- emphasis on securing the rights of persons with disabilities to spiritual care as a means of advancing wellness within a public health framework;
- advancing chaplaincy as social justice praxis.

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<sup>92</sup> “One Care: MassHealth plus Medicare, May Enrollment Report,” MassHealth, May 2014, <https://www.mass.gov/doc/may-2014-enrollment-report-0/download>; “Demonstration to Integrate Care for Dual Eligible Individuals (One Care),” MassHealth, February 10, 2021, <https://www.mass.gov/doc/one-care-cy2020-payment-rates-february-2021-av/download>.

<sup>93</sup> J.R. Peteet MD. “Spirituality and Mental Health: Implications for Ethics, Medicine, and Public Health,” *Ethics, Medicine and Public Health* 9 (April-June 2019): 76, <https://doi.org/10.1016/j.jemep.2019.05.002>; Marcus Y. L. Chiu et al., “Operationalization of the SAMHSA Model of Recovery: A Quality of Life Perspective,” *Quality of Life Research* 19, (2010): 7, 10, <https://doi.org/10.1007/s11136-009-9555-2>.

## CHAPTER 1—DEFINING DISABILITY

### **Definition of Disability**

As a social construct, disability does not fit easily into any one category. Persons from every racial, ethnic, cultural, economic, and religious background experience disability if not in their own person, in the persons of people they love.<sup>94</sup> Persons with disabilities are a heterogeneous population. Many people are born with a disability, but most people with disabilities acquired them as they age because of injury, illness, or a chronic condition. The major categories of disability identified by the federal government are sensory, cognitive, and mental health.<sup>95</sup> Disability disproportionately impacts black and African American communities due to social determinants of health including racism.

### **Models of Disability**

Given the heterogeneity of the disability community, and competing interests of society, it is not surprising that there are a number of models of disability. These models seek to understand disability as a social construct and situate it, and persons with disabilities as a population, into neatly defined categories. Models of disability include the medical, social, functional rehabilitation, cultural, and psychological models. Most

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<sup>94</sup> Sheryl A. Kujawa-Holbrook and Karen B. Montagno, *Injustice and the Care of Souls: Taking Oppression Seriously in Pastoral Care* (Minneapolis: Fortress Press, 2009), 220.

<sup>95</sup> “Disability and Health Overview,” Centers for Disease Control and Prevention, September 16, 2020, <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>; “Able-Bodied Public Health Statement: American’s Health Rankings,” United Health Foundation, accessed December 30, 2021, <https://www.americashealthrankings.org/explore/disparity>.

prominent public health models are the medical, social, and functional rehabilitation models.<sup>96</sup>

The medical model ascended in the late nineteenth century and views disability as a problem residing in the person and the result of disease, or other medical condition. The emphasis of the medical model is on curing the person. The medical model presumes a priori that “The medical model thus built upon 2 assumptions: first, that individuals should strive, largely through their own efforts guided by physicians, to overcome disabilities; and second, that physicians know what is best for patients.”<sup>97</sup>

The medical model holds that disability is the “consequence of a health condition, disease or caused by a trauma . . . It is a condition a person has and focuses on the prevention, treatment or curing of the disabling condition.”<sup>98</sup> The functional model, like the medical model, sees disability as “an impairment or deficit. . . . [however the] disability itself limits a person’s functioning or the ability to perform functional activities.”<sup>99</sup> Identifying a person as defective or impaired legitimizes othering and the notion of full personhood being equivalent to one’s ability to independently perform activities of daily living without assistance from others.

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<sup>96</sup> “Compare and Contrast Different Models of Disability,” Disability in Public Health, accessed January 16, 2022, <https://disabilityinpublichealth.org/1-1/>.

<sup>97</sup> Lisa I. Iezzoni and Vicki A. Freedman, “Turning the Disability Tide: The Importance of Definitions,” *JAMA* 299, no. 3 (2008): 332, doi:10.1001/jama.299.3.332.

<sup>98</sup> “Compare and Contrast Different Models of Disability.”

<sup>99</sup> “Compare and Contrast Different Models of Disability.”

In contrast to these models, the social model, until recently, most often embraced by disability advocates, “focuses on barriers facing people with disabilities instead of concentrating on impairments and deficits of the person with a disability.”<sup>100</sup> This model emphasizes the external social environment as a cause of limitations in participation in society rather than a person’s impairment.<sup>101</sup> While critical to advancing civil rights, the social model too often ignores personal suffering.<sup>102</sup>

Feminist theologians and theologians from developing nations connect the epidemiological understandings of personhood in Western medicine and dominant theologies of imago Dei which presuppose that wholeness. With it, personhood require a rational sense of self, self-sufficiency, and autonomy. One’s identification as human, and therefore imago Dei, is contingent on one’s cognitive capacity and physical ability to be self-sufficient—independent. As noted by feminist disability theorists examining disability, the social model can lead to the subversion of emotional suffering by emphasizing advocacy. According to feminist theorists, the social model of disability too often ignores subjective experiences of ongoing psychic trauma stemming from oppression. Therefore, they seek to promote activism while affirming the importance of addressing the ongoing subjective psychic trauma persons with disabilities experience as a result of ongoing discrimination.

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<sup>100</sup> “Compare and Contrast Different Models of Disability.”

<sup>101</sup> “Compare and Contrast Different Models of Disability.”

<sup>102</sup> Jerome Bickenbach. “Ethics, Disability, and the International Classification of Functioning, Disability and Health,” *American Journal of Physical Medicine and Rehabilitation* 91, no. 13 (2012): 163–167, <https://doi.org/10.1097/phm.0b013e31823d5487>; Lennard J. Davis, *The Disability Studies Reader* (New York: Routledge, 2017), 417.

Lacking a single model or definition of disability, researchers such as Lisa Iezzoni recommend using the International Classification of Functioning (ICF) tool to advance health equity for persons with disabilities. The ICF incorporates “both medical and social perspectives . . . an all-encompassing approach leads to fundamentally different calls, solutions and targets for interventions and therefore offers the greatest hope to guide policies. . . . Through the broad lens of the ICF, society can acknowledge the need to cure and prevent disease and the equally important goal of maximizing participation in daily life.”<sup>103</sup>

### **International Classification of Functioning**

The ICF is a neutral framework designed to be used as a tool to assist care teams coordinate and manage care of individuals. The ICF is a tool that provides a systematic way of measuring factors that support the health of persons with disabilities and those factors that lead to increased morbidity and mortality.<sup>104</sup> This framework is designed to assist care teams in providing an improved patient experience using a bio-psycho-social-spiritual approach that strengthens health systems and improves interprofessional education and collaboration through task sharing and coordination. The ICF provides a public health framework for analyzing, interpreting, and communicating information about environmental factors concerning social determinants of health, public health

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<sup>103</sup> Iezzoni and Freedman, “Turning the Disability Tide,” 332.

<sup>104</sup> T. B. Üstün, “The ICF: An Overview,” Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, accessed September 6, 2021, [https://www.cdc.gov/nchs/data/icd/icfoverview\\_finalforwho10sept.pdf](https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf).

outcomes and coordination with community-based stakeholders to promote improved health outcomes and support prevention.<sup>105</sup> Importantly, the ICF integrates spirituality as a health impactor as part of an integrative biosocial-spiritual framework.<sup>106</sup>

The ICF was created with input from disability organizations from around the world and is meant to be an interactive alternative to the medical model of disability by integrating environmental factors that act as facilitators or barriers to societal participation. In response to advancements in understanding of health and wellness, the ICF bio-psychosocial dimension of disability.<sup>107</sup> Despite advancements, concerns about using the ICF to identify the functional needs of persons with disabilities remain.

Some stakeholders with disabilities take offense at using a classification system as it can reduce individualized care by a medical professional.<sup>108</sup> Other stakeholders, including policymakers, are skeptical of its value in making policy.<sup>109</sup> However, it has

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<sup>105</sup> “How to Use the ICF: A Practical Manual for Using the International Classification of Functioning, Disability and Health (ICF),” World Health Organization, October 2013, [https://cdn.who.int/media/docs/default-source/classification/icf/drafticfpracticalmanual2.pdf?sfvrsn=8a214b01\\_4&download=true](https://cdn.who.int/media/docs/default-source/classification/icf/drafticfpracticalmanual2.pdf?sfvrsn=8a214b01_4&download=true).

<sup>106</sup> Katie L. Buckley and Lindsay B. Carey, “Systems Approaches to Occupational Vocal Health: Considerations for Community Faith Leaders,” *Journal of Religion and Health* 61, no. 2 (2022): 1183–1206, <https://doi.org/10.1007/s10943-021-01444-x>.

<sup>107</sup> Jörgen Lundälv et al., “Awareness and the Arguments for and Against the International Classification of Functioning, Disability and Health among Representatives of Disability Organisations,” *International Journal of Environmental Research and Public Health* 12, no. 3 (2015): 3294, <https://doi.org/10.3390/ijerph120303293>; “International Classification of Functioning, Disability and Health: Children & Youth Version,” World Health Organization, 2007, [https://apps.who.int/iris/bitstream/handle/10665/43737/9789241547321\\_eng.pdf](https://apps.who.int/iris/bitstream/handle/10665/43737/9789241547321_eng.pdf).

<sup>108</sup> Lundälv et al., “Awareness and the Arguments,” 3298.

<sup>109</sup> Lundälv et al., 3298.

been shown to be a positive policy making instrument that can move nations to fulfill obligations under the UN Convention for People with Disability.<sup>110</sup>

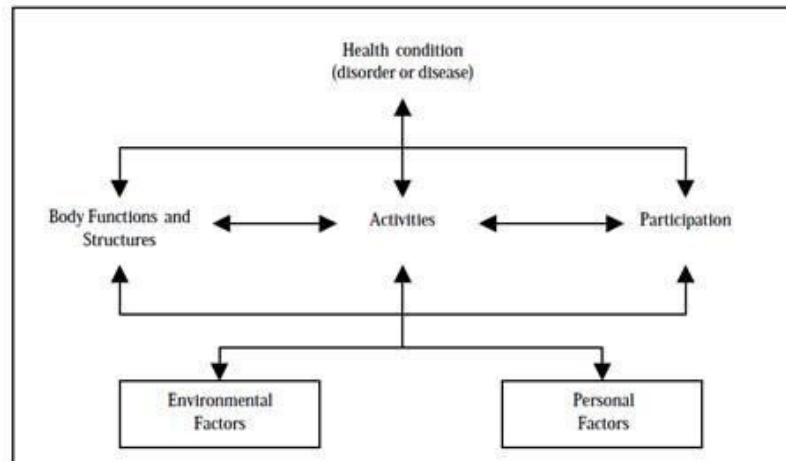


Fig. 1—Interactions between the components of ICF. The functionality of an individual in a particular area is a complex interaction or relationship between health conditions and the contextual factors. There is a dynamic interaction between these entities: an intervention in an element can potentially modify one or more other elements. These interactions are specific and operate in all directions.<sup>111</sup>

The ICF frees the individual from being defined by a disability, to being a full person who lives within the larger context of social, political, and other impactors. The ICF situates disability within a larger context away from mere bodily function towards a more holistic view of personhood that integrates the spiritual and existential dimensions of being.<sup>112</sup> Dimensions of health therefore include “bodily functions, mental functions and

<sup>110</sup> Lundälv et al., “Awareness and the Arguments,” 3298.

<sup>111</sup> Ana Isabel Martins et al., “The International Classification of Functioning, Disability and Health as a Conceptual Model for the Evaluation of Environmental Factors,” *Procedia Computer Science, Proceedings of the 4th International Conference on Software Development for Enhancing Accessibility and Fighting Info-exclusion (DSAI 2012)*, 14 (January 1, 2012): 295, <https://doi.org/10.1016/j.procs.2012.10.033>.

<sup>112</sup> Buckley and Casey, “Systems Approaches to Occupational Vocal Health,” 1183–1206.



perception, a spiritual/existential dimension, quality of life, social and societal participation in daily functioning, with underlying aspects.”<sup>113</sup> The challenge is to shift public health from an ableist biomedical model of disability to a more holistic biopsychosocial-spiritual model that uses the ICF as a tool to reduce health disparities and advance health equity for persons with disabilities.

## **Ableism**

### *Epistemology of Ableism*

The ableist epistemology sees disability as “an error, a mistake, or a failing, rather than a simple consequence of human diversity, akin to race, ethnicity, sexual orientation, or gender.”<sup>114</sup>

Ableism is deeply seeded . . . [it] is not just a matter of ignorance or negative attitudes towards disabled people; it is a trajectory of perfection, a deep way of thinking about bodies, wholeness, permeability, and how certain clusters of people are enabled via valued entitlements.<sup>115</sup>

So, not only are persons with disabilities considered an error or a failing, in contrast to other populations, they lack value and are not worthy of entitlements made available to

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<sup>113</sup> M. Huber et al., “Towards a ‘Patient-Centered’ Operationalization of the New Dynamic Concept of Health: a Mixed Methods Study,” *BMJ Open* 6, no. 1 (2016): 7–8, <https://doi.org/10.1136/bmjopen-2015-010091>.

<sup>114</sup> William Gaventa, *Disability and Spirituality: Recovering Wholeness* (Waco, TX: Baylor University Press), 404.

<sup>115</sup> Fiona Kumari Campbell, “The Violence of Technicism: Ableism as Humiliation and Degrading Treatment,” in *Ableism in Academia* (London: UCL Press, 2020), 206.

others in society.<sup>116</sup> They are distinct from other populations regardless of race, religion, or culture, their identity as fully human, as “being” is called into question.

Persons with disabilities face profound barriers to “being” that are distinct from those of any other population. Starting with Leviticus 21 down through the eugenics movement in the United States and the T4 experiments of the Nazis, there has been a general ambivalence in recognizing Persons with disabilities as fully human beings.<sup>117</sup> Current laws in the United States permit, and some might say endorse, the termination of fetuses with genetic anomalies.<sup>118</sup> External negative messages render them as other, as well as internal messages that lead negative perceptions of self as being other than “normal.”

This ableist “epistemic schema” permeates the healthcare delivery system, where implicit biases and ableist norms dictate values, knowledge, assumptions, and desires.<sup>119</sup> This schema permeates the culture of healthcare and leads to anti-disability biases. As the head of the National Council on Disability Andres J. Gallegos has expressed, “[e]xplicit and implicit discriminatory bias within the health care professions represent an insidious

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<sup>116</sup> Christine Wieseler, “Epistemic Oppression and Ableism in Bioethics,” *Hypatia* 35, no. 4 (2020): 715, <http://dx.doi.org/10.1017/hyp.2020.38>.

<sup>117</sup> *Bible: New American Bible, Revised Edition 2011*, ed. United States Conference of Catholic Bishops, sec. 4760.

<sup>118</sup> Dorothy C. Wertz, “Eugenics Is Alive and Well: A Survey of Genetic Professionals around the World,” *Science in Context* 11, no. 3–4 (1998): 493–510, <https://doi.org/10.1017/S0269889700003173>.

<sup>119</sup> David M. Peña-Guzmán and Joel Michael Reynolds, “The Harm of Ableism: Medical Error and Epistemic Injustice,” *Kennedy Institute of Ethics Journal; Baltimore* 29, no. 3 (September 2019): 206, <http://dx.doi.org.ezproxy.bu.edu/10.1353/ken.2019.0023>.

virus against which people with disabilities have been fighting for decades.”<sup>120</sup> Similarly, researcher Heidi L Janz describes the medical model as a virus that infects providers, causing them to reduce persons with disabilities to the “other.”<sup>121</sup> Our biomedical society has given license to discrimination against persons with disabilities. It is a moral failing that pathologizes persons with disabilities and supports the ongoing violation of their civil rights. Until the medical system changes, there will be continued institutionalization of people with disabilities across the United States, increasing burden put on families caring for loved ones with disabilities, and new waves of legislative action being sought to legalize euthanasia.

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<sup>120</sup> Adrés J. Gallegos, “Misperceptions Of People With Disabilities Lead To Low-Quality Care: How Policy Makers Can Counter The Harm And Injustice,” *Health Affairs*, accessed June 12, 2021, <https://www.healthaffairs.org/doi/10.1377/hblog20210325.480382/full/>.

<sup>121</sup> Heidi L. Janz, “Ableism: The Undiagnosed Malady Afflicting Medicine,” *CMAJ : Canadian Medical Association Journal* 191, no. 17 (April 29, 2019): 478, <https://doi.org/10.1503/cmaj.180903>.

## CHAPTER 2—REORIENTING THE MORAL COMPASS OF PUBLIC HEALTH

The public health field has an obligation to value persons with disabilities as fully human and take “effective and appropriate measures” to remove barriers to prevent persons with disabilities from loving and being loved.<sup>122</sup>

The passage of the Americans With Disabilities Act and other laws protecting the rights of persons with disabilities does not mean that disability is now recognized as a normative way of being in American culture. The failure of the United States to sign on to the Convention on the Rights of Persons with Disabilities (CRPD) may serve as an example. While in many ways a symbolic document, the CRPD includes in its guiding principles respect for the inherent unity and freedom of persons with disabilities, and “[r]espect for difference and acceptance of persons with disabilities as part of human diversity and humanity.”<sup>123</sup>

The principles within the CRPD provide a lens into how public health discriminates against persons with disabilities. Two distinct forms of discrimination perpetrated by public health are failure to recognize as a normative way of being, and failure to recognize or address the intersectional determinants of health that lead to increased morbidity and mortality of persons with disabilities in BIPOC populations. By viewing disability as a nonnormative way of being, public health continues to promote

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<sup>122</sup> “Compendium of the Social Doctrine of the Church,” The Holy See, accessed January 20, 2019, [http://www.vatican.va/roman\\_curia/pontifical\\_councils/justpeace/documents/rc\\_pc\\_justpeace\\_doc\\_20060526\\_compendio-dott-soc\\_en.html#Creatures%20in%20the%20image%20of%20God](http://www.vatican.va/roman_curia/pontifical_councils/justpeace/documents/rc_pc_justpeace_doc_20060526_compendio-dott-soc_en.html#Creatures%20in%20the%20image%20of%20God).

<sup>123</sup> “Guiding Principles of the Convention,” Department of Economic and Social Affairs: Disability, United Nations, accessed April 3, 2022, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html>.

public policy that perpetuates discrimination even as it purports to advance health equity.

One might call this a sin of “omission.”

For example, public health prioritizes prevention of disability, while excluding prevention of secondary disabling conditions that result from social determinants of health. Social determinants of health (SDOH) “are the conditions in the environment where people are born, live, learn, work, play, worship, and age that affect a wide range of health functioning, and quality-of-life outcomes and risks.”<sup>124</sup> Social determinants of health include safe housing, transportation and neighborhood, racism, ableism, and discrimination. Stable access to nutritious food, participation in physical activities, and language literacy are social determinants of health. SDOH that facilitate positive health outcomes are inequitably available based on a person’s race, disability status, gender, sexual orientation etc. For persons who experience negative determinants of health, there is increased risk of heart disease, diabetes, obesity, isolation, and lower life expectancy.<sup>125</sup> Omitting social determinants of health in public health analysis makes the ongoing discrimination against persons with disabilities as a nonnormative population possible. Perhaps more disheartening is the disproportionate impact of public health’s priorities on persons with disabilities within BIPOC populations. As a result, people with disabilities from racial and ethnic minority populations face the compounding impact of systemic racism and ableism.

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<sup>124</sup> “Social Detriments of Health,” U.S. Department of Health & Human Services, <https://health.gov/healthypeople/priority-areas/social-determinants-health>.

<sup>125</sup> “Social Detriments of Health,” U.S. Department of Health & Human Services.

For example, one dynamic attributed to racism and other social determinants is that Blacks are more likely to undergo lower limb extremity amputation and African Americans and Latinos who have undergone lower limb amputation are at greater risk of mortality and morbidity compared with their white and non-Latino counterparts. These same populations are also more likely to experience loss of independence and lower quality of life, predictors of readmission and death post hospital discharge. Despite the increased risk of loss of independence and increased risk of mortality among Blacks and Latinos who have undergone lower limb habitation, public health still focuses primarily on prevention of disability (e.g., amputation) while not addressing conditions that lead to secondary disability and death.<sup>126</sup>

Persons with disabilities are identified as a priority population yet in practice do not receive the same level of attention as other populations in the literature and in policy priorities.<sup>127</sup> According to the 2019 National Institute on Minority Health and Health Disparities Research Framework, priority populations are “racial/ethnic minorities, socioeconomically disadvantaged populations, underserved rural populations, and sexual and gender minorities (which include lesbian, gay, bisexual, transgender, and gender-

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<sup>126</sup> Zachary Spiera et al., “Loss of Independence as a Metric for Racial Disparities in Lower Extremity Amputation for Diabetes: A National Surgery Quality Improvement Program (NSQIP) Analysis,” *Journal of Diabetes Complications* 36, no. 1 (2022): 1, <https://doi.org/10.1016/j.jdiacomp.2021.108105>.

<sup>127</sup> Gloria L. Krahn, Deborah Klein Walker, and Rosaly Correa-De-Araujo, “Persons with Disabilities as an Unrecognized Health Disparity Population,” *AJPH* 105, no. 2 (April 2015), <https://doi.org/10.2105%2FAJPH.2014.302182>; Nambi Ndugga and Samantha Artiga, “Disparities in Health and Health Care: 5 Key Questions and Answers,” Kaiser Family Foundation, May 11, 2021, <https://www.kff.org/racial-equity-and-health-policy/issue-brief/disparities-in-health-and-health-care-5-key-question-and-answers/>.

nonbinary or gender-nonconforming individuals).”<sup>128</sup> The Framework only includes disability status “as these factors which may interact with race/ethnicity, socioeconomic status, rural/urban status, and sexual or gender minority status to produce unique health determinants or health outcomes.”<sup>129</sup>

In its development as a social science field, public health has primarily focused on utilitarian outcomes by which public health is achieved through eliminating preventable death and disability.<sup>130</sup> The term “social justice” is ubiquitous in public health literature, but there is no clear definition of the meaning of health justice in addressing health inequities.<sup>131</sup> In fact, the literature shows that utilitarianism is far more normative in practice with the goal of public health being the reduction of death and disability.<sup>132</sup> This theoretical framework does not leave room for people living with disability. We saw this paradigm playing out in the violations of civil rights by public health bodies in how they dealt with the COVID pandemic.

A qualitative study of Canadian public health policymakers engaged in emergency preparedness and response (PHEPR) found that respondents formulated the

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<sup>128</sup> Jennifer Alvidrez et al., “The National Institute on Minority Health and Health Disparities Research Framework,” *American Journal of Public Health* 109, no. S1 (2019): 16–20, <https://doi.org/10.2105/ajph.2018.304883>.

<sup>129</sup> Alvidrez et al., “The National Institute,” S18.

<sup>130</sup> Brenda Appleby and Nuala P. Kenny, “Relational Personhood, Social Justice and the Common Good: Catholic Contributions towards a Public Health Ethics,” *Christian Bioethics: Non-Ecumenical Studies in Medical Morality* 16, no. 3 (2010): 298–299, <https://doi.org/10.1093/cb/cbq022>.

<sup>131</sup> Maxwell J. Smith, Alison Thompson, and Ross E. G. Upshur, “Public Health as Social Justice? A Qualitative Study of Public Health Policy-Makers’ Perspectives,” *Social Justice Research* 32, no. 1 (2019): 385–386, <https://doi.org/10.1007/s11211-019-00327-7>.

<sup>132</sup> Smith, Thompson, and Upshur, “Public Health as Social Justice?” 385–386.

goals and scope of their actions based on an assumption of scarcity with the intention of restoring the “status quo.”<sup>133</sup> Among study participants, social justice was identified as a constraint, or secondary to achieving the primary goal of returning to normative state.<sup>134</sup> Massachusetts residents are watching this utilitarian emphasis on “status quo” play out as policymakers reduce the hourly wages of personal care attendants (PCAs) in the state. The hourly wage of PCAs was raised during the state of emergency but will be reduced to the pre-pandemic hourly wage. This return to status quo leaves residents of Massachusetts who rely on PCAs to assist them with their activities of daily living struggling as the supply of PCAs continues to decline. In addition to harming persons with disabilities, the wage reduction also exacerbates the near-poverty conditions of PCAs who need to find work that will pay a living wage.

Despite its impact on minority populations, public health remains committed to a biomedical definition of wellness that emphasizes disability as a nonnormative way of being as key American ideals such as self-determination, are shaped by ableist bias. The persistent emphasis of public health on autonomy offers opportunity for self-determination to a segment of the disability population, but self-determination continues to be restricted to a very narrow biomedical framework of health.

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<sup>133</sup> Smith, Thompson, and Upshur, “Public Health,” 390–392.

<sup>134</sup> Smith, Thompson, and Upshur, 392–393.



This biomedical framework, emphasizing disability as a nonnormative way being, continues to shape health policy.<sup>135</sup> As a result, public health lacks an adequate strategy or framework to address injustices experienced by persons living with disability,<sup>136</sup> This less-than-whole person care model perpetuates “othering” and inequitable care to persons with disabilities.<sup>137</sup> Absence of attention to the distinct needs of persons with disabilities by policymakers is a direct form of “othering.”<sup>138</sup>

### **Biases Endemic in Biomedical Models**

Biomedical bias is evident in reproductive rights, prenatal screening, genetics, end-of-life decisions, and resource allocation within society at large and within healthcare. This bias is perhaps no more evident than in states like Massachusetts which have the most liberal reproductive rights laws in the country, laws that do not protect fetuses with disabilities. Among persons with disabilities, individuals with a history of a mental health diagnosis or trauma are subjected to distinctive forms of stigma, stereotyped as dangerous, violent, morally deficient, erratic, and incapable of participating in society.<sup>139</sup>

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<sup>135</sup> Katherine R. McDonald, William Gaventa, and Devan Stahl, “Public Health Ethics and Disability: Centering Disability Justice,” in *Public Health Perspectives on Disability* (New York: Springer, 2021), 131–132.

<sup>136</sup> Peña-Guzmán and Reynolds, “The Harm of Ableism.”

<sup>137</sup> Letty M. Russell, “Encountering the ‘Other’ in a World of Difference and Danger,” *The Harvard Theological Review* 99, no. 4 (2006): 457–68.

<sup>138</sup> Russell, 457.

<sup>139</sup> Lilavati Krishnan, “Social Exclusion, Mental Health, Disadvantage and Injustice,” *Psychology and Developing Societies* 27, no. 2 (September 1, 2015): 161, <https://doi.org/10.1177/0971333615594053>.

Biomedical degradation is becoming more sophisticated and impacting a wider range of persons with disabilities as it expands. Examples include the increasing number of states passing so-called “death with dignity laws.”<sup>140</sup> These laws are strongly opposed by the World Medical Association (WMA). In 2019 the MWA stated its opposition to any means that “deliberately enables the patient to end his or her own life by prescribing or providing medical substances with the intent to bring about death.”<sup>141</sup> Bioethicists and disability advocates agree that changes are needed at every level of the healthcare system, starting with integrating the perspectives and voices of persons with disabilities in the medical school curriculum.<sup>142</sup> Advocates rail against the hegemonic utilitarian devaluation of persons with disabilities yet too often ignore the spiritual dimension of human identity.<sup>143</sup>

Isolation and loneliness have been identified as the invisible enemy of persons with disabilities.<sup>144</sup> Persons with disabilities are more likely to experience emotional loneliness and social isolation than persons without disabilities.<sup>145</sup> Pathways through

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<sup>140</sup> “Death with Dignity Acts - States That Allow Assisted Death,” Death With Dignity, accessed September 3, 2021, <https://deathwithdignity.org/learn/death-with-dignity-acts/>.

<sup>141</sup> “WMA Declaration on Euthanasia and Physician-Assisted Suicide,” *World Medical Journal* 65, (November 2019): 22.

<sup>142</sup> Janz, “Ableism,” 479.

<sup>143</sup> Jackie Leach Scully, “Disability, Disablism, and COVID-19 Pandemic Triage,” *Journal of Bioethical Inquiry* 17 (2020), <https://doi.org/10.1007/s11673-020-10005-y>.

<sup>144</sup> Stephen J. Macdonald et al., “‘The Invisible Enemy’: Disability, Loneliness, and Isolation,” *Disability and Society* 33, no. 7 (2018): 1138–1159, <https://doi.org/10.1080/09687599.2018.1476224>.

<sup>145</sup> Eric Emerson et al., “Loneliness, Social Support, Social Isolation and Wellbeing among Working Age Adults with and without Disability: Cross-Sectional Study,” *Disability and Health Journal* 14, no. 1 (January 2021): 4, <https://doi.org/10.1016/j.dhjo.2020.100965>.

isolation and loneliness include living arrangements, employment status, and maintaining contact with family and friends.<sup>146</sup> Greater focus needs to be placed on disabling barriers to conceptualize how othering can lead to loneliness and isolation.

The COVID 19 pandemic has provided solid evidence of anti-disability bias in public health. Throughout the COVID 19 pandemic public health, in collusion with policymakers, violated or attempted to violate the human and civil rights of persons with disabilities. Despite repeated calls for attention to public health long before this pandemic, and a robust and growing body of literature on the challenges of chronic illness, high-risk health behavior, the importance of the socioeconomic determinants of health, and the interaction between health and the environment, public health has languished in the shadow of individual focused, cure-oriented, technologically driven health care.<sup>147</sup>

COVID-19 puts a spotlight on the epistemic injustice perpetrated by able-bodied policymakers. The disproportionate impact of COVID-19 on persons with disabilities clearly reflects the hierarchy of human value in public health. Policymakers exacerbated the disproportionate morbidity and mortality rate impacting persons with disabilities by advancing policies that would deny persons with disabilities access to care. Social constructs of disability are chief among the many reasons for the lack of critical and

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<sup>146</sup> Emerson et al., “Loneliness, Social Support, Social Isolation,” 4.

<sup>147</sup> Appleby and Kenny, “Relational Personhood,” 297.

informed attention to people with disability in this pandemic and in other catastrophic events.<sup>148</sup>

Too often persons with disabilities experience poorer quality of care from healthcare providers who, in their ableist healthcare perceptions of persons with disabilities, reflect and reinforce negative constructs of disability. As a consequence of the ableist culture in which they are raised and practice medicine, healthcare providers too often devalue persons with disabilities and provide lower quality of care when compared with other populations.<sup>149</sup> Implicit bias reduces the value of persons with disabilities based on an ableism and “objective” observation results in lower quality of care and potential or perpetuated harm.<sup>150</sup> The reductionistic approach to disability leads to the medicalization of wheelchairs, canes, feeding tubes, ventilators, equipment, and supplies that persons with disabilities use every day to perform daily living activities. Ableist healthcare defines wheelchairs, canes, and other devices as medical devices rather than facilitators of independence. This framework may have had catastrophic effects during COVID-19 when several states, including Massachusetts, sought to deny access to

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<sup>148</sup> “Concerns for People with Disability During COVID-19,” Berkley Center for Religion Affairs Peace and World, accessed June 18, 2021, [https://berkleycenter.georgetown.edu/responses/concerns-for-people-with-disability-during-covid-19?fbclid=IwAR3rdTH380QO0Ooc\\_RDz7Ez73JqANMWgUpf-XphgGcwVYcoG8taxY0nCY8Q](https://berkleycenter.georgetown.edu/responses/concerns-for-people-with-disability-during-covid-19?fbclid=IwAR3rdTH380QO0Ooc_RDz7Ez73JqANMWgUpf-XphgGcwVYcoG8taxY0nCY8Q).

<sup>149</sup> Janz, “Ableism,” 479; Janz, 478; Giulia Galli et al., “Don’t Look at My Wheelchair! The Plasticity of Longlasting Prejudice,” *Medical Education* 49, no. 12 (December 2015): 1239–47, <https://doi.org/10.1111/medu.12834>.

<sup>150</sup> Janz, “Ableism,” 478–479.

care and potentially deny people's ongoing use of ventilators using ableist, "objective," quality of life criteria.<sup>151</sup>

It is important to note how racism, homophobia, ageism, and other forms of bias can compound disparities impacting persons with disabilities. COVID-19 revealed the degree of systemic bias impacting African Americans and persons with disabilities and the compounding effects of intersectional discrimination.<sup>152</sup> For example, persons with disabilities, a disproportionate number of whom are African-American living in congregate settings such as nursing homes, have borne a disproportionate burden of morbidity and mortality resulting from COVID 19.<sup>153</sup> Practices put in place by policymakers that were considered to be "population neutral" were in fact discriminatory and in part responsible for the disproportionate impact of COVID on persons with disabilities, people of color, and other marginalized groups.<sup>154</sup> Perhaps the most egregious story of discrimination that emerged from the COVID-19 pandemic was that of Michael Hickson. Against the will of Mr. Hickson's wife, Hickson, a quadriplegic, was

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<sup>151</sup> "CPR and Partners File Second Complaint Regarding Illegal Disability Discrimination in Treatment Rationing During COVID-19 Pandemic," Center for Public Representation, accessed April 5, 2020, <https://www.centerforpublicrep.org/news/cpr-and-partners-file-second-complaint-regarding-illegal-disability-discrimination-in-treatment-rationing-during-covid-19-pandemic/>; "COVID-19 Medical Rationing & Facility Visitation Policies," Center for Public Representation, September 17, 2020, <https://www.centerforpublicrep.org/covid-19-medical-rationing/>.

<sup>152</sup> Priscilla Bustamante, Gaurav Jashnani, and Brett G. Stoudt, "Theorizing Cumulative Dehumanization: An Embodied Praxis of 'Becoming' and Resisting State-Sanctioned Violence," *Social and Personality Psychology Compass* 13, no. 1 (2019): 9, <https://doi.org/10.1111/spc3.12429>.

<sup>153</sup> Monica Verduzco-Gutierrez, Allan M. Lara, and Thiru M. Annaswamy, "When Disparities and Disabilities Collide: Inequities during the COVID-19 Pandemic," *PM&R*, 2, <https://doi.org/10.1002/pmrj.12551>.

<sup>154</sup> Manchanda, "Inequity in Crisis Standards of Care."

appointed an independent guardian and denied treatment after the physicians ruled that he had a “low quality of life.” Mr. Hickson died after being deprived of food and hydration for six days.<sup>155</sup>

Beyond COVID, bioethicists and disability advocates are now fighting against utilitarian constructs policymakers are using to determine who is worthy of accessing life-saving care.<sup>156</sup> Such methodologies determine the benefit of a medical intervention based on a person’s anticipated life expectancy and subjective evaluation of a person’s quality of life.<sup>157</sup> Policymakers, insurers, hospitals, and other corporations utilize an actuarial formula known as Quality-Adjusted Life Years (QALYs) to decide a person’s eligibility to receive a particular service or medication.<sup>158</sup> This methodology reflects ongoing biases against persons with disabilities as fully valued human beings.

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<sup>155</sup> “Examining How Crisis Standards of Care May Lead to Intersectional Medical Discrimination against Covid-19 Patients,” Center for Public Representation, 2, accessed October 3, 2022, <https://www.centerforpublicrep.org/wp-content/uploads/FINAL-Intersectional-Guide-Crisis-Care-PDF.pdf>.

<sup>156</sup> Janz, “Ableism,” 478–479; Mary Jo Iozzio, “Radical Dependence and the Imago Dei: Bioethical Implications of Access to Healthcare for People with Disabilities,” *Christian Bioethics: Non-Ecumenical Studies in Medical Morality* 23, no. 3 (December 2017): 234–60, <https://doi.org/10.1093/cb/cbx013>; Iezzoni et al., “Physicians’ Perceptions Of People With Disability And Their Health Care,” *Health Affairs* 40, no. 2 (February 1, 2021), <https://doi.org/10.1377/hlthaff.2020.01452>.

<sup>157</sup> Janz, 478.

<sup>158</sup> “What Is a QALY?” AUCD Policy Talk, November 8, 2019, <https://aucdpolicytalk.org/2019/11/08/what-is-a-qaly/>.

## **A Snapshot of Populations Impacted by Medical Bias**

### *Spinal Cord Injuries*

People with spinal cord injuries are categorized as “C3Bs,” one of the highest-need, highest-cost populations in One Care.<sup>159</sup> The costs are high because of the intensive medical, LTSS and HCBS needs.<sup>160</sup> As with other populations of persons with disabilities, physicians engage in transactional relationships with persons with spinal cord injuries. The physicians act as experts who view low-quality life as intrinsic to disability and substance misuse as an aspect of the disability. As a result, physicians do not discuss the unhealthy behavior directly with the individual, but instead focus on interventions that support family members.<sup>161</sup> The skewed view of medical providers towards disability can lead to individuals with disability having a reduced sense of agency and self-determination.<sup>162</sup>

### **Behavioral Health Diagnoses**

Another high-cost population are people with behavioral health diagnoses categorized as “C2Bs.” These are people with complex mental health or substance use disorders. People with schizophrenia and accompanying substance misuse who may be

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<sup>159</sup> Colleen Barry et al., “Early Insights from One Care: Massachusetts’ Demonstration to Integrate Care and Align Financing for Dual Eligible Beneficiaries - Issue Brief,” Kaiser Family Foundation, May 12, 2015, <https://www.kff.org/report-section/early-insights-from-one-care-massachusetts-issue-brief-8725/>.

<sup>160</sup> Barry et al., Early Insights from One Care.“

<sup>161</sup> Maggi A. Budd, Omar Sultan Haque, and Michael Ashley Stein, “Biases in the Evaluation of Self-Harm in Patients with Disability Due to Spinal Cord Injury,” *Spinal Cord Series and Cases* 6, no. 43 (May 27, 2020), <https://doi.org/10.1038/s41394-020-0293-6>; Budd, Haque, and Stein, Biases in the Evaluation of Self-Harm

<sup>162</sup> Budd, Haque, and Stein, 42.

homeless or at risk of homelessness and have a history of incarceration are among the enrollees in One Care. Because of the biomedical system and views of mental health and substance use as moral weakness, these populations face distinct barriers to health and wellness. The moral failing framework of behavioral health has led to stigma and the unjust social isolation of people with behavioral health needs and in turn distrust of the medical system.<sup>163</sup> Doctor and ethicist Michael Grodin points to “a social distaste for issues pertaining to mental health and disability” as one potential cause.<sup>164</sup> Gordon calls for a paradigm shift in public health approach to mental disability, away from a medical model to one that destigmatizes mental disability. Like so many other scholars, Gordon points to the utilitarian framing of disability that centers on a person’s ability to perform a task rather than the environmental barriers and facilitators of positive mental health.<sup>165</sup> Persons living with substance use disorder or having history of substance use disorder face similar or even more intense stigma as their substance use is viewed as criminal activity rather than a disabling condition.<sup>166</sup>

### **Persons with ID/DD**

Persons with intellectual and developmental disabilities (ID/DD) who have intensive medical and community needs are “carved out of One Care.” That is, because

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<sup>163</sup> Pollyanna Santos da Silveira et al., “The Stigmatization of Drug Use as Mechanism of Legitimation of Exclusion, in *Drugs and Social Context* Telmo Ronzani ed. (New York: Springer, 2018), 15, [https://doi.org/10.1007/978-3-319-72446-1\\_2](https://doi.org/10.1007/978-3-319-72446-1_2).

<sup>164</sup> Michael Grodin et al., eds., *Health and Human Rights in a Changing World*, 3rd ed. (New York: Routledge, 2013), 450, <https://doi.org/10.4324/9780203576298>.

<sup>165</sup> Grodin et al., *Health and Human Rights in a Changing World*, 451.

<sup>166</sup> Krishnan, “Social Exclusion, Mental Health, Disadvantage and Injustice,” 161.



advocates were concerned MA plans would not provide this group's required level of care and services needed to live in the community.<sup>167</sup> However there are people, people who are autistic who are enrolled in One Care. Autism Spectrum Disorder (ASD) is still not fully understood, and too often autistic people are perceived as “nonnormative” and “inferior.”<sup>168</sup> Adults with autism are likely to encounter healthcare providers without awareness of the complex nature of their multiple chronic health conditions or potential co-occurring behavioral health complications.<sup>169</sup> Misconceptions of autistic people result in denied access to reproductive and other services.<sup>170</sup>

### **Health and Economic Disparities among Persons with Disabilities**

By definition, the majority of people in One Care live at or below the poverty level. Given the research, it is not surprising that compared to persons without disabilities, persons with disabilities experience higher rates of depression and anxiety, are less likely to be physically active. As a result, persons with disabilities have higher occurrences of preventable morbidity and premature mortality rates than persons without

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<sup>167</sup> “Report to Congress on Medicaid and CHIP,” Medicaid and CHIP Payment and Access Commission, June 2021, 127–128, <https://www.macpac.gov/wp-content/uploads/2021/06/June-2021-Report-to-Congress-on-Medicaid-and-CHIP.pdf>.

<sup>168</sup> Laura R. Parker, Margo J. Monteith, and Susan C. South, “Dehumanization, Prejudice, and Social Policy Beliefs Concerning People with Developmental Disabilities,” *Group Processes & Intergroup Relations* 23, no. 2 (February 2020): 263, <https://doi.org/10.1177/1368430218809891>..“SAGE PDF Full Text,” 263, accessed August 8, 2021, <http://journals.sagepub.com/doi/pdf/10.1177/1368430218809891>.

<sup>169</sup> Lauren Bishop-Fitzpatrick and Eric Rubenstein, “The Physical and Mental Health of Middle Aged and Older Adults on the Autism Spectrum and the Impact of Intellectual Disability,” *Research in Autism Spectrum Disorders* 63 (2019): 9, <https://doi.org/10.1016/j.rasd.2019.01.001>.

<sup>170</sup> Natasha Malik-Soni et al., “Tackling Healthcare Access Barriers for Individuals with Autism from Diagnosis to Adulthood,” *Pediatric Research* 91 (2022): 1029–1030, <https://doi.org/10.1038/s41390-021-01465-y>.

disabilities. People with disabilities are also more likely to report poorer health than people with no disability, and five times more likely to report experiencing mental distress.<sup>171</sup>

People with disabilities are less likely to engage in healthy activities such as eating fresh fruits and vegetables or participating in physical activity.<sup>172</sup> They are more likely to be obese and engage in unhealthy activities such as smoking.<sup>173</sup> Other findings reveal substantial disparities in receipt of oral health care and tooth loss among people with disabilities compared to those without disabilities.<sup>174</sup>

Systems level othering includes violation of housing, education and communication rights by states and the federal government.<sup>175</sup> These violations keep persons with disabilities isolated in subpar institutional or impoverished settings, denying persons with disabilities the opportunity to live in the community and limiting their access to “less than equal” educational opportunities. Government entities inadequately

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<sup>171</sup> “Disability and Health Promotion,” Centers for Disease Control and Prevention, accessed March 27, 2022, <https://www.cdc.gov/ncbddd/disabilityandhealth/features/mental-health-for-all.html>.

<sup>172</sup> “Disability and Health Promotion.”

<sup>173</sup> “Disability and Health Overview,” Centers for Disease Control and Prevention, September 16, 2020, <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>; “Able-Bodied Public Health Statement: American’s Health Rankings,” United Health Foundation, accessed December 30, 2021, <https://www.americahealthrankings.org/explore/disparity>.

<sup>174</sup> Brian S. Armour et al., “A Profile of State-Level Differences in the Oral Health of People with and without Disabilities, in the US, 2004,” *Public Health Reports* 123, no. 1 (January-February 2008): 67–75, <https://doi.org/10.1177%2F003335490812300110>; “Able-Bodied Public Health Statement,” United Health Foundation.

<sup>175</sup> “Joint Statement on Maintaining the Least Restrictive Environment Requirements of the Individuals with Disabilities Education Act,” Center for Public Representation, July 18, 2019, <https://publicrep.wpengine.com/wp-content/uploads/2019/12/Joint-Statement-on-LRE.pdf>; “National Disability Policy: A Progress Report,” National Council on Disability, October 31, 2019, [https://ncd.gov/sites/default/files/NCD\\_Progress%20Report\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Progress%20Report_508.pdf).

resource services needed by persons with disabilities to live meaningful lives in the community and thereby fail to uphold their civil rights.

Despite these violations, the Department of Health and Human Services (HHS) is all but silent about health disparities impacting persons with disabilities.<sup>176</sup> Persons with disabilities are only found in a subsection of the HHS website identifying disability status as a poor health outcome impacting minority populations. The priorities listed exclude mention of persons with disabilities as a population disproportionately impacted by health disparities resulting from historical bias and discriminatory practice.<sup>177</sup> Disparities resulting from structural discrimination and bias include poverty and inadequate access to safe living environments, transportation and education opportunities, and healthcare, resulting in poorer health outcomes than persons without disability.<sup>178</sup> It's important to note that disparities resulting from ableism are exacerbated at the intersectional level of identity-based discrimination e.g. racism, xenophobia, homophobia and transphobia.

Over an 11–12 year period, longitudinal research conducted by the CDC examined specific causes of death among different populations.<sup>179</sup> The research found that “adults with any disability were more likely to die of heart disease, cancer,

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<sup>176</sup> “Home Page—Office of Minority Health,” OMH, accessed September 9, 2019, <https://minorityhealth.hhs.gov/Default.aspx>.

<sup>177</sup> “Discrimination on the Basis of Disability,” U.S. Department of Health and Human Services, August 14, 2007, <https://www.hhs.gov/civil-rights/for-individuals/disability/index.html>.

<sup>178</sup> “Health Equity for People with Disabilities,” Centers for Disease Control and Prevention, June 23, 2021, <https://www.cdc.gov/ncbddd/humandevelopment/health-equity.html>.

<sup>179</sup> Valerie L. Forman-Hoffman et al., “Disability Status, Mortality and Leading Causes of Death in the United States Community Population,” *Medical Care* 53, no. 4 (2015): 346–354, <https://doi.org/10.1097%2FMLR.0000000000000321>.

cerebrovascular diseases, chronic lower respiratory diseases, unintentional accidents, and suicide or assaults than those without any disability.”<sup>180</sup> Based on the importance of disparities identified in the research results, the CDC recommended public health officials prioritize prevention strategies to reduce disparities in mortality rates disproportionately impacting persons with disabilities.<sup>181</sup>

People with disabilities are far more likely to be unemployed, earn lower wages and live in poverty compared with people without disabilities. Education rates among persons with disabilities are lower than persons without disabilities at the high school and even lower college-levels.<sup>182</sup> Persons with disabilities are also more likely to be victims of violence, abuse, or neglect than persons without disabilities. Persons with disabilities have higher levels of health care utilization and cost.<sup>183</sup> Working-age persons with disabilities who have higher Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL) needs also have higher use of prescription medications, mental health visits, and emergency department utilization.<sup>184</sup> This population is also more likely than the general population to have unmet healthcare needs.<sup>185</sup>

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<sup>180</sup> Forman-Hoffman et al., “Disability Status,” 6.

<sup>181</sup> Centers for Disease Control and Prevention, “Strategies for Reducing Health Disparities—Selected CDC-Sponsored Intervention, United States, 2016,” *Morbidity and Mortality Weekly Report* 65, no. 1 (February 12, 2016), <https://www.cdc.gov/mmwr/volumes/65/su/pdfs/su6501.pdf>.

<sup>182</sup> “2018 Annual Report of People with Disabilities in America,” Institute on Disability at the University of New Hampshire, 2019, 2–14, [https://disabilitycompendium.org/sites/default/files/user-uploads/Annual\\_Report\\_2018\\_Accessible\\_AdobeReaderFriendly.pdf](https://disabilitycompendium.org/sites/default/files/user-uploads/Annual_Report_2018_Accessible_AdobeReaderFriendly.pdf).

<sup>183</sup> Gulley, Rasch, and Chan, “The Complex Web of Health,” 500.

<sup>184</sup> Reichard et al., “Diagnosis Isn’t Enough,” 544.

<sup>185</sup> Reichard et al., “Prevalence and Reasons for Delaying and Foregoing Necessary Care,” 39.

Addressing the social determinants of health that lead to disparities in morbidity and mortality is a public health priority. A recent study on the intersection of race and disability found that racial disparities among people with disabilities were solely the result of earlier onset of disability in African Americans, which impacts their ability to carry out ADL/IADLs. Black women experience a more rapid decline in function than other groups within the same working-age range.<sup>186</sup> African Americans are disproportionately impacted by brain and spinal cord injuries.<sup>187</sup> They have the highest death rates from traumatic brain injuries and experience spinal cord injuries almost two times the level of their share of the general population since 2000.<sup>188</sup>

Black indigenous people of color (BIPOC) as a group are receiving increasing attention. However, the needs of persons with disabilities who identify as members of a BIPOC group or other population, e.g., LGBTQ communities, do not get the same level of attention. For example, the 2019 National Institute on Minority Health and Health Disparities Research Framework identifies “racial/ethnic minorities, socioeconomically disadvantaged populations, underserved rural populations, and sexual and gender minorities (which include lesbian, gay, bisexual, transgender, and gender-nonbinary or

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<sup>186</sup> David F. Warner and Tyson H. Brown, “Understanding How Race/Ethnicity and Gender Define Age-Trajectories of Disability: An Intersectionality Approach,” *Social Science & Medicine* 72, no. 8 (April 1, 2011): 1245–46, <https://doi.org/10.1016/j.socscimed.2011.02.034>.

<sup>187</sup> “Profiles of Medicaid’s High Cost Populations,” The Kaiser Commission on Medicaid and the Uninsured, accessed August 5, 2021, 23, <https://www.kff.org/wp-content/uploads/2013/01/7565.pdf>.

<sup>188</sup> “Profiles of Medicaid’s High Cost Populations,” 23.

gender-nonconforming individuals)” as priority populations.<sup>189</sup> The Framework only includes disability status as a factor which may interact with “race/ethnicity, socioeconomic status, rural/urban status, and sexual or gender minority status to produce unique health determinants or health outcomes.”<sup>190</sup>

## **Public Health and Spirituality**

### *Religion and Spirituality as Social Determinants of Health*

There is increasing evidence that religion and spirituality are key social determinants of health.<sup>191</sup> Religious practice can be an effective way of promoting and maintaining a healthier lifestyle and well-being<sup>192</sup> Persons who attend religious services at least weekly are more likely to experience greater life satisfaction, a greater sense of mission, greater sense of forgiveness and engage in volunteering compared with persons who never attend religious services.<sup>193</sup> Persons who engage in spiritual practices such as prayer or meditation on a daily basis have greater capacity to engage in emotional expression and emotional processing, and like those who regularly attend

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<sup>189</sup> Krahn, Walker, and Correa-De-Araujo, Persons with Disabilities as an Unrecognized Health Disparity Population 198; Ndugga and Artiga, “Disparities in Health and Health Care”; Alvidrez et al., “The National Institute on Minority Health,” 16–20.

<sup>190</sup> “HHS Action Plan to Reduce Racial and Ethnic Health Disparities: A Nation Free of Disparities in Health and Healthcare,” U.S. Department of Health & Human Services, accessed March 22, 2022, [https://www.minorityhealth.hhs.gov/assets/pdf/hhs/HHS\\_Plan\\_complete.pdf](https://www.minorityhealth.hhs.gov/assets/pdf/hhs/HHS_Plan_complete.pdf).

<sup>191</sup> Ying Chen, and Tyler J. VanderWeele, “Associations of Religious Upbringing with Subsequent Health and Well-Being From Adolescence to Young Adulthood: An Outcome-Wide Analysis,” *American Journal of Epidemiology* 187, no. 11 (November 2018): 2363, <https://doi.org/10.1093/aje/kwy142>.

<sup>192</sup> Chen and VanderWeele, “Associations of Religious Upbringing,” 2361.

<sup>193</sup> Chen and VanderWeele, 2357.

religious services have a higher sense of mission, and embrace forgiveness, compared to persons who do not pray or meditate.

Persons who engage in these practices may also have greater life satisfaction, self-esteem, and partake in civic activities compared to persons who do not meditate or pray. Those who regularly attend religious services or pray or meditate are less likely to use tobacco, less likely to experience depressive symptoms, and engage with fewer sexual partners over their lifetime.<sup>194</sup> It should also be noted that frequent engagement in prayer or meditation may be associated with physical health problems. Still, this relationship is probably more reflective of a population of persons with physical health problems who engage in prayer and meditation to manage those health problems.<sup>195</sup>

Despite this evidence incorporating over 3000 empirical studies and hundreds of systematic reviews of spirituality and religion,<sup>196</sup> public health research continues to ignore spirituality and religion as key factors impacting health and wellness. “[T]o its own detriment, the field of public health has ignored a proverbial elephant in the room,” empirical evidence that links spirituality and religion to health both as a facilitator and barrier.<sup>197</sup> At the same time, public health also has a long history of dehumanizing and

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<sup>194</sup> Monica Verduzco-Gutierrez, Allan M. Lara, and Thiru M. Annaswamy, “When Disparities and Disabilities Collide: Inequities during the COVID-19 Pandemic,” *PM&R*, 2, <https://doi.org/10.1002/pmrj.12551>.

<sup>195</sup> Priscilla Bustamante, Gaurav Jashnani, and Brett G. Stoudt, “Theorizing Cumulative Dehumanization: An Embodied Praxis of ‘Becoming’ and Resisting State-Sanctioned Violence,” *Social and Personality Psychology Compass* 13, no. 1 (2019): 9, <https://doi.org/10.1111/spc3.12429>.

<sup>196</sup> Doug Oman, *Why Religion and Spirituality Matter for Public Health: Evidence, Implications, and Resources* (Cham, Switzerland: Springer International Publishing, 2018), 336.

<sup>197</sup> Oman, 339, 350.

alienating persons with disabilities. Mass institutionalized, sterilized, and selectively aborted, persons with disabilities are deemed defective and unworthy of life. There is continued institutionalization of persons with disabilities throughout the United States violates the Americans with Disabilities Act and Olmstead agreement.<sup>198</sup>

Pope Francis speaks of persons with disabilities as “hidden exiles” who are treated as foreign bodies in society.”<sup>199</sup> Persons with disabilities are not seen as having “value to be cared for and respected.”<sup>200</sup> He reminds us that “[m]any persons with disabilities “feel that they exist without belonging and without participating.”<sup>201</sup> Central to the thesis of this Dmin project, Pope Francis also tells us that liberation of persons with disabilities must go beyond providing care. Liberation includes an obligation to ensure persons with disabilities can fully participate “in the civil and ecclesial community.”<sup>202</sup>

The CDC outlines the following recommendations in addressing the health needs of persons with disabilities: develop strategies to reduce the risk of premature death

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<sup>198</sup> “The Current ADA Regulations,” ADA.gov, accessed January 11, 2022, [https://www.ada.gov/2010\\_regs.htm](https://www.ada.gov/2010_regs.htm); “Olmstead V. LC: History and Current Status,” Olmstead Rights, accessed January 11, 2022, <https://www.olmsteadrights.org/about-olmstead/>; “Justice Department Reaches Landmark Settlement Agreement with the State of Oregon Regarding Americans with Disabilities Act,” The United States Department of Justice, December 30, 2015, <https://www.justice.gov/opa/pr/justice-department-reaches-landmark-settlement-agreement-state-oregon-regarding-americans>; “Olmstead: Community Integration for Everyone,” ADA.gov, accessed January 11, 2022, [https://www.ada.gov/olmstead/olmstead\\_cases\\_list2.htm](https://www.ada.gov/olmstead/olmstead_cases_list2.htm); “Special Litigation Section Cases and Matters: Disability Rights Docket,” The United States Department of Justice, accessed January 11, 2022, <https://www.justice.gov/crt/special-litigation-section-cases-and-matters/download#disability>.

<sup>199</sup> Francis, “Fratelli Tutti of the Holy Father, on Fraternity and Social Friendship,” The Holy See, October 3, 2020, 98, [https://www.vatican.va/content/francesco/en/encyclicals/documents/papa-francesco\\_20201003\\_enciclica-fratelli-tutti.html](https://www.vatican.va/content/francesco/en/encyclicals/documents/papa-francesco_20201003_enciclica-fratelli-tutti.html).

<sup>200</sup> Francis, 18.

<sup>201</sup> Francis, 18.

<sup>202</sup> Francis, 18.



among adults with disabilities by addressing their poorer health in comparison to adults without disabilities; realize that healthcare, health promotion and preventive services must be designed so they can effectively meet the needs of persons with disabilities; improve availability and access to behavioral health prevention services and interventions; and further prioritize addressing the needs of persons with disabilities who are seriously ill to ensure delivery of timely and appropriate care.<sup>203</sup> However, the CDC recommendations do not speak to the importance of religion or spiritual care.

Health emergencies as we have experienced with COVID 19 “demand more than fair distribution of resources . . . A failure to act expeditiously and with equal concern for all citizens, including the poor and less powerful . . . signals to those affected and to everyone else that the basic human needs of some matter less than those of others, and it thereby fails to show the respect due to all members of the community.”<sup>204</sup> COVID 19 has made clear that public health ethics must shift away from an individualistic understanding of personhood to a more relational framework that recognizes health is impacted by “systems of privilege, disadvantage and discrimination.”<sup>205</sup> Beyond individualism, public health must be more firmly grounded in a relational health

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<sup>203</sup> “Key Findings: Disability Status, Mortality, and Leading Causes of Death in the United States Community Population,” Centers for Disease Control and Prevention, accessed January 9, 2022, <http://medbox.iiab.me/modules/en-cdc/www.cdc.gov/ncbddd/disabilityandhealth/features/disabilitystatus.html>.

<sup>204</sup> Lawrence O. Gostin, and Madison Powers. “What Does Social Justice Require for the Public’s Health? Public Health Ethics and Policy Imperatives,” *Health Affairs* 25, no. 4 (July-August 2006): 1058–1059, <https://doi.org/10.1377/hlthaff.25.4.1053>.

<sup>205</sup> Appleby and Kenny, “Relational Personhood,” 299.

framework and valuing human identity as one of mutual vulnerability and interdependence.

Pope Francis reminds us of the importance of upholding the value of persons with disabilities who have no value in a market-driven society ruled by utility and efficiency. In making clear the absurdity of expecting persons with disabilities to compete in a market-driven economy, Pope Francis shines a spotlight on the social impactors that dehumanize persons with disabilities and lead to their marginalization and poorer health outcomes. To be of value, the public health framework must embrace Pope Francis's commitment to direct action that advances the rights and personhood of persons with disabilities. Who unlike other groups need action by the government to recognize their freedom.<sup>206</sup> Public health advocates must have the courage "to give a voice to those who are discriminated against due to their disability, because sadly . . . even today, people find it hard to acknowledge them as persons of equal dignity."<sup>207</sup>

### **Correcting Anti-Spiritual Bias in Public Health**

In contrast, leaders in the field of spirituality, religion and healthcare Arndt Bussing and Harold G. Koenig describe how comprehensive health assessment instruments which cover physical, psychological, social and other needs are "remarkable" in their overt absence of collecting information on a person's "spiritual and existential"

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<sup>206</sup> Francis, "Fratelli Tutti of the Holy Father," 109.

<sup>207</sup> Francis.

needs.<sup>208</sup> According to Bussing and Koenig, by analyzing the categories of spiritual need, it is possible to identify “four (interconnected) core dimensions, i.e., Connection, Peace, Meaning/Purpose, and Transcendence, which can be attributed to the underlying categories of social, emotional, existential, and religious.”<sup>209</sup> As such, it is imperative that social justice advocates move policymakers and healthcare entities to take seriously and act on their responsibility “to safeguard and promote human dignity.”<sup>210</sup>

Persons should be provided the opportunity to develop the ability to better understand “the fullness of being, to the unlimited horizon of being.”<sup>211</sup> This includes developing the ability to understand the existence “as an ‘I’ capable of self-understanding, self-possession and self-determination.”<sup>212</sup> In practice, a person’s annual assessment and care planning process should include a spiritual care assessment, an offer of a chaplain to participate as a member of the person’s care team, and information about chaplaincy services to support the person’s ability to make an informed decision.

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<sup>208</sup> Harold G. Koenig, James N. Kvale, and Carolyn Ferrell, “Religion and Well-Being in Later Life,” *The Gerontologist* 28, no. 1 (February 1, 1988): 18–28, <https://doi.org/10.1093/geront/28.1.18>; Harold G. Koenig, D. B. Larson, and D. A. Matthews, “Religion and Psychotherapy with Older Adults,” *Journal of Geriatric Psychiatry* 29, no. 2 (1996): 155–84; Harold G. Koenig, M. E. McCullough, and D. B. Larson, *Handbook of Religion and Health* (Oxford, UK: Oxford University Press, 2001).

<sup>209</sup> Arndt Büssing and Harold G. Koenig, “Spiritual Needs of Patients with Chronic Diseases,” *Religions* 1, no. 1 (December 2010): 20, <https://doi.org/10.3390/rel1010018>.

<sup>210</sup> “Compendium of the Social Doctrine of the Church,” 145.

<sup>211</sup> “Compendium of the Social Doctrine of the Church,” 130.

<sup>212</sup> “Compendium of the Social Doctrine of the Church,” 131.

Persons with disabilities bear an “existential burden” that impacts their quality of life.<sup>213</sup> A study of persons with amputations found existential spirituality to be a key indicator of long-term overall health and life satisfaction. The study’s authors suggested that existential spirituality can be a mediator that supports improved health and well-being. While the connection of spirituality, existential meaning and quality of life is complex, it is an important aspect of human identity requiring increased attention.<sup>214</sup> It is posited that unmet existential needs may lead to substance use disorders, obesity and other addictive disorders.<sup>215</sup> Spiritual needs may also manifest in “undifferentiated illness.”<sup>216</sup> Undifferentiated illness can be expressed in a general sense of loss of well-being, depression or anxiety.<sup>217</sup> Increasingly research is providing evidence that having a long-term chronic condition is independently correlated with a decrease in value placed on the ability to carry out occasional daily living and an increase in the value placed on spiritual or existential meaning.<sup>218</sup>

Despite evidence of a positive correlation between religion, spirituality, improved health outcomes, and overall wellness, there is little to no integration of spirituality in

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<sup>213</sup> Mark R. Luborsky, “The Cultural Adversity of Physical Disability: Erosion of Full Adult Personhood,” *Journal of Aging Studies* 8, no. 3 (1994): 258, [https://doi.org/10.1016/0890-4065\(94\)90002-7](https://doi.org/10.1016/0890-4065(94)90002-7).

<sup>214</sup> Amanda H. Peirano and Randall W. Franz, “Spirituality and Quality of Life in Limb Amputees,” *International Journal of Angiology* 21, no. 1 (March 2012): 51, <https://doi.org/10.1055/s-0032-1304275>.

<sup>215</sup> Gordon W. Macdonald, “Primary Care Chaplaincy: an Intervention for Complex Presentation,” *Primary Health Care Research & Development* 20 (2019): 1–2, <https://doi.org/10.1017/S1463423618000737>.

<sup>216</sup> Macdonald, “Primary Care Chaplaincy,” 2.

<sup>217</sup> Macdonald, 2.

<sup>218</sup> Huber et al., “Towards a ‘Patient-Centred’ Operationalisation,” 10.

healthcare.<sup>219</sup> A major challenge to integrating spiritual care is the lack of a definitive understanding of spirituality.<sup>220</sup> There is consensus that spirituality is correlated with an individual's sense of being and the ability to identify existential meaning. Religious persons may interpret existential meaning in religious or spiritual terms while atheists or nonspiritual persons may interpret existence through an existential and humanistic framework.<sup>221</sup>

The health Insurance industry prioritizes care efficiency, too often disregarding the person's spiritual needs.<sup>222</sup> Public and private insurers provide limited access to spiritual care, overlooking the value of spiritual care in the person's ability to achieve wellness. Feminist writer Aida Hurtado points to the hegemonic powers that dismiss spirituality as essential in shaping a socially just society.<sup>223</sup> Denied spiritual sustenance, a person's physical and psychological health may suffer. As described by Hurtado,

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<sup>219</sup> Wilfred McSherry, Adam Boughey, and Peter Kevern, "'Chaplains for Wellbeing' in Primary Care: A Qualitative Investigation of Their Perceived Impact for Patients' Health and Wellbeing," *Journal of Health Care Chaplaincy* 22, no. 4 (October 1, 2016): 151, 152, <https://doi.org/10.1080/08854726.2016.1184504>; Büssing and Koenig, "Spiritual Needs of Patients with Chronic Diseases," 24.

<sup>220</sup> Chitra G. Paul Victor, and Judith V. Treschuk, "Critical Literature Review on the Definition Clarity of the Concept of Faith, Religion, and Spirituality," *Journal of Holistic Nursing* 38, no. 1 (March 2020): 109–111, <https://doi.org/10.1177/0898010119895368>; Seyedeh Zahra Nahardani et al., "Spirituality in Medical Education: A Concept Analysis," *Medicine, Health Care and Philosophy* 22, no. 2 (2019): 181–182, <https://doi.org/10.1007/s11019-018-9867-5>; Patricia Boston, Anne Bruce, and Rita Schreiber, "Existential Suffering in the Palliative Care Setting: An Integrated Literature Review," *Journal of Pain and Symptom Management* 41, no. 3 (March 2011): 615–616, <https://doi.org/10.1016/j.jpainsymman.2010.05.010>.

<sup>221</sup> Büssing and Koenig, "Spiritual Needs of Patients with Chronic Diseases," 20.

<sup>222</sup> McSherry, Boughey, and Kevern, "'Chaplains for Wellbeing' in Primary Care," 1, 2; Büssing and Koenig, "Spiritual Needs of Patients with Chronic Diseases," 24.

<sup>223</sup> Anna-Leila Williams, "Perspectives on Spirituality at the End of Life: A Meta-Summary," *Palliative and Supportive Care* 4, no. 4 (December 2006): 407–117, <https://doi.org/10.1017/S1478951506060500>.

“[d]enial of emotion, spiritual needs, and nurturance lead to both physical ailments as well as social destruction.”<sup>224</sup>

Further, there is a shortage of literature on community-based spiritual care needs of persons with long-term complex disabilities and social needs. There is existing research on the benefits of chaplaincy care for persons with developmental disabilities, but a review of the existing literature reveals little to no information on the spirituality or spiritual needs of persons with physical disabilities between the ages of 21 and 64.<sup>225</sup> In general, research on the needs of persons with disabilities focuses on gaps in community-based services needed by the population to carry out ADLs including eating, bathing, dressing, and IADLs like cooking and shopping.<sup>226</sup>

The failure to make chaplaincy services available to persons with disabilities living in the community perpetuates the ongoing binary view of health and wellness solely as physical and psychological. Absent is the spiritual component. Gaventa writes, “patient-centered planning that does not include spirituality is not patient-centered planning.”<sup>227</sup> Spiritual care should not be limited to hospitals or, palliative or hospice

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<sup>224</sup> Aída Hurtado, “Theory in the Flesh: Toward an Endarkened Epistemology,” *International Journal of Qualitative Studies in Education* 16, no. 2 (March 2003): 217, <https://doi.org/10.1080/0951839032000060617>.

<sup>225</sup> Cis Vrijmoeth et al. “Physicians’ Identification of the Need for Palliative Care in People with Intellectual Disabilities,” *Research in Developmental Disabilities* 59 (December 1, 2016): 55–64, <https://doi.org/10.1016/j.ridd.2016.07.008>; Hodge and Reynolds, “Spirituality among People with Disabilities,” 81.

<sup>226</sup> Monika Mitra et al., “Unmet Needs for Home and Community-Based Services among Persons with Disabilities in Massachusetts,” *Disability and Health Journal* 4, no. 4 (October 1, 2011): 219–228, <https://doi.org/10.1016/j.dhjo.2011.08.003>.

<sup>227</sup> William Gaventa, “Transcript of ‘Hidden in Plain Sight - Spirituality, Disability, and Wholeness,’” Boston College, November 8, 2019,

care. Spiritual care must be understood as integral to a truly patient-centered planning and goal setting process.

### **The Two Sides of Religion and Spirituality**

While this project focuses on religion and spirituality as resiliency factors, it is also important to note that religion and spirituality can negatively impact health. Religion is a social construct that impacts morbidity and mortality rates at the individual and population levels. It can serve as a source of social capital that promotes public health. For example, the Greater Boston Interfaith Organization (GBIO) addresses equity issues by advocating for reductions in prescription drug prices and increasing access to affordable mental health and substance use disorder (SUD) services.<sup>228</sup> At the same time, religion can also be a cause of harm by shaping normative practice in a manner that is destructive to public health. We see this in Christian nationalists' response to preventative measures such as wearing masks and getting vaccinations, because they believe COVID 19 is one of several blights brought upon this country by God to bring us back to our moral roots.<sup>229</sup>

Religion and spirituality can also be destructive at the individual level. Many conservative religious people blame themselves when they become ill or believe

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<https://www.bc.edu/content/dam/bc1/schools/stm/continuing%20education/encore/pdf/TranscriptGaventa-11.8.19.pdf>.

<sup>228</sup> "Health Care," Greater Boston Interfaith Organization, accessed February 15, 2021, <https://www.gbio.org/health-care.html>.

<sup>229</sup> Samuel L. Perry, Andrew L. Whitehead, and Joshua B. Grubbs, "Culture Wars and COVID-19 Conduct: Christian Nationalism, Religiosity, and Americans' Behavior During the Coronavirus Pandemic," *Journal for the Scientific Study of Religion* 59, no. 3 (2020): 406–407, <https://doi.org/10.1111/jssr.12677>.

disability itself is a result of sin. Nonreligious persons may perceive illness or disability as caused by unhealthy attitudes or mindsets resulting in illness or disability.<sup>230</sup>

In his seminal work about the disability rights movement in the United States and abroad, *Nothing About Us Without Us*, James Charlton identifies several sources that shape attitudes about disability: religion, language, and the body (or body image).<sup>231</sup> He highlights religion's negative impact on societal perceptions of disability by linking it with sinfulness and emphasizing disability as a means of atonement for sin or attainment of rewards to come in the afterlife.<sup>232</sup> Institutional religion, having squeezed persons with disabilities into these two categories, fosters a sense of passivity and acceptance of oppression from which salvation will be attained in the next life.<sup>233</sup>

Given the negative role of religion in contributing to stigma and discrimination of persons with disabilities, it is incumbent on chaplains to advance a healthier framing of religion by taking on both the doctrinal and the institutional sins of religious institutions that have harmed persons with disabilities as active liberative praxis. As representatives of institutional religions, chaplains are uniquely positioned to bring healing to persons with disabilities most directly harmed by negative religious practice and teachings on disability.

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<sup>230</sup> Donald Moss, "The Circle of the Soul: The Role of Spirituality in Health Care," *Applied Psychophysiology and Biofeedback* 27, no. 4 (2003): 280, <http://dx.doi.org/10.1023/A:1021013502426>.

<sup>231</sup> James I. Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment*, 1<sup>st</sup> ed. (Berkeley, CA: University of California Press, 1998), 55.

<sup>232</sup> Charlton, *Nothing About Us Without Us*, 55–56.

<sup>233</sup> Charlton, 65.



## Disability and the Denial of Imago Dei

“Though change beckons slowly and similar to recognition of the scourge of racism and sexism, ableism persists in an as yet decidedly ableist hermeneutic. However, like women and people of color, people with disability are “people first” and, as people, they too are created in the image and likeness of God.”<sup>234</sup>

So God created humanity in their own image, in their own image, God created them; male and female God created them.<sup>235</sup>

What we know about the nature of imago Dei is shared with us in Scripture<sup>236</sup> and interpreted by theologians ranging from Augustine of Hippo to Thomas Aquinas to more recent theologians such as Mary Jo Iozzio. Understanding the image of God as a dynamic interdependent relationship provides opportunity for people with disabilities to be identified as the image of God through their way of being rather than through their intellectual capacity or physical attributes.

Jesus replied: “‘Love the Lord your God with all your heart and with all your soul and with all your mind.’ This is the first and greatest commandment. And the second is like it: ‘Love your neighbor as yourself.’ All the Law and the Prophets hang on these two commandments.”<sup>237</sup>

In giving these commandments, Jesus shapes the imago Dei as right relationship in which loving God and loving neighbor are the means to fully realize our identities as made in God’s image. Love is not passive, but relational and the words of Jesus point to the interdependent nature of God and humans as imago Dei. In this paradigm disability,

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<sup>234</sup> “Concerns for People with Disability During COVID-19,” Berkley Center for Religion, Peace and World Affairs.

<sup>235</sup> Gen 1:27 (NIV).

<sup>236</sup> Gen 1:26–27; Ps 139:14–18; Rom 8:29; 1 Cor 11:7, 15:49; 2 Cor 3:18, 4:16; Eph 4:23–24; Col 3:9–10.

<sup>237</sup> Matt 22:37–40.

rather than being a flaw, is an opportunity for right relationship and appreciation of the image of God that transcends physical likeness. As eloquently stated by Reynolds in his book *Vulnerable Communion*, “Full personhood is neither diminished by disability nor confirmed by ability. Instead, it is a factor of the interdependent relationships we share with one another as creatures loved into being by God in the image of God. . . .

Personhood lies in being affirmed by God as a dependent creature loved into being with others.”<sup>238</sup> As articulated in 1 John, our humanity, our call to love is because we were first loved.<sup>239</sup>

### **Imago Dei as Trinity: A Theology of Disability**

Feminist disability theologians are putting forward a counter narrative of personhood as imago Dei. Therese Marie Ignacio Bjoernaas argues, “traditional theology and contemporary social ideology have deprived people with disabilities of their dignity and prevented them from flourishing. . . . by defining the soul as disembodied, rational, and autonomous.”<sup>240</sup> Bjoernaas also describes how the medical model “evokes the principles of the rational imago Dei.”<sup>241</sup> The medical model reduces human identity to either being normal or abnormal. In this framework, persons with disabilities are not whole and therefore need to be fixed. The medical model’s denial of personhood to

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<sup>238</sup> Reynolds, *Vulnerable Communion*, 186.

<sup>239</sup> 1 John 19.

<sup>240</sup> Bjoernaas, 284.

<sup>241</sup> Bjoernaas, 284.

persons with cognitive disabilities is rooted in the misguided dependency of imago Dei as rational rather than relational.<sup>242</sup>

The layers of public health discrimination and social discrimination are overlaid to make persons with disabilities feel as though they are not embodying imago Dei. The othering of persons with disabilities that happens because of this discrimination leads to the denial of people with disabilities as created in the image and likeness of God.

The goal of my proposed intervention is to reduce the impact of bias and discrimination against persons with disabilities in One Care. The secondary goal is to advance a model for spiritual care that can be replicated in other healthcare systems.

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<sup>242</sup> Bjoernaas, 284.

### CHAPTER 3—SPIRITUALITY AND WHOLE-PERSON CARE

The word “spiritual” describes courses of action taken by people that are motivated by relational experiences.<sup>243</sup> Religion is more than just a set of spiritual beliefs or broader concept of spirituality. As with other social determinants, religion is about habitus. It includes daily routines and annual rituals to mark the seasons: Diwali, the Hindu festival of lights is celebrated in late fall/early winter and the Jewish feast of Passover commemorating liberation of the Israelites from Egypt is celebrated in the spring. Other practices commemorate significant moments in a family or community—birth, marriage, and death. Infant baptism in Christianity marks a baby’s entrance into the Christian community; in India, the Islamic pre-wedding ritual of Salat ul Ishtikara is a prayer conducted by the Imam asking Allah’s blessings over the marriage of a couple. Spirituality is a broad concept that attempts to capture the human experience of meaning and transcendence.<sup>244</sup>

In his article “Lessons from Suffering: How Social Justice Informs Spirituality,” John Powell describes social justice as a “practice and development of spirituality.”<sup>245</sup> He proclaims social justice to be a “recursive relationship the runs in both directions.”<sup>246</sup> In other words, our own ontological suffering and the social suffering of the other bring

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<sup>243</sup> Paul R. Dokecki, J. R. Newbrough, and Robert T. O’Gorman, “Toward a Community-Oriented Action Research Framework for Spirituality: Community Psychological and Theological Perspectives,” *Journal of Community Psychology* 29, no. 5 (2001): 497–518, <https://doi.org/10.1002/jcop.1033>.

<sup>244</sup> Kaye and Raghavan, “Spirituality in Disability and Illness,” 232.

<sup>245</sup> John A. Powell, “Lessons from Suffering: How Social Justice Informs Spirituality,” *University of St. Thomas Law Journal* 1, no. 1 (2003): 102, <https://ir.stthomas.edu/ustlj/vol1/iss1/7/>.

<sup>246</sup> Powell, “Lessons from Suffering,” 102.

about spiritual transformation for all involved. Humanist and existential theorist Viktor Frankl viewed spirituality as a quest for meaning in one's life and, for many, a transcendent meaning. To possess meaning is to have a sense of purpose for one's life regardless of circumstance. As Frankl wrote, "Truly, there is a healing force in meaning."<sup>247</sup> To have meaning is to reach out beyond oneself to encounter other human beings in love. This search for meaning is an existential quest. It is a search for human identity that engages one's full humanity. To aid a person in finding meaning is to assist them and request to live a life of value in spite of the dehumanizing and mechanistic concepts that define what it means to be human. Health as defined within the medical model is not the goal of many with disabilities. For persons with disabilities there can be an increased urgency to find meaning amid suffering or oppression. According to Frankl, "the need for meaning is independent of other needs."<sup>248</sup> Meaning is profoundly individual, with each person discovering meanings unique to them. Ignoring the cry for meaning of persons with disabilities denies them the opportunities to find a will to meaning that provides the person "the courage to be" alone.<sup>249</sup>

A review of literature on social isolation provides evidence of a correlation between isolation, loneliness and existential spiritual suffering and reduced life expectancy. Unconscious bias against disability can lead to persons with disability being

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<sup>247</sup> Viktor E. Frankl, *The Unheard Cry for Meaning: Psychotherapy and Humanism* (New York: Simon and Schuster, 2011), 18.

<sup>248</sup> Frankl, 30.

<sup>249</sup> Frankl, 10–17, 67.

isolated, segregated from the larger society, and persecuted to the point of becoming social outcasts.<sup>250</sup> They are likely to be isolated, underemployed, unable to go to the doctor due to cost, and more likely to report being in poor health than other populations. These research findings as well as other research on the positive correlation between spiritual care and increased quality of life validate offering chaplains to patients in primary care practices.<sup>251</sup>

People who receive spiritual support exhibit less decisional conflict along with a higher quality of life and spiritual well-being. People who identify as religious value spirituality and believe spiritual care along with specialized care is beneficial in supporting decision-making connected to one's values and beliefs.<sup>252</sup> Spiritual care provided by a chaplain does not itself lead to a healthy spiritual life. Involvement in a faith community is a key social support and factor in mediating spiritual well-being and quality of life.<sup>253</sup> Therefore, chaplaincy services must include outreach and engagement with faith communities and other resources that can increase opportunities for individuals to meaningfully participate in them.

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<sup>250</sup> Nikki Murdick et al., "Cross-Cultural Comparison of the Concept of 'Otherness' and Its Impact on Persons with Disabilities," *Education and Training in Developmental Disabilities* 39, no. 4 (2004): 310.

<sup>251</sup> Stewart W. Mercer et al., "Multimorbidity in Primary Care: Developing the Research Agenda," *Family Practice* 26, no. 2 (April 1, 2009): 79, <https://doi.org/10.1093/fampra/cmp020>.

<sup>252</sup> Francisca Rego et al., "The Influence of Spirituality on Decision-Making in Palliative Care Outpatients: A Cross-Sectional Study," *BMC Palliative Care* 19, no. 22 (2020): 9, <https://doi.org/10.1186/s12904-020-0525-3>.

<sup>253</sup> Rego et al., 9.

## **Religion, Spirituality, and the Disability Rights Movement**

Much is written about the theological barriers to spiritual wholeness for persons with disabilities within faith communities but not enough can be said about this bias in praxis. Rather than rehash 2000 years of Christian theology, this thesis provides a snapshot of ways Christians and other religious groups in the United States have alienated persons with disabilities and reduced their trust in representatives of religious institutions in recent history. For the purposes of this thesis, it is more important to focus on more contemporary forms of discrimination that are systemic and create barriers to health.

Perhaps what stands out most is the ongoing purposeful denial of civil rights to persons with disabilities by faith communities in the United States. In 1990 Congress passed the Americans with Disabilities Act. Thirty-two years since the passage of the Americans with Disabilities Act in 1990, churches, mosques, and synagogues as well as other houses of worship remain inaccessible to persons with disabilities due to religious exemption in the law.<sup>254</sup>

The ADA's exemption of religious organizations and religious entities controlled by religious organizations is very broad, encompassing a wide variety of situations.<sup>255</sup> Under the ADA, religious organizations and entities controlled by religious organizations have no obligations under the ADA. The Individuals with Disabilities Education Act

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<sup>254</sup> "Religious Entities Under the Americans With Disabilities Act," ADA National Network, 2018, <https://adata.org/factsheet/religious-entities-under-americans-disabilities-act>.

<sup>255</sup> "Religious Entities Under the Americans with Disabilities Act," ADA National Network.

(IDEA) and Section 504 of the Rehabilitation Act of 1973 do provide some protections for students attending religious schools. However, these protections are not rigorous enough to offset the religious exemption clause in the ADA.<sup>256</sup>

The religious exemption is not only for the religious organization itself, but also entities controlled by a religious organization. Even when a religious organization carries out activities that would otherwise make it a public accommodation, the religious organization is exempt from ADA coverage.

Thus, if a church itself operates. . . a private school, or a diocesan school system, the operations of the . . . school or schools would not be subject to the ADA. . . The religious entity would not lose its exemption merely because the services provided were open to the general public. The test is whether the church or other religious organization operates the public accommodation, not which individuals receive the public accommodation's services.<sup>257</sup>

Results from an online survey of 293 persons with disabilities (226 Protestant, 67 Catholics) revealed that the majority of respondents answered that they either had positive or neutral experiences of churches.<sup>258</sup> However, over 30% of respondents felt

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<sup>256</sup> Campbell Sode, "Unlocking Accommodations for Disabled Students in Private Religious Schools," *Northwestern University Law Review* 116 (2021): 171–197, [https://scholarlycommons.law.northwestern.edu/cgi/viewcontent.cgi?article=1315&context=nulr\\_online](https://scholarlycommons.law.northwestern.edu/cgi/viewcontent.cgi?article=1315&context=nulr_online); "IDEA, ADA, IEP'S, and Section 504 Plans: What Happens in College?" College of Western Idaho, accessed March 6, 2022, <https://cwi.edu/current-students/idea-ada-and-section-504/>; "Americans with Disabilities Act: ADA Title III Technical Assistance Manual Covering Public Accommodations and Commercial Facilities," ADA.gov, accessed March 6, 2022, <https://www.ada.gov/taman3.html>; Veronica Rose, "Churches and Handicapped Accessibility Requirements," Connecticut General Assembly, December 8, 2006, <https://www.cga.ct.gov/2006/rpt/2006-R-0756.htm>.

<sup>257</sup> Veronica Rose, "Churches and Handicapped Accessibility Requirements," Old Research Report, December 8, 2006, accessed October 3, 2022, <https://www.cga.ct.gov/2006/rpt/2006-R-0756.htm>.

<sup>258</sup> Matthew S. Stanford, "Demon or disorder: A Survey of Attitudes toward Mental Illness in the Christian Church," *Mental Health, Religion, and Culture* 10, no. 5 (2007): 446, <https://doi.org/10.1080/13674670600903049>.



like the church made them feel like mental illness was a result of personal sin, over 30% responded that their church suggested that they or a loved one did not have a mental illness even if diagnosed by a mental health professional. Over 25% of respondents answered that their involvement in a church made their problem worse and 14% responded that involvement in the church reduced their faith.<sup>259</sup>

Groups such as the Catholic Church have made strides to create more inclusive welcoming communities for persons with disabilities. In its Guidelines for the Celebration of the Sacraments with Persons with Disabilities and Pastoral Statement of US Catholic Bishops on Persons with Disabilities, the bishops affirmed the dignity of persons with disabilities as valued members of the Church uniquely called by God to participate in the sacramental life of the Church.<sup>260</sup> While laudable, the Guidelines are not experienced by too many persons with disabilities who remain unable to engage in the full life of the Catholic Church whether it be because of inaccessible altars or accessible bathrooms in parish centers or creating barriers to education in a Catholic school.<sup>261</sup>

Religious organizations still seek to exploit ADA religious exclusions in a manner that harms children with disabilities and their families and all families in America desperate for affordable daycare. In 2004, a schoolteacher, Cheryl Perich was fired from

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<sup>259</sup> Stanford, "Demon or Disorder," 447.

<sup>260</sup> "Pastoral Statement of U.S. Catholic Bishops on Persons with Disabilities," United States Catholic Conference, November 1978, <https://www.usccb.org/beliefs-and-teachings/what-we-believe/catholic-social-teaching/upload/Pastoral-Statement-of-U-S-Catholic-Bishops-on-Persons-with-Disabilities.pdf>; Lorraine Cuddeback, "'Excused from the Table' – Churches and the Americans with Disabilities Act," Political Theology Network, July 24, 2015, <https://politicaltheology.com/excused-from-the-table-churches-and-the-americans-with-disabilities-act-lorraine-cuddeback/>.

<sup>261</sup> Cuddeback, "'Excused from the Table.'"

her position at a Lutheran Church after being diagnosed with narcolepsy.<sup>262</sup> Perich sued the Church under the Americans with Disabilities Act. Ms. Perich lost her case after the Church successfully argued before the Supreme Court that because they considered Ms. Perich to be a “minister,” and as a minister, she could be hired and fired without the protection of civil rights laws.<sup>263</sup>

Today, religiously based daycare centers are fighting President Biden’s Build Back Better childcare provision citing religious freedom.<sup>264</sup> These religious groups are concerned that they will not receive federal funding through the program because their facilities do not comply with the Americans with Disabilities Act or the child care plan will force them to hire gay people.<sup>264</sup> Michael Sheedy, Executive Director the Florida Conference of Catholic Bishops stated that, “Catholic schools and most nonpublic schools purposely avoid federal financial recipients status, because it triggers a whole host of federal regulatory obligations with which nonpublic schools are not currently required to comply.”<sup>264</sup> Nathan J Diamant, public policy director at the Union of Orthodox Jewish Congregations of America, was concerned that Build Back Better

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<sup>262</sup> “Hosanna-Tabor Evangelical Lutheran Church and School v. Equal Employment Opportunity Commission,” Supreme Court of the United States, October 2011, <https://www.supremecourt.gov/opinions/11pdf/10-553.pdf>.

<sup>263</sup> Nina Totenberg, “Justices Rule Ministers Exempt from Anti-Bias Laws,” NPR, January 11, 2012, <https://www.npr.org/2012/01/11/145055102/high-court-upholds-church-state-separation>.

<sup>264</sup> Luke Broadwater, “Biden’s Child Care Plan Faces Resistance from Religious Groups,” *New York Times*, November 14, 2021, <https://www.nytimes.com/2021/11/14/us/politics/religious-groups-child-care.html>; “Hosanna-Tabor Evangelical Lutheran Church and School,” Supreme Court of the United States.

legislation would “deter if not make it impossible for faith-based providers to participate.”<sup>265</sup>

The power of these groups cannot be understated. In December 2020, the Bipartisan Policy Center conducted a poll and discovered that 31% of working parent households used center-based daycare with roughly 53% of families using centers affiliated with a faith-based organization.<sup>266</sup> Much to the dismay of persons with disabilities and their families, it seems these organizations, much like the mother in the King Solomon story, would rather the bill be killed than be held accountable to nondiscriminatory laws.<sup>267</sup>

Of course, faith communities are not always on the wrong side of disability rights. In 1988 15 faith groups and two mental health organizations came together to form Pathways To Promise “to promote caring ministry with persons who have prolonged mental illness and their families.”<sup>268</sup> The group is affiliated with national mental health organizations including the National Alliance on Mental Illness (NAMI). NAMI is the largest grassroots mental health organization in the United States dedicated to building their lives for persons affected by mental illness.<sup>269</sup> NAMI works with faith communities

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<sup>265</sup> Broadwater, “Biden’s Child Care Plan.”

<sup>266</sup> Suzann Morris and Linda Smith, “Examining the Role of Faith-Based Child Care,” Bipartisan Policy Center, June 4, 2021, <https://bipartisanpolicy.org/report/faith-based-child-care/>.

<sup>267</sup> 1 Kings 3:16–28

<sup>268</sup> “Historical Highlights,” Pathways to Promise, accessed March 22, 2022, <https://www.pathways2promise.org/historical-highlights/>.

<sup>269</sup> “Home,” National Alliance on Mental Illness, accessed March 22, 2022, <https://www.nami.org/home>.

to develop their capacity and competency to support persons and families impacted by mental illness, get involved in programs to eliminate stigma associated with mental illness and advocate for larger systemic change.<sup>270</sup>

### **The Disability Paradox and Spiritual Care**

Persons with severe disabilities live high quality of life despite perceptions of medical providers and the larger society that one cannot live a high-quality life with a cognitive or physical impairment.<sup>271</sup> This seeming contradiction is known as the “disability paradox.” Society “grossly” underestimates the importance of social supports, and spiritual and existential meaning that shape the quality of life of person with a disability.<sup>272</sup> The disability paradox is reflected in an individual’s ability to balance their mind, body, and spirit in a manner that provides meaning in that person’s larger social environment and context.<sup>273</sup> It is important to look at the disability paradox in the context of physicians’ perception of disability and how that may impact their care of persons with disabilities.

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<sup>270</sup> “Resources,” National Alliance on Mental Illness, accessed March 22, 2022, [https://www.NAMI.org/Get-Involved/NAMI-FaithNet/Resources\\_](https://www.NAMI.org/Get-Involved/NAMI-FaithNet/Resources_).

<sup>271</sup> Henning Eichberg, “Disabled People in Play: Toward an Existential and Differential Phenomenology of Moving with Dis-Ease,” *Physical Culture and Sport Studies and Research* 65, no. 1 (April 2015): 20–22, <https://doi.org/10.1515/pcssr-2015-0007>; Peter A. Ubel et al., “Misimagining the unimaginable: the disability paradox and health care decision making,” *Health Psychology* 24, no. 4S (2005), <https://doi.org/10.1037/0278-6133.24.4.s57>.

<sup>272</sup> “Home,” National Alliance on Mental Illness, accessed March 22, 2022, <https://www.nami.org/home>.

<sup>273</sup> Gary L. Albrecht and Patrick J. Devlieger, “The Disability Paradox: High Quality of Life against All Odds,” *Social Science and Medicine* 48, no. 8 (January 1999): 977–988, [https://doi.org/10.1016/S0277-9536\(98\)00411-0](https://doi.org/10.1016/S0277-9536(98)00411-0).

In a recent study of 714 practicing physicians in the United States, 82% of the respondents believed that Persons with complex disabilities have a lower quality of life than those without complex disabilities, and only 18.1% strongly agreed that persons with disabilities are treated unfairly in the medical system, despite evidence to the contrary.<sup>274</sup> Yet over 40% of physicians in the study were confident of their ability to provide the same quality services to persons with disabilities.<sup>275</sup> The responses of these physicians are reflective of the larger ableist disease-centric view of society that limits human identity to a medical model of disability that “grossly” underestimates “the importance of the mental, spiritual, emotional and social components that contribute to the persons with disabilities’ quality of life.”<sup>276</sup> Failing to realize the resiliency of the human spirit and the potential of persons with significant disabilities can be detrimental.

Persons with spinal cord injuries are three times more likely to die by suicide than persons in the general population.<sup>277</sup> Non-Hispanic whites were among the highest risk for suicide. One potential cause of suicide is isolation that may be related to

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<sup>274</sup> “COVID-19 and Disability-Based Discrimination in Health Care,” American Bar Association, accessed July 9, 2020, <https://www.americanbar.org/groups/diversity/disabilityrights/resources/covid19-disability-discrimination/>; Iezzoni et al., “Physicians’ Perceptions Of People With Disability And Their Health Care,” 4.

<sup>275</sup> Iezzoni et al., “Physicians’ Perceptions Of People With Disability And Their Health Care,” 4.

<sup>276</sup> Albrecht, “The Disability Paradox,” 987.

<sup>277</sup> Yue Cao et al., “Suicide Mortality After Spinal Cord Injury in the United States: Injury Cohorts Analysis,” *Archives of Physical Medicine and Rehabilitation* 95 (October 22, 2013): 230, <https://doi.org/10.1016/j.apmr.2013.10.007>.

unemployment or impaired social integration and psychological well-being.<sup>278</sup> Prevention and intervention to increase life expectancy of persons with SCI are cited as a critical need given the disproportionate instances of suicide in this population.<sup>279</sup> Suicide prevention is also one of the primary national objectives in the United States.<sup>280</sup>

Suicide prevention in this population faces many challenges. Physician discomfort with death or suicidal ideation are aspects of bias that lead to physician avoidance of psychological assessments for suicide risk of patients with SCI.<sup>281</sup> The failure of doctors to discuss matters of existential importance to persons with SCI can damage the relationship and increase risk of harm to patients with SCI.<sup>282</sup> Failure to recognize the disability paradox, physicians expect persons with spinal cord injuries to engage in unhealthy behaviors such as excessive drinking and adopting a sedentary lifestyle. Budd, et al, state: “clinicians are more likely to discount and place less emphasis on the experiences of a patient with SCI in diagnostic formulations, presuming they are not fully competent.”<sup>283</sup> Unfortunately, such patients often exercise passive suicidality through self-neglect, which may be overlooked.<sup>284</sup>

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<sup>278</sup> P. Kennedy and L. Garmon-Jones, “Self-Harm and Suicide before and after Spinal Cord Injury: A Systematic Review,” *Spinal Cord* 55, no. 1 (January 2017): 5, <https://doi.org/10.1038/sc.2016.135>.

<sup>279</sup> Cao et al., “Suicide Mortality After Spinal Cord Injury in the United States,” 232.

<sup>280</sup> Cao et al., 232.

<sup>281</sup> Budd, Haque, and Stein, “Biases in the Evaluation of Self-Harm,” 43.

<sup>282</sup> Budd, Haque, and Stein, 43.

<sup>283</sup> Budd, Haque, and Stein, 43.

<sup>284</sup> Budd, Haque, and Stein, 2.

## Current Practices of Spiritual Care in Healthcare

Primary care chaplaincy (PCC) is a covered service in the United Kingdom (UK) National Health Service (NHS). General practitioners (GPs) in NHS Primary Care Chaplaincy (PCC) programs recognize spirituality as essential to personhood but do not necessarily feel comfortable addressing spiritual needs with their patients.<sup>285</sup> In contrast to the United States, primary care chaplaincy is central to the country's healthcare model. In the United Kingdom, chaplaincy services have been available to people as part of their primary care team for more than 20 years.<sup>286</sup> PCC is viewed as a form of talking therapy, provided by chaplains in general practice, with the aim of helping people find meaning amid suffering, and offering spiritual direction.<sup>287</sup> As members of the primary care team, chaplains are specialists in the field of spiritual care. Their role is to focus singularly on the spiritual and existential challenges a person may be facing, whether those challenges are a result of isolation and lack of community or unresolved questions about meaning.<sup>288</sup>

In 2009, the NHS established the United Kingdom Board of Healthcare Chaplaincy (UKBHC) and the College of Healthcare Chaplains (CHC). The UKBHC sets

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<sup>285</sup> Macdonald, "Primary Care Chaplaincy," 1–2.

<sup>286</sup> Sarah Giffen and Gordon Macdonald, "Report for the Association of Chaplaincy in General Practice on Spiritual Care During the COVID-19 Pandemic," *Health and Social Care in the Community* 8, no. 2 (2020): 266, <https://doi.org/10.1558/hssc.41767>.

<sup>287</sup> "Primary Care Chaplaincy," Christian Medical Fellowship, accessed September 4, 2021, <https://www.cmf.org.uk/resources/publications/content/?context=article&id=26922>.

<sup>288</sup> "The Case for Community Healthcare Chaplaincy: facilitating whole-person care in General Practice," Professional Association of Community Healthcare Chaplaincy, accessed September 4, 2021, 11, [http://acgp.co.uk/wp-content/uploads/2019/06/the\\_case\\_for\\_community\\_healthcare\\_chaplaincy.pdf](http://acgp.co.uk/wp-content/uploads/2019/06/the_case_for_community_healthcare_chaplaincy.pdf).

standards for professional practices of accredited healthcare chaplains.<sup>289</sup> The College of Healthcare Chaplains is an interfaith professional organization for chaplains and pastoral care providers that promotes the professional standing of chaplaincy.<sup>290</sup> The Association of Chaplaincy in General Practice promotes a high standard for provision of primary care chaplaincy.<sup>291</sup> Research conducted by the Scottish NHS found that spiritual care provided at the primary care level enhances the person's health care experience and also supports resiliency at the community level.<sup>292</sup>

Provision of community-based chaplaincy is accepted practice in populations receiving either palliative or hospice care in the United States as well as other countries. Hospice or end-of-life care is provided in the community as well as other settings. "Hospice care focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life."<sup>293</sup> Hospice is provided in a range of settings ranging from the person's home to hospice center, hospital, or nursing

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<sup>289</sup> "UK Board of Healthcare Chaplaincy," UKBHC, accessed November 7, 2021, <https://www.ukbhc.org.uk/>.

<sup>290</sup> "Home," Chaplaincy Innovation Lab, accessed March 17, 2021, <https://chaplaincyinnovation.org/>.

<sup>291</sup> "About Us: What We Do," The Association of Chaplaincy in General Practice, accessed November 7, 2021, <http://acgp.co.uk/about-us/>.

<sup>292</sup> Suzanne Bunniss, Harriet Mowat, and Austyn Snowden, "Community Chaplaincy Listening: Practical Theology in Action," accessed February 15, 2020, 42, <https://pdfs.semanticscholar.org/86bd/a09feb8ebc6f905308c0afc46c6200a35275.pdf>.

<sup>293</sup> "What Are Palliative Care and Hospice Care?" National Institutes of Health, May 14, 2021, <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#hospice>.



facility.<sup>294</sup> Hospice teams are available to someone 24 hours a day by phone at a minimum.

Palliative care is available to persons with complex needs and/or serious illness that could lead to death. “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”<sup>295</sup> As defined by the World Health Organization (WHO),

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient’s prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.<sup>296</sup>

The WHO also identifies a wide array of persons with varying conditions requiring palliative care. Populations identified by the WHO that might benefit from palliative care include persons living with multiple sclerosis, diabetes, Parkinson’s disease, congenital conditions and neurological deficits.<sup>297</sup> Care management must include integration of adequate and appropriate care if unplanned acute services are

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<sup>294</sup> “What Are Palliative Care and Hospice Care?”

<sup>295</sup> “WHO Definition of Palliative Care,” WHO, accessed August 3, 2019, <https://www.who.int/cancer/palliative/definition/en/>.

<sup>296</sup> “What is Palliative Care?” GetPalliativeCare.org, accessed December 26, 2021, <https://getpalliativecare.org/whatis/>.

<sup>297</sup> “WHO Definition of Palliative Care.”

needed for persons with spinal cord injuries and other chronic conditions.<sup>298</sup> For example, a person with a spinal injury needs shift from chronic care management to palliative level care if the person develops osteomyelitis from a decubitus ulcer.

The Center to Advance Palliative Care (CAPC), a national nonprofit organization in the United States dedicated to increasing the availability of quality health care for people facing serious illness, provides health care organizations the technical support and other services needed to assist healthcare entities in providing palliative level care.<sup>299</sup> CAPC provides a case study describing Angela, a woman with many autoimmune disorders, including lupus, rheumatoid arthritis, scleroderma, and Raynaud’s phenomenon. She felt alone and misunderstood, and as her physical symptoms worsened so did her emotional distress until receiving palliative level care. The palliative care team provides Angela whole person care, managing her symptoms and physical pain while also supporting her emotional and spiritual needs.<sup>300</sup>

According to researcher and palliative care expert Dr. Ellen Hummel, palliative care should focus on “providing good, comprehensive care to patients—care that attends to their physical, psychological, emotional and spiritual needs at any stage of a serious

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<sup>298</sup> Janice L. Clarke et al., “An Innovative Approach to Health Care Delivery for Patients with Chronic Conditions,” *Population Health Management* 20, no. 1 (2017): 27, <https://www.liebertpub.com/doi/pdf/10.1089/pop.2016.0076>..“Clarke et al. - 2017 - An Innovative Approach to Health Care Delivery for.Pdf,” 27, accessed June 20, 2021, <https://www.liebertpub.com/doi/pdf/10.1089/pop.2016.0076>.

<sup>299</sup> “About GetPalliativeCare.org,” GetPalliativeCare.org, accessed December 26, 2021, <https://getpalliativecare.org/about/>.

<sup>300</sup> “Living Well with Serious Illness: Angela’s Palliative Care Story,” GetPalliativeCare.org, September 23, 2015, <https://getpalliativecare.org/living-well-with-serious-illnesses-angelas-palliative-care-story/>.

illness . . . Palliative care focuses on improving a patient’s quality of life—not only physically but also mentally—through the availability of physicians, social workers and spiritual care providers. The need for this type of care continues to grow.”<sup>301</sup> A significant percentage of One Care enrollees meet the WHO and Dr. Hummel’s definition of positive care eligible populations.

There are examples of community-based chaplaincy organizations that support patients in non-hospital settings in the United States that do not require palliative or hospice level care needs. However, because Medicaid and Medicare do not cover nonpalliative or nonhospice chaplaincy services in the community, entities that provide chaplaincy services must rely on contracts with hospitals or foundations for funding.<sup>302</sup> For example, Blue Cross Blue Shield Foundation in Massachusetts recently funded a spiritual care project to examine the role of religion and spirituality in healthcare as “often untapped, social determinants of public health.”<sup>303</sup> The project seeks to build the capacity of staff at several Massachusetts federally qualified health centers (FQHCs).<sup>304</sup> Certified chaplains work with clinical staff to build the capacity to address the spiritual needs of low-income residents served

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<sup>301</sup> Jane Racey Gleeson, “Palliative Care Provides Help for Patients with Chronic Illness,” University of Michigan Health, October 10, 2016, <https://healthblog.uofmhealth.org/heart-health/palliative-care-provides-help-for-patients-chronic-illness>.

<sup>302</sup> “About,” HealthCare Chaplaincy Network, accessed January 7, 2022, <https://healthcarechaplaincy.org/about/>.

<sup>303</sup> Katie Rimer, Mary Martha Thiel, and Wendy Cadge, “Spiritual Care Disparities in the Culture of Health in Community Clinics in Massachusetts,” Chaplaincy Innovation Lab, accessed August 16, 2022, <https://chaplaincyinnovation.org/projects/spiritual-care-disparities>.

<sup>304</sup> Rimer, “Spiritual Care Disparities,” Chaplaincy Innovation Lab; “About,” HealthCare Chaplaincy Network.

by the FQHCs.<sup>305</sup> The Veteran’s Administration has integrated mental health and spiritual care based on research findings done by the VA to improve a more integrated person-centered approach to mental health and spiritual care.<sup>306</sup> In addition to the VA, there are non-profit entities that offer frontline spiritual care. However, these entities are funded through convoluted contracting practices that make procuring chaplains a challenge—this idea will be explored in more detail later in the thesis.

### **Spiritual Care in the United States, Going Beyond the Research**

Increasingly there is agreement on the importance of spirituality as integral to health and the importance of integrating mind, body, and spirit in patient care.<sup>307</sup> Research over the last ten years also shows increasing competency of healthcare providers in assessing the spiritual needs of patients.<sup>308</sup> Yet, care provider resistance to addressing the spiritual needs of patients remains high. There remains a need for increasing provider comfort and competency in valuing spiritual care as an essential aspect of whole-person care that requires ongoing training and research.<sup>309</sup> A key

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<sup>305</sup> Rimer, “Spiritual Care Disparities.”

<sup>306</sup> “Mental Health and Chaplaincy Clinical Integration,” U.S. Department of Veteran Affairs, Mental Illness Research Education and Clinical Center, accessed January 18, 2022, [https://www.mirecc.va.gov/mentalhealthandchaplaincy/learning\\_collaborative.asp](https://www.mirecc.va.gov/mentalhealthandchaplaincy/learning_collaborative.asp).

<sup>307</sup> Kate Fiona Jones et al., “The Content, Teaching Methods and Effectiveness of Spiritual Care Training for Healthcare Professionals: A Mixed-Methods Systematic Review,” *Journal of Pain and Symptom Management*, March 21, 2021, Introduction, <https://doi.org/10.1016/j.jpainsymman.2021.03.013>.

<sup>308</sup> Jones et al., Conclusion.

<sup>309</sup> Jones et al., Conclusion.

problem is that the rhetoric of integration has not yet led to a commitment to providing spiritual care in community or primary care settings in the United States.

Dr. Nishant Anand, Chief Medical Officer of Adventist Health System (the largest faith-based healthcare system in the United States) spoke before the one hundred fifteenth Congress Subcommittee on Health of the Committee on Energy and Commerce.<sup>310</sup> Dr. Anand discussed the importance of value-based care as essential to providing spiritual care within a framework of person-centered holistic care. His statement in part reads:

So, from an organizational perspective, we fundamentally believe in holistic care. We believe that medical care is a small portion of the overall health and wellbeing of our patients and beneficiaries.

And so, we focus on things that affect their social determinants of health—their mental wellbeing, their spiritual wellbeing, some of their financial issues that we have. And so, we really take a holistic picture and approach to improving the health and wellbeing of those patients. The literature has confirmed over and over that when you apply that holistic approach you’re going to get better health outcomes.<sup>311</sup>

Dr. Anand speaks to the need for holistic care and the importance of mental and spiritual well-being in improving health. However, he stops short of defining the support and services the healthcare industry should provide patients to support spiritual wellness.

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<sup>310</sup> “Adventist Health System/Sunbelt, Inc,” D&B Business Directory, [https://www.dnb.com/business-directory/company-profiles.adventist\\_health\\_system-sunbelt\\_inc.bedbe4aeae33476480858a651067961.html#:~:text=Company%20Description%3A%20Adventist%20Health%20System,\(mostly%20in%20the%20Southeast\).](https://www.dnb.com/business-directory/company-profiles.adventist_health_system-sunbelt_inc.bedbe4aeae33476480858a651067961.html#:~:text=Company%20Description%3A%20Adventist%20Health%20System,(mostly%20in%20the%20Southeast).)

<sup>311</sup> “Examining Barriers to Expanding Innovative, Value-Based Care in Medicare,” U.S. Government Publishing Office, September 13, 2018, <https://www.govinfo.gov/content/pkg/CHRG-115hhrg36533/html/CHRG-115hhrg36533.htm>.

The lack of commitment to offering spiritual care as a primary service is also evident in the Oregon Association of hospitals and health systems Community Benefit Update from 2017.<sup>312</sup> The report highlights the importance of community-based spiritual care and cites as an example Find Your Own Words, an organization that aids people struggling with depression and suicidality.<sup>313</sup> Find Your Own Words speaks to the importance of spiritual care, but rather than providing spiritual care resources, only provides the following advice to people experiencing depression, “If you’re not sure about talking to friends or family, start with your doctor or a trusted counselor, teacher, or spiritual advisor.”<sup>314</sup> This is not adequate or appropriate spiritual care.

### **Spiritual Care as an Intervention to Advance Whole-Person Care**

There is no direct or easy path to providing spiritual care to persons with disabilities living in community settings or to the larger population of Americans who may benefit from spiritual care as part of a whole-person healthcare approach. According to a recent Pew Charitable Trust report, Americans in different demographic groupings increasingly identify as atheist or agnostic.<sup>315</sup> White people are more likely to self-

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<sup>312</sup> “Oregon Health Policy Board Agenda,” Oregon.gov, May 2, 2017, 21, <https://www.oregon.gov/oha/OHPB/MtgDocs/May%20202017%20OHPB%20Meeting%20Packet.pdf>.

<sup>313</sup> “Resilience and Mental Health,” Find Your Words, 2020, <https://findyourwords.org/self-care/>.

<sup>314</sup> “How to Talk to Someone About Depression,” Find Your Words, 2020, <https://findyourwords.org/depression-help/how-to-talk-about-it/>.

<sup>315</sup> Gregory Smith, Alan Cooperman, and Pew Research Center, “America’s Changing Religious Landscape,” Pew Research Center’s Religion & Public Life Project, May 12, 2015, <https://www.pewforum.org/2015/05/12/americas-changing-religious-landscape/>.

identify as unaffiliated compared with Black people and Hispanics.<sup>316</sup> Nevertheless, reduced identification with a particular religious tradition does not mean that Americans do not feel a need for spiritual grounding and peace as increasing numbers of Americans self-identify as “spiritual, but not religious.”<sup>317</sup> In a recent study, a baseline description of the chaplaincy healthcare workforce findings provides evidence of a “demand” for professional Chaplains, which may correlate with the “prevalence of spiritual distress in a population or the need for more innovative care team composition.”<sup>318</sup>

This study’s findings seem to bear out findings in an earlier study by Kaye and Raghavan on spiritual practices and stress among persons with disabilities.<sup>319</sup> The latter study explores the relationship between spirituality, disability, and illness among HIV-positive women. It found a positive correlation between a reduction in stress-related symptoms arising from functional impairment and other HIV-related symptoms and an increased engagement in spiritual activities, leading to “reduced emotional stress and an enhanced quality of life.”<sup>320</sup> Another study also showed baseline changes in mental health well-being with multiple presenting issues among patients taking antidepressants and those not

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<sup>316</sup> “Religion in America: U.S. Religious Data, Demographics and Statistics,” Pew Research Center’s Religion & Public Life Project, accessed August 17, 2019, <https://www.pewforum.org/religious-landscape-study/>.

<sup>317</sup> Michael Lipka and Claire Gecewicz, “More Americans Now Say They’re Spiritual but Not Religious,” FactTank - News in Numbers, September 6, 2017, <https://www.pewresearch.org/fact-tank/2017/09/06/more-americans-now-say-theyre-spiritual-but-not-religious/>.

<sup>318</sup> Kelsey B. White et al., “Mapping the Healthcare Chaplaincy Workforce: A Baseline Description,” *Journal of Health Care Chaplaincy* 27, no. 4 (2021), <https://doi.org/10.1080/08854726.2020.1723192>.

<sup>319</sup> Kaye and Raghavan, “Spirituality in Disability and Illness,” 234.

<sup>320</sup> Kaye and Raghavan, 234–36.

taking antidepressants. In both the AD and no-AD groups provided chaplaincy services showed an increase in mental health well-being.<sup>321</sup> Among persons not prescribed AD, PCC was correlated with reduction in follow-up GP. This study “suggests that PCC is relevant to the many and varied presentations seen in primary care.”<sup>322</sup> Findings in these and other studies call for reimagining professional chaplaincy and other spiritual companions in healthcare.

Having increased meaning can lead to increased strength, resiliency and purpose.<sup>323</sup> Albrecht and Devlieger describe this experience as a process of finding one’s purpose and growing in one’s “ability to live in an interdependent social world with mutual emotional relationships.”<sup>324</sup> Well-being is manifest in the integration of mind, body and soul.<sup>325</sup> In contrast with persons with disabilities who have meaning and purpose, persons lacking a spiritual center or interconnectedness may experience a poorer quality of life.<sup>326</sup> With interconnectedness and purpose can come resiliency, understanding, and deepening of one’s relationships. Resiliency also goes beyond the body, emphasizing the relationship between mind and spirit.<sup>327</sup> Spiritual or existential wholeness comes from the realization that one is part of a larger transcendent world—a

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<sup>321</sup> Kaye and Raghavan, 7.

<sup>322</sup> Kaye and Raghavan, 8.

<sup>323</sup> Albrecht and Devlieger, “The Disability Paradox,” 983.

<sup>324</sup> Albrecht and Devlieger, 984.

<sup>325</sup> Albrecht and Devlieger, 984–985.

<sup>326</sup> Albrecht and Devlieger, 985.

<sup>327</sup> Albrecht and Devlieger, 985.



world that calls one integrated relationship and purpose with others.<sup>327</sup> In this respect, foundational to wholeness is meaningful relationship with one's chosen family, community, and larger social system.<sup>328</sup>

There is a strong association between frequent involvement in religious services and lower mortality rates. Involvement in faith communities is associated with increased resilience to social determinants of health that lead to poor health outcomes. This includes reduced engagement in unhealthy behaviors such as smoking and alcohol consumption, healthier diet, and more frequent engagement in physical activities. Activity in faith communities, including engagement in religious services, acts as a resiliency mechanism that improves psychological well-being and reduced experience of depression as well as increased social supports.<sup>329</sup>

Involvement in a faith community is a key social support and factor in mediating spiritual well-being and quality of life.<sup>330</sup> Religious attendance has been correlated with elevated levels of social support and integration and lower levels of loneliness.<sup>331</sup> For persons with complex care needs, membership in a religious organization can be central

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<sup>328</sup> Albrecht and Devlieger, "The Disability Paradox," 985.

<sup>329</sup> Wanqing Wen et al., "Does Religious Involvement Affect Mortality in Low-Income Americans? A Prospective Cohort Study," *BMJ Open* 9, no. 7 (July 2019): 1–2, <https://doi.org/10.1136/bmjopen-2018-028200>.

<sup>330</sup> Rego et al., "The Influence of Spirituality," 9.

<sup>331</sup> Neal Krause, "Assessing the Relationships among Religiousness, Loneliness, and Health," *Archive for the Psychology of Religion* 38, no. 3 (December 1, 2016): 293, <https://doi.org/10.1163/15736121-12341330>.

to a person's identity and provide crucial access to social networks.<sup>332</sup> Engagement in a religious organization can reduce feelings of isolation and be a source of social support.<sup>333</sup> Stronger faith and religious belief experiences can also reduce feelings of loneliness for people with complex care needs compared to people with less intense religious beliefs.<sup>334</sup>

People who receive spiritual support exhibit less decisional conflict along with a higher quality of life and spiritual well-being. People who identify as religious value spirituality and believe spiritual care along with specialized care is beneficial in supporting decision-making connected to one's values and beliefs.<sup>335</sup>

### **Spirituality and Disability**

Framing spiritual care as engagement in liberative praxis puts chaplains squarely at the center of the crossroads of physical, spiritual, and existential pain resulting from suffering and suffering resulting from oppression. There is ample literature showing the value of spiritual care in addressing the linkages between isolation and loneliness with poor health outcomes and increased morbidity rates resulting from preventable secondary

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<sup>332</sup> National Academies of Sciences, Engineering, and Medicine and National Academies of Sciences, Engineering, and Medicine, *Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System* (Washington, D.C.: National Academies Press, 2020), 80, <https://doi.org/10.17226/25663>.

<sup>333</sup> National Academies of Sciences, Engineering, and Medicine and National Academies of Sciences, Engineering, and Medicine, 81.

<sup>334</sup> National Academies of Sciences, Engineering, and Medicine and National Academies of Sciences, Engineering, and Medicine, 81.

<sup>335</sup> Rego et al., "The Influence of Spirituality," 9–10.

conditions, such as coronary heart disease.<sup>336</sup> Using persons in hospice experiencing their mortality as a proxy, persons with acquired disability may benefit from chaplaincy intervention that supports human connection, community, personal agency, and meaning and purpose in life.<sup>337</sup> Numerous studies show a need for public health practitioners and institutions to integrate spiritual care and chaplaincy into healthcare.<sup>338</sup> In recent decades, scientific research has shown a positive link between spiritual practices and spiritual involvement with reduced stress and fewer hospitalizations.<sup>339</sup> A review of the literature shows that “higher levels of spirituality tend to be positively associated with hope, self-esteem, social support, adaption to bereavement and inversely associated with anxiety, depression, loneliness, and suicide.”<sup>340</sup>

The evidence shows a dire need for spiritual care in community settings and for people with disabilities in particular. There are examples of community-based chaplaincy organizations that support patients in non-hospital settings in the United States. These services are often provided by non-profit entities that rely on grants and

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<sup>336</sup> Valtorta et al. “Loneliness and Social Isolation as Risk Factors for Coronary Heart Disease and Stroke,” 1015; Steptoe et al., “Social Isolation, Loneliness, and All-Cause Mortality in Older Men and Women,” 5797.

<sup>337</sup> Fiona Timmins and Silvia Caldeira, eds., *Spirituality in Healthcare: Perspectives for Innovative Practice* (Cham, Switzerland: Springer International Publishing, 2019), 178–79, <https://doi.org/10.1007/978-3-030-04420-6>.

<sup>338</sup> Hannah Tough, Johannes Siegrist, and Christine Fekete, “Social Relationships, Mental Health and Wellbeing in Physical Disability: A Systematic Review,” *BMC Public Health* 17, no. 1 (May 8, 2017): 18, <https://doi.org/10.1186/s12889-017-4308-6>; Simon Lasair, “Ethics, Politics, and Religion in Public Health Care: A Manifesto for Health Care Chaplains in Canada,” *Journal of Pastoral Care & Counseling* 70, no. 1 (March 1, 2016): 63–69, <https://doi.org/10.1177/1542305015619888>.

<sup>339</sup> Aru Narayanasamy, “Palliative Care and Spirituality,” *Indian Journal of Palliative Care* 13, no. 2 (2007): sec. Giving Spiritual Support.

<sup>340</sup> Hodge and Reynolds, “Spirituality among People with Disabilities,” 76.

contracts through hospitals to provide care in the community. However, these services are fragmented and not available to everyone. The primary reason for limited access to spiritual care in the healthcare system is insurance coverage provided to pay for spiritual care by commercial and government insurance (Medicaid and Medicare).<sup>341</sup> Addressing this crisis in unmet spiritual need requires governmental entities and insurance companies to work together and create solutions. A starting place is a provision of spiritual care to persons with disabilities in managed care.

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<sup>341</sup> “About,” HealthCare Chaplaincy Network.

## CHAPTER 4—CHAPLAINCY AS A COMPONENT OF PRIMARY CARE

Chaplains are uniquely positioned to journey with persons with disabilities and, as appropriate, support them as they reconnect with their faith or spiritual source of meaning and agency.<sup>342</sup> The Centers for Medicare and Medicaid Services (CMS) are placing increased emphasis on spiritual care as a key element of quality care, particularly in palliative and hospice care. As such, integration of spiritual care providers in care teams and the quality of spiritual assessments is becoming an important priority.<sup>343</sup>

A primary role of the spiritual care provider is to stand in solidarity with persons with disabilities to counter “values and structures that exclude, discriminate, hide or otherwise diminish people living with disabilities.”<sup>344</sup> In keeping with Catholic social justice teaching, a spiritual care provider works in solidarity with the person to ensure the healthcare delivery system provides them with the opportunity to “make their own decisions in relation to their own needs, relationships and communities.”<sup>345</sup> Chaplains are to engage with the healthcare system from a place of solidarity to ensure persons with disabilities have the right to self-determination, dignity of risk and the right to fail. It is therefore important that chaplains support the growth of an individual’s sense of agency

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<sup>342</sup> Albrecht, “The Disability Paradox,” 982.

<sup>343</sup> Arif H. Kamal et al., “The Quality Imperative for Palliative Care,” *Journal of Pain and Symptom Management* 49, no. 2 (February 2015): 247, <https://doi.org/10.1016/j.jpainsymman.2014.06.008>.

<sup>344</sup> “Catholic Social Teaching and Living with Disability,” Justice and Peace Office, accessed January 4, 2021, <http://justiceandpeace.org.au/catholic-social-teaching-and-living-with-disability/>.

<sup>345</sup> “Catholic Social Teaching and Living with Disability,” Justice and Peace Office.

and ability to make decisions that are meaningful and consistent with their personal values.

It is imperative that chaplains internalize a hermeneutic of solidarity with the people whom they are accompanying and become allies in their individual struggles and the larger struggle for just healthcare and social services for this population.<sup>346</sup> It is essential that chaplains involved in this endeavor do so engaging in continual action and reflection to understand their biases and develop communication and language that empowers agency, their own as well as those whom they are accompanying. Perhaps most important is the chaplain being open to move outside their comfort zones and value the person they are accompanying as a peer.<sup>347</sup> In the words of Pope Francis chaplains are called to engage a self-transformative process. They are to “perceive differences as a treasure. For Jesus does not call us servants, women and men of lesser dignity.”<sup>348</sup> The competency and capacity of the chaplain is directly connected with their ability to engage in a theology of humble presence.<sup>349</sup> A life-giving theology of presence in practice includes observation, listening, theological analysis and accompaniment that is dynamic.<sup>350</sup> As stated by McClure, “pastoral care is shaped by a hermeneutical circle of

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<sup>346</sup> Iozzio, “God Bends Over Backwards to Accommodate Humankind,” 29.

<sup>347</sup> Iozzio, “God Bends Over Backwards,” 29.

<sup>348</sup> Francis, “Message of the Holy Father Francis for the International Day of Persons with disabilities,” The Holy See, 2021, [https://www.vatican.va/content/francesco/en/messages/pont-messages/2021/documents/papa-francesco\\_20211120\\_messaggio-disabilita.html](https://www.vatican.va/content/francesco/en/messages/pont-messages/2021/documents/papa-francesco_20211120_messaggio-disabilita.html).

<sup>349</sup> Bonnie J. Miller-McLemore, *The Wiley Blackwell Reader in Practical Theology* (Hoboken, NJ: Wiley Blackwell, 2019), 270.

<sup>350</sup> Miller-McLemore, *The Wiley Blackwell Reader in Practical Theology*, 273.

reflective practice and practical theology.”<sup>351</sup> To be authentic, pastoral care that is life-giving has as its heart meaningful relationship.<sup>352</sup>

### **The Role of the Chaplain**

Healthcare chaplaincy in the modern era is radically different from healthcare chaplaincy in the past. In previous times, the chaplain represented a specific religious tradition and promoted the values of that tradition when accompanying patients and their families. The work of the chaplain was bound to an individual religious tradition and accountable to a specific church.<sup>353</sup> In the latter half of the twentieth century, chaplaincy moved from “religion serving the religious, to spirituality serving the community.”<sup>354</sup> In tandem with expanding the understanding of chaplaincy as a form of spiritual engagement has come a deeper understanding of chaplaincy as a profession that has a collective purpose and identity.<sup>355</sup>

Clinical Pastoral Education (CPE) has played a pivotal role in advancing a more humanist approach to chaplaincy that is not aligned with a particular faith tradition.<sup>356</sup> CPE focuses less on specific religious identity, using case studies that emphasize analysis

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<sup>351</sup> Miller-McLemore, *The Wiley Blackwell Reader in Practical Theology*, 270.

<sup>352</sup> Miller-McLemore, 270.

<sup>353</sup> Christopher Swift, “The Role of the Healthcare Chaplain: A Summary of the Contribution of Healthcare Chaplains to Modern Healthcare Practice,” in *Spirituality in Healthcare: Perspectives for Innovative Practice*, ed. Fiona Timmins and Sílvia Caldeira (Cham, Switzerland: Springer International Publishing, 2019), 152.

<sup>354</sup> Swift, “The Role of the Healthcare Chaplain,” 153.

<sup>355</sup> Swift, 152–153.

<sup>356</sup> Swift, 153.

of pastoral encounters.<sup>357</sup> Because CPE does not promote a particular religious tradition or culture, chaplains trained in this model can be more effective in advancing a standard of chaplaincy that better meets the needs of a secular society.<sup>358</sup> With increased professionalization has come increased integration of chaplaincy with care teams to better support and educate care team members about issues of spirituality and religion.<sup>359</sup> Positive working relationships between healthcare providers and chaplains can advance equity and justice by strengthening whole person care.<sup>360</sup>

Spiritual care can be identified as accompaniment with persons as they seek meaning and understanding in the context of pain or suffering.<sup>361</sup> In addition to spiritual care, chaplains may accompany a person creating a cohesive religious and spiritual narrative that is life-giving.<sup>362</sup> Ideally, spiritual care should begin with a spiritual assessment to identify a person's individual spiritual or religious needs, particularly in times of crisis.<sup>363</sup> The spiritual assessment is a valuable tool not just for chaplains, but for the entire care team as they seek to better understand and address a person's needs.<sup>364</sup>

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<sup>357</sup> Swift, "The Role of the Healthcare Chaplain," 153.

<sup>358</sup> Swift, 153–154.

<sup>359</sup> Swift, 154.

<sup>360</sup> Lynette Dungan, "Supervision, Spiritual Care and People-Centered Healthcare: Proposing Interdisciplinary Partnerships to Support Holistic Care," *Practical Theology* 9, no. 4 (2016): 345, <https://doi.org/10.1080/1756073X.2016.1223396>.

<sup>361</sup> Swift, "The Role of the Healthcare Chaplain," 155.

<sup>362</sup> Swift, 156.

<sup>363</sup> Swift, 157.

<sup>364</sup> Swift, 157.



One might identify three areas of potential spiritual pain or drivers of spiritual crisis using a spiritual care assessment tool: pain resulting from oppression, pain resulting from chronic pain, and psychic or existential pain.

Spiritual needs assessments provide information needed to develop a care plan for responding to the gaps in spiritual care needed by these persons.<sup>365</sup> Measuring spiritual needs requires specific knowledge about what the individual persons require and expect. Swinton makes clear that “spirituality may be universal, but it is worked out in the particularities of people’s lives.”<sup>366</sup> One’s designation as Muslim, Hindu, Christian, Buddhist or Jew or atheist provides very little information about what gives a person intimate meaning.<sup>367</sup> It is for this reason that going beyond what is personal self-designation through a spiritual assessment is vital to understanding and developing a person-centered care plan.

Spiritual assessment tools are part of the process of integrating spiritual care into an individual’s care plan. When conducted appropriately the assessment tool is a first step in identifying spiritual distress and identifying areas of spiritual or religious need.<sup>368</sup> Assessment of spiritual distress is of unique importance to persons with spinal cord

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<sup>365</sup> Arndt Büssing et al., “Factor Structure of the Spiritual Needs Questionnaire (SpNQ) in Persons with Chronic Diseases, Elderly and Healthy Individuals,” *Religions* 9, no. 1 (January 2018): 2, <https://doi.org/10.3390/rel9010013>.

<sup>366</sup> Wilfred McSherry and Linda Ross, eds., *Spiritual Assessment in Healthcare Practice* (Keswick, England: M&K Update Ltd, 2010), 28.

<sup>367</sup> McSherry and Ross, *Spiritual Assessment in Healthcare Practice*, 28.

<sup>368</sup> Robert Mundle, “‘I Should Be Closer To God Because of This’—A Case Study of Embodied Narratives and Spiritual Reconstruction in Spinal Cord Injury and Stroke Rehabilitation,” *Journal of Disability & Religion* 19, no. 1 (January 2, 2015): 35, <https://doi.org/10.1080/23312521.2014.990551>.

injuries and other survivors of physical trauma who are increasingly recognized as experiencing “much deeper inflictions and afflictions than just physiological or psychological harm, for there may also be wounds affecting the ‘soul’ that are far more difficult to heal—if at all.”<sup>369</sup>

Mental suffering can be equal to or surpass physical suffering in the face of inner conflict resulting from unresolved feelings of immorality, hypocrisy, or shame. These inner conflicts can be spiritual or religious and create barriers to inner harmony which in turn can exacerbate physical pain.<sup>370</sup> Whether such a conflict becomes a motivator that supports the person’s spiritual journey or barrier to spiritual existential growth may be contingent on access to spiritual supports.<sup>371</sup>

The biomedical model of disability inflicts a distinct form of pain on persons with disabilities by situating disability in the individual absent the social contextual framework that shapes the definition of disability.<sup>372</sup> This oppression, regardless of whatever access may be provided to persons with disabilities, will not disappear.<sup>373</sup> Our culture remains individualistic and focused on utilitarianism regardless of the built environment and accommodations provided to persons with disability.<sup>374</sup> Alongside the reality of physical

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<sup>369</sup> Lindsay B Carey et al., “Moral Injury, Spiritual Care and the Role of Chaplains: An Exploratory Scoping Review of Literature and Resources,” *Journal of Religion and Health* 55, no. 4 (2016): 1218, <https://doi.org/10.1007/s10943-016-0231-x>.

<sup>370</sup> Timmins and Caldeira, *Spirituality in Healthcare*, 33.

<sup>371</sup> Timmins and Caldeira, 33.

<sup>372</sup> Bryan S. Turner, *Routledge Handbook of Body Studies* (New York: Routledge, 2012), 256–257.

<sup>373</sup> Turner, *Routledge Handbook of Body Studies*, 258.

<sup>374</sup> Turner, 259–260.

and often chronic physical pain experienced by persons with disabilities is the permeating pain caused by mental distress or existential pain.

Disability can disrupt a person's sense of place in the universe. Spirituality or religion or combination of both can be an important source of meaning, but without support, this meaning may not be found, leading to spiritual crisis. Chaplains have an important role in addressing the gap, particularly if an individual feels isolated, depressed and without community.<sup>375</sup>

Chaplains are guests of the person with whom they are engaging. Successful chaplains gain permission from a person to enter into dialogue and develop trust, and discern the person's spiritual or religious history and concerns.<sup>376</sup> Chaplains actively listen, asking questions that support the person to share an unfolding narrative of their life, hopes and needs.<sup>377</sup> Dependent on an individual's expressed needs, chaplains work with the person one time or multiple times.<sup>378</sup> While it is important for the chaplain to protect an individual's confidences, it is also important that the chaplain provides some documentation of the visit or visits with a person in electronic health records as needed to support the care team's approach.<sup>379</sup> In addition to individual accompaniment, Chaplains

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<sup>375</sup> Swift, "The Role of the Healthcare Chaplain," 162.

<sup>376</sup> Swift, 159.

<sup>377</sup> Swift, 159.

<sup>378</sup> Swift, 159.

<sup>379</sup> Swift, 159.

assist with religious services including funerals or other important rituals as requested by an individual or family.<sup>380</sup>

### **Chaplaincy as Social Justice Praxis**

Chaplains not only have the “task of supporting the existential and spiritual processes of individuals, but they also have a role to play in the organizations in which they work and in society at large . . . it is their task to promote dialogue, moral deliberation, and social justice and to critique oppressive or dehumanizing practices.”<sup>381</sup> Chaplains must therefore engage in spiritual care as an activity of social justice praxis and liberative action. At the heart of liberative spiritual care is an affirmation of the imago Dei; that is, seeing and valuing persons with disabilities as full representations of imago Dei.<sup>382</sup> As stated by Reynolds,

Full personhood is neither diminished by disability nor confirmed by ability. Instead, it is a factor of the interdependent relationship to share with one another as creatures loved into being by God and in the image of God.<sup>383</sup>

Allyship begins with valuing people with disabilities as imago Dei. The chaplaincy being called for is one of liberative action. Chaplains engaged in One Care should support the individual’s immediate existential and wellness needs while ensuring

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<sup>380</sup> Swift, “The Role of the Healthcare Chaplain,” 159.

<sup>381</sup> Carmen Schuhmann and Annelieke Damen, “Representing the Good: Pastoral Care in a Secular Age,” *Pastoral Psychology* 67, no. 4 (2018): 405–417, <https://doi.org/10.1007/S11089-018-0826-0>

<sup>382</sup> Amos Young, *Theology and Down Syndrome: Reimagining Disability in Late Modernity (Studies in Religion, Theology, and Disability)* (Waco, TX: Baylor University Press, 2007), 158, 181, 184, 185.

<sup>383</sup> Reynolds, *Vulnerable Communion*, 42.

this type of chaplaincy. The chaplain's role is to support personal agency and peace whether in the form of religious, spiritual, or existential peace. In doing so, a chaplain can be part of a person's spiritual healing process and support their growth as agents of change.

Engaging in systems transformation means supporting the person's goals even if they do not fit into a strict medical construct, but instead advance the individual's ability to live a life of meaning. Chaplains should be promoting an understanding of *imago Dei* to persons with disabilities to prevent their dehumanization and the treatment of their diagnoses as poor health outcomes rather than as persons deserving of love and respect.<sup>382</sup>

Chaplains are called to be change agents in a medical construct that devalues persons with disabilities and too often denies their value as community members. They are to disrupt the status quo and help change the healthcare paradigm by breaking down narrowly defined frameworks of what are acceptable, normative physical, cognitive, mental or intellectual ways of being.<sup>384</sup> Chaplains must also grow beyond and embrace a theology that values *Imago Dei*.<sup>385</sup> Chaplains should not ignore disability but reject assumptions that reduce persons with disabilities to those experiencing punishment for sin or a means for God's will to be accomplished.

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<sup>384</sup> Deborah Beth Creamer, "Theology and the Disabled Body," in *Disability and Christian Theology: Embodied Limits and Constructive Possibilities* (New York: Oxford University Press, 2009), 53–74.

<sup>385</sup> Creamer, "Theology and the Disabled Body," 53–74.

Spiritual care is an engagement in liberation theology and in the struggle of people and populations who are poor and oppressed. Spiritual care is therefore a call to social justice, one that includes a duty to denounce injustice and defend the rights of peoples who are poor and vulnerable, whose rights have been dismissed or violated by violence.<sup>386</sup>

Therefore, central to accompaniment is being present to how the person's disability and other personal identifications shape their understanding of God or bring existential meaning. Spiritual care involves supporting an individual's capacity for self-determination by aiding the person as she develops her sense of agency and ability to define goals and take on new challenges.<sup>387</sup> Spiritual interventions must therefore incorporate the values of choice, control, and dignity of risk as integral to disability identity.<sup>388</sup> Dignity of risk involves providing the services and supports that enable people to do things they want to do but cannot do independently.<sup>389</sup> At the heart of the dignity of risk principle is the right to self-determination, even when the process requires

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<sup>386</sup> "Compendium of the Social Doctrine of the Church," The Holy See.

<sup>387</sup> Patrick J. Schloss, Sandra Alper, and Donna Jayne, "Self-Determination for Persons with Disabilities: Choice, Risk, and Dignity," *Exceptional Children* 60, no. 3 (1993): 223–24.

<sup>388</sup> Marta H. Woolford et al., "Applying Dignity of Risk Principles to Improve Quality of Life for Vulnerable Persons," *International Journal of Geriatric Psychiatry* 35, no. 1 (2020): 122–29, <https://doi.org/10.1002/gps.5228>.

<sup>389</sup> Marta H. Woolford et al., "Applying Dignity of Risk Principles to Improve Quality of Life for Vulnerable Persons," *International Journal of Geriatric Psychiatry* 35, no. 1 (2020): 125, <https://doi.org/10.1002/gps.5228>.

taking on risk.<sup>390</sup> It is the inherent belief that personal growth and quality of life requires some level of risk.<sup>391</sup>

#### Rev. Wade Blank

While the disability rights movement is not religious, one of the most radical disability rights organizations that shaped the movement had as one of its leaders minister Rev. Wade Blank. Blank was instrumental in establishing the American Disabled for Attendant Programs Today (ADAPT), “a national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom.”<sup>392</sup> Blank, an “iconoclastic minister and civil rights worker,” was an able-bodied Presbyterian minister who cut his teeth in the civil rights movement supporting Martin Luther King Jr and then as an antiwar protester.<sup>393</sup> He envisioned a “society where human beings could live in equality and develop the power to effect change.”<sup>394</sup>

While not a chaplain, Blank embodied the true spirit of what it means to be a chaplain in his role as a recreational director working in a nursing home. Blank “found himself in the midst of a ‘community’ of people with severe disabilities, whose only

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<sup>390</sup> Gerben DeJong, “Independent Living: From Social Movement to Analytic Paradigm,” *Archives of Physical Medicine and Rehabilitation* 60 (1979): 442.

<sup>391</sup> Woolford et al., “Applying Dignity of Risk Principles,” 123.

<sup>392</sup> “Welcome to American Disabled for Attendant Programs Today,” ADAPT.

<sup>393</sup> “History of ADAPT’s Founder Wade Blank,” Transitional Paths to Independent Living; “The Denver Public Library EAD Project.”

<sup>394</sup> “History of ADAPT’s Founder Wade Blank.”

community structure was one of oppression—the confines of the institution—he took on the challenge of making the ‘liberated community’ a reality”<sup>395</sup>

Ignoring disability not only hinders our possibilities for reflecting on the fact that the full range of human embodiedness includes experiences of disability; it also causes us to fail to reflect appropriately on the real lived experiences of “nondisability.”<sup>396</sup>

This failure leads us to uncritically accept an assumption that most of us are “normal,” that disability and other related experiences are “abnormal,” and that “normal” perspectives are central and have theological priority. To be meaningful, the advancement of spiritual care for persons with disabilities must—in the spirit of Paulo Freire—not only be a struggle to gain the humanity of persons with disabilities, but to restore the humanity of oppressors who shape the healthcare delivery system.<sup>397</sup>

To be authentic, chaplains engaging with One Care members must follow the example of Blank. They need to have the same openness to embracing community among persons with disabilities and the same vision to be reformers, taking on the structures of oppression that prevent people from realizing their identities as wholly human beings created in the image and likeness of their creator. To be relevant, they must embrace the opportunities to recognize Kairos in the postmodern setting and revel in their opportunity to connect with “different others, God, or the sacred, and the cosmos passes along

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<sup>395</sup> “History of ADAPT’s Founder Wade Blank.”

<sup>396</sup> Creamer, “Theology and the Disabled Body.”

<sup>397</sup> Paulo Freire, *Pedagogy of the Oppressed: 30th Anniversary Edition* (New York: Bloomsbury Publishing, 2014), 530.



unexplored.”<sup>398</sup> In essence, they are to be a sign of the times and embrace the signs. To do otherwise is to be trapped in paradigms of the past and ineffectual in pastoral efforts to journey with people who seek new understandings of their spiritual identity and opportunities to be in interdependent relationship with others.

In the post-Christian, postcolonial era, chaplains have an important role in healing harm caused by religious beliefs across traditions by engaging in spiritual accompaniment that demythologizes hegemonic models of religion.<sup>399</sup> They can do so by embracing accompaniment with the understanding that a person’s spirituality reflects their lived experience and need not conform to any specific religious or theological framework. For example, chaplains must embrace transgender identity and disability as two normative ways of being. Trans persons experience singular forms of secular and religious discrimination and, apart from disability, are too often viewed as evil or “disabled.” It is important that chaplains not only ally with transgender persons but include transgender chaplains.

Chaplains are in a unique position to engage in liberative activities that promote “negative freedom”<sup>400</sup> by taking on the systems that actively oppress persons with disabilities to demand rights beyond the bounds of the medical model and “positive

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<sup>398</sup> Cesar Gabad Espineda, “Leading Patients: Emerging Paradigms of Pastoral Leadership in Multi-Faith Health Care Facilities” (PhD diss., Fordham University, 2001), 5, <http://search.proquest.com/docview/250825373/abstract/8BE84140BCE34DFBPQ/1>.

<sup>399</sup> Charlton, *Nothing About Us Without Us*, 64.

<sup>400</sup> Stephen Pattison, *Pastoral Care and Liberation Theology* (Cambridge, UK: Cambridge University Press, 1994), 28.

freedom”<sup>401</sup> by accompanying persons in a manner that promotes personal agency and wholeness.<sup>402</sup> In this respect, it is incumbent on chaplains to analyze the pastoral care needs of a person within their social and political context. The spiritual assessment done by the chaplain is not just an assessment of the person but of the systems that impact the person.<sup>403</sup>

In his book *Disability and Spirituality: Recovering Wholeness*, William Gaventa calls on each of us to “deepen our understanding and capacity to support persons with disabilities and their families as they seek to live lives full of quality and meaning.”<sup>404</sup> He calls on us to be people engaged in “repairing the world” from the Jewish concept of tikkun [olam].<sup>405</sup> He also describes this work as embracing the call to actively engage in repairing the “breach between God and humankind. . . . Bridging the gap between spirituality and disability as are commonly understood.”<sup>406</sup> Addressing the breach requires us to overcome the limitations that divide us into what Gaventa describes as “separate boxes of knowledge, distinguished more by their differences and limits than by

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<sup>401</sup> Pattison, *Pastoral Care and Liberation Theology*, 28.

<sup>402</sup> “Healing the Healers,” Faith Matters Network, accessed January 19, 2022, <https://www.faithmattersnetwork.org/our-vision>.

<sup>403</sup> Pattison, *Pastoral Care and Liberation Theology*, 8.

<sup>404</sup> Gaventa, *Disability and Spirituality*, 23.

<sup>405</sup> Gaventa, 23.

<sup>406</sup> Gaventa, 24.

the gifts.”<sup>407</sup> Gaventa contends, and I agree, that there is a deep need to restore wholeness “between the ‘world’ of disability and spirituality.”<sup>408</sup>

Central to healing this breach is opening oneself to the extent of the “vulnerability and fragility of human life.”<sup>409</sup> Important questions to address include “‘Who am I?,’ ‘Why am I?’ and ‘Whose am I?’”<sup>410</sup> Existential suffering arising from the denial of human rights can exceed or exacerbate the suffering that may be inherent within disability itself.<sup>411</sup> It is therefore incumbent on chaplains to engage in spiritual care within care teams in a manner that supports self-determination, choice, risk, and dignity.<sup>412</sup> This is not a denial of the suffering that may be inherent in some impairments; it emphasizes changing systems and making it clear that disability is not a poor medical outcome but instead part of the human experience.<sup>413</sup> It is about identity.

Given the number of people an individual with disabilities may interact with in healthcare, it is important to have clearly identified roles for parties. Spiritual care is not only the domain of chaplains. In fully integrated care systems, providers need to feel

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<sup>407</sup> Gaventa, *Disability and Spirituality*, 295.

<sup>408</sup> Gaventa, 295.

<sup>409</sup> Gaventa, 296.

<sup>410</sup> Gaventa, 295-296.

<sup>411</sup> Brian Watermeyer and Leslie Swartz, “Disablism, Identity and Self: Discrimination as a Traumatic Assault on Subjectivity,” *Journal of Community and Applied Social Psychology* 26, no. 3 (December 2015): 270, 272, <https://doi.org/10.1002/casp.2266>.

<sup>412</sup> Schloss, Alper, and Jayne, “Self-Determination for Persons with Disabilities.”

<sup>413</sup> Margaret Wangui Murugami, “Disability and Identity,” *Disability Studies Quarterly* 29, no. 4 (November 5, 2009), <http://dsq-sds.org/article/view/979>.

comfortable identifying the spiritual needs of the individuals in their care so they can effectively work with certified chaplains as care team members.<sup>414</sup> Certified healthcare chaplains are already familiar with the needs of persons with complex cognitive, mental health, medical and other needs within the medical setting. They are also familiar with working with medical teams.<sup>415</sup> Health professionals, chaplains and patients' relatives will then have a chance to respond to those needs.

Chaplains should also receive training on how care teams in community settings function compared to medical settings. It is important that chaplains have the ability to connect people in need of spiritual and other supports to faith communities or communities that can foster growth of their sense of existential meaning. Support provided by these communities should include practical assistance in the form of food, clothing, and community services; “socioemotional” support by welcoming a person so they feel loved, cared for, and have a sense of worth; and spiritual support by aiding a person to live out their faith more fully.<sup>416</sup>

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<sup>414</sup> Harold G. Koenig, “The Spiritual Care Team: Enabling the Practice of Whole Person Medicine,” *Religions* 5, no. 4 (2014): 1161–1174. <https://doi.org/10.3390/rel5041161>.

<sup>415</sup> Paula Teague et al., “The Role of the Chaplain as a Patient Navigator and Advocate for Patients in the Intensive Care Unit: One Academic Medical Center’s Experience,” *Journal of Religion and Health* 58, no. 5 (2019): 1841, <https://doi.org/10.1007%2Fs10943-019-00865-z>.

<sup>416</sup> Tracy A. Balboni et al., “Provision of Spiritual Support to patients with Advanced Cancer by Religious Communities and Associations with Medical Care at the End of Life,” *JAMA Internal Medicine* 173, no. 12 (2013): 1117, <https://doi.org/10.1001/jamainternmed.2013.903>.

## CHAPTER 5—ONE CARE AS UNIQUE SPIRITUAL CARE OPPORTUNITY

The Massachusetts Medicaid agency known as “MassHealth” is responsible for insuring “1.9 million residents: children in low-income households; low wage workers; elders in nursing homes; people with disabilities; and others with very low incomes who cannot afford insurance.”<sup>417</sup> MassHealth is presently engaging in systemwide healthcare delivery transformation with the goal of building a more sustainable and integrated whole-person-centered model of care for its 1.9 million members.<sup>418</sup>

Integrated whole-person-centered care emphasizes the importance of relationships and the individual’s interconnectedness with their social world and values as important care elements.<sup>419</sup> Ideally, interpersonal, and integrated care focuses on prevention and promotes the ability of individuals living with disabilities to maintain harmony and balance as they strive to live a life of meaning and well-being.<sup>420</sup> In this model, care teams build partnerships with social service organizations as well as healthcare providers to meet the social needs of a person.<sup>421</sup> Of great importance is providing individuals the

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<sup>417</sup> “What Is the Actual State Cost of MassHealth in 2018?” MassBudget, Massachusetts Budget and Policy Center, accessed January 12, 2019, [http://massbudget.org/report\\_window.php?loc=What-Is-the-Actual-State-Cost-of-MassHealth-in-2018.html](http://massbudget.org/report_window.php?loc=What-Is-the-Actual-State-Cost-of-MassHealth-in-2018.html).

<sup>418</sup> “MassHealth Innovations,” MassHealth, accessed January 12, 2019, <https://www.mass.gov/masshealth-innovations>.

<sup>419</sup> Zahra Ebrahimi et al., “A Systematic Review on Implementation of Person-Centered Care Interventions for Older People in out-of-Hospital Settings,” *Geriatric Nursing* 42, no. 1 (2021): 214, <https://doi.org/10.1016/j.gerinurse.2020.08.004>.

<sup>420</sup> Ebrahimi et al., “A Systematic Review,” 221.

<sup>421</sup> “Weaving Whole-Person Health Throughout An Accountable Care Framework: The Social ACO,” Health Affairs Blog, January 25, 2017, accessed October 3, 2022, <https://doi.org/10.1377/hblog20170125.058419>.

opportunity to develop the medical and nonmedical care goals as part of the care planning process. This includes providing opportunities for people to reflect on and integrate spiritual aspects of their lives into the care plans.<sup>422</sup>

Working age persons with disabilities form a large subset of this population. Over 60% of working age adults with disabilities receive health insurance from both Medicaid and Medicare (dual eligibles).<sup>423</sup> As of 2019, 148,000 or 47% of those dual eligible are under age 65.<sup>424</sup> Dual-eligible enrollees comprise 18% of the total MassHealth enrollment but 29% of the MassHealth budget. Dual-eligible members “often require high-touch, high-intensity-and ultimately high cost-services to support their daily living.”<sup>425</sup>

Working age adults with disabilities are disproportionately women of color, do not have a usual healthcare provider, and have unmet health care needs and did not have a routine checkup in the past year.<sup>426</sup> This population also experiences greater levels of isolation, depression, socio—economic disadvantage and increased risk of morbidity and mortality compared with people of the same age group who do not report having a

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<sup>422</sup> Sandra Ellen Schellinger et al., “Patient Self-Defined Goals: Essentials of Person-Centered Care for Serious Illness,” *The American Journal of Hospice & Palliative Care* 35, no. 1 (2018): 161–163, doi:10.1177/1049909117699600.”

<sup>423</sup> “19 Million Working-Age Americans Have a Disability that Limits or Prevent Work,” AARP Public Policy Institute, accessed July 5, 2021, [https://assets.aarp.org/rgcenter/econ/fs153\\_ssdi.pdf](https://assets.aarp.org/rgcenter/econ/fs153_ssdi.pdf).

<sup>424</sup> Stephanie Anthony, Kevin McAvey, and Jacqueline Marks, “The Dual Eligible Population in Massachusetts: Data Chart Pack,” Blue Cross Blue Shield of Massachusetts Foundation, March 2021, [https://www.bluecrossmafoundation.org/sites/g/files/ksphws2101/files/2021-03/Primer\\_Data\\_Chartpack\\_FINAL\\_1.pdf](https://www.bluecrossmafoundation.org/sites/g/files/ksphws2101/files/2021-03/Primer_Data_Chartpack_FINAL_1.pdf).

<sup>425</sup> Anthony, McAvey, and Marks.

<sup>426</sup> “Disability Impacts All of Us,” Disability and Health Promotion, Centers for Disease Control and Prevention, March 8, 2019, <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>.

disability. Dual-eligible adults 21–64 are also disproportionately impacted by negative social determinants of health such as low levels of education, poverty, social isolation, and depression.<sup>427</sup>

The spiritual needs of persons with disabilities enrolled in the Massachusetts One Care Dual Eligible plan go unmet. As of December 2019, enrollment in One Care was approximately 25,000 members.<sup>428</sup> The population eligible for One Care services has complex medical, behavioral health, social, and other support needs. The plan seeks to provide “patient-centered care” by offering enhanced care coordination and services to improve its members’ health and wellness and reduce costs.<sup>429</sup> Lacking from the One Care model, however, is the inclusion of chaplaincy or other spiritual services.

### **Why One Care?**

One Care requires plans to provide integrated whole-person-centered care to Massachusetts residents with Medicaid and Medicare between the ages of 21–64 based

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<sup>427</sup> Emerson et al., “Loneliness, Social Support, Social Isolation and Wellbeing,” 4; Petroutsou Alexandra, Hassiotis Angela, and Afia Ali, “Loneliness in People with Intellectual and Developmental Disorders across the Lifespan: A Systematic Review of Prevalence and Interventions,” *Journal of Applied Research in Intellectual Disabilities* 31, no. 5 (2018): 643658, <https://doi.org/10.1111/jar.12432>; Johanna Mithen et al., “Inequalities in Social Capital and Health between People with and without Disabilities,” *Social Science and Medicine* (2015): 32–33, <https://doi.org/10.1016/j.socscimed.2014.12.009>.

<sup>428</sup> “One Care: December 2019 Enrollment Report,” Executive Office for Health and Human Services, Commonwealth of Massachusetts, accessed December 27, 2021, <https://www.mass.gov/doc/december-2019-enrollment-report-0/download>.

<sup>429</sup> “One Care Background Information,” Commonwealth of Massachusetts, 2020, <https://www.mass.gov/service-details/one-care-background-information>; “One Care Fact Sheets & Other Materials,” Commonwealth of Massachusetts, 2020, <https://www.mass.gov/service-details/one-care-fact-sheets-other-materials>.

on disability status.<sup>430</sup> Dual eligibles in this age group experience high levels of substance use disorder, mental health diagnoses, complex medical diagnoses, and social need.<sup>431</sup> In addition, dual-eligible people are at increased risk of loneliness, isolation and other factors that lead to poor health outcomes.<sup>432</sup>

Most enrollees in One Care have a complex disability or illness “that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life or excessively strains the caregiver.”<sup>433</sup> One Care is mandated to offer flexible services to assist enrollees to get their individual healthcare needs met and achieve their personal wellness goals.<sup>434</sup> Wellness includes the opportunity for meaningful engagement in the community.<sup>435</sup> By requiring One Care to offer spiritual care to enrollees,

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<sup>430</sup> “OneCare Report.” Blue Cross Blue Shield of Massachusetts Foundation, accessed July 13, 2019, [https://bluecrossmafoundation.org/sites/default/files/download/publication/OneCare\\_Report\\_FINAL.pdf](https://bluecrossmafoundation.org/sites/default/files/download/publication/OneCare_Report_FINAL.pdf).

<sup>431</sup> “The CBHSQ Report,” Substance Abuse and Mental Health Services Administration, accessed September 25, 2021, <https://www.samhsa.gov/data/sites/default/files/SR180/sr180-dual-eligibles-2014.pdf>.

<sup>432</sup> Christina R. Victor and Keming Yang, “The Prevalence of Loneliness Among Adults A Case Study of the United Kingdom,” accessed September 25, 2021, <https://doi.org/10.1080/00223980.2011.613875>; Ellen E. Lee et al., “High Prevalence and Adverse Health Effects of Loneliness in Community-Dwelling Adults across the Lifespan: Role of Wisdom as a Protective Factor,” *International Psychogeriatrics* 31, no. 10 (October 2019): 1447–62, <http://dx.doi.org.ezproxy.bu.edu/10.1017/S1041610218002120>; Tilmann von Soest et al., “Development of Loneliness in Midlife and Old Age: Its Nature and Correlates,” *Journal of Personality and Social Psychology* 118, no. 2 (February 2020): 388–406, <https://doi.org/10.1037/pspp0000219>; Julianne Holt-Lunstad et al., “Loneliness and Social Isolation as Risk Factors for Mortality: A Meta-Analytic Review,” *Perspectives on Psychological Science* 10, no. 2 (March 1, 2015): 227–37, <https://doi.org/10.1177/1745691614568352>.

<sup>433</sup> Amy S. Kelley and Evan Bollens-Lund, “Identifying the Population with Serious Illness: The “Denominator” Challenge,” *Journal of Palliative Medicine* 21, no. S2 (2018): 7–16, <https://doi.org/10.1089/jpm.2017.0548>.

<sup>434</sup> Barry et al., “Early Insights from One Care.”

<sup>435</sup> “One Care,” Boston Center for Independent Living,” accessed November 17, 2019, <https://bostoncil.org/community-living-and-participation/one-care/>.



policymakers will be ensuring increased availability of resources and services that support health and wellness they are not receiving right now.

Spiritual care in community-based health care to persons with disabilities enrolled in Massachusetts One Care should be provided to enrollees as an optional service. A high percentage of enrollees in One Care has significant cognitive, physical, and behavioral needs exacerbated by inequities resulting from discrimination and structural bias endemic to the health care system and society at large. Outlined below are reasons why One Care's unique model of care and financing structure provides an opening for the integration of spiritual care. One Care insurance coverage is available to the State's residents, ages 21–64, who are covered by Medicaid and Medicare. It provides enhanced whole-person-centered care to the Commonwealth's highest need and highest cost populations.

Community-based serious illness care does not have a standard definition, but usually includes medical care focused on managing and improving symptoms associated with disease or treatments and 24/7 telephone support. Less frequently, it includes services such as in-home physician visits for primary or palliative care, aide visits, in-home nursing care, behavioral health care and spiritual support.”<sup>436</sup>

I have already provided examples of existing healthcare chaplaincy programs available to people seeking spiritual care outside of a hospital and other institutional walls. Community-based palliative care team's flexibility built into the 2010 Affordable

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<sup>436</sup> “Serious Illness Care: Person-Driven Measures for Accountability,” National Committee for Quality Assurance, accessed August 26, 2020, [https://www.ncqa.org/wp-content/uploads/2019/11/20180306\\_Report\\_SeriousIllnessCare.pdf](https://www.ncqa.org/wp-content/uploads/2019/11/20180306_Report_SeriousIllnessCare.pdf).

Care Act (ACA) has the potential to make chaplaincy services available beyond the current limited scope of institutional medical settings and end-of-life care. In the UK, chaplains are integrated into general practice care teams.

The ACA includes provisions that enable eligible states to implement “dual-eligible” demonstration projects.<sup>437</sup> The “duals” population includes the highest cost populations in the nation: “frail elders,” persons with physical disabilities, cognitive impairments, developmental disabilities, mental illness, and substance use disorder (SUD).<sup>438</sup>

The goal of the dual-eligible project is to achieve cost savings and improved quality of care for persons whose only sources of insurance are Medicaid and Medicare.<sup>439</sup> States have the latitude to leverage Medicaid and Medicare funding streams to better meet this population’s needs. This leverage includes a requirement that states rebalance spending away from high-cost medical services, including preventable

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<sup>437</sup> Sandra L. Strokoff and Edward G. Grossman, “Compilation of Patient Protection and Affordable Care Act—Patient Protection and Affordable Care Act Health-Related Portions of the Health Care and Education Reconciliation Act of 2010,” *Office of the Legislative Counsel*, 2010, 974; Strokoff, 225–26; Strokoff, 233–35.

<sup>438</sup> “Medicare-Medicaid Integration Demonstration for Massachusetts (Duals Demonstration 2.0),” MassHealth, The Commonwealth of Massachusetts, June 2018, 3, 9, <https://www.mass.gov/doc/draft-concept-paper-duals-demonstration-20-06-13-18/download>; “CMS Guidance: Reporting Expectations for Dual-Eligible Beneficiaries, Updated,” Centers for Medicare & Medicaid Services, accessed October 11, 2020, <https://www.medicare.gov/medicaid/data-and-systems/macbis/tmsis/tmsis-blog/entry/51064>; “Frail Elder Waiver: Information for Applicants and Participants,” MassHealth and Executive Office of Elder Affairs, accessed October 11, 2020, sec III, <https://www.mass.gov/info-details/frail-elder-waiver-information-for-applicants-and-participants#:~:text=I-,About%20the%20Program,in%20FEW%20at%20any%20time>.

<sup>439</sup> “Section 1115 Demonstration Project Request (SFY 2015 – SFY 2019),” MassHealth, September 30, 2013, 5, <https://www.mass.gov/doc/section-1115-demonstration-extension-request-submitted-to-cms-3/download>.

emergency department (ED) visits and preventable hospitalizations, and investing those resources into community-based services.<sup>440</sup>

The University of Massachusetts (UMass) recently reported findings from its 2017 to 2019 surveys of One Care member self-reported quality of life indicators. Most survey respondents reported that spirituality or religion is important to their life. The UMass findings are in line with other research on disability and spirituality.<sup>441</sup> Most respondents also reported that they wanted more support from other people. In 2019 UMass included a question on feelings of loneliness. Almost half of the respondents reported they often experience loneliness.

Responses of One Care enrollees are also consistent with the literature on the intersection of loneliness, isolation, and disability status. Offering spiritual care to this population is necessary for three reasons: A literature review shows a direct correlation between loneliness, isolation and depression that can result in preventable morbidity and

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<sup>440</sup> “Medicare-Medicaid Integration Demonstration for Massachusetts MassHealth, 2.

<sup>441</sup> Kaye and Raghavan, “Spirituality in Disability and Illness,” 231–242; Carlos A Reyes-Ortiz. “Spirituality, Disability and Chronic Illness,” *Southern Medical Journal* 99, no. 10 (2006): 1172–1173, <https://doi.org/10.1097/01.smj.0000242805.02180.63>; Boni Boswell et al., “Disability and Spirituality: A Reciprocal Relationship with Implications for the Rehabilitation Process,” *Journal of Rehabilitation* 67, no. 4 (2001): 20–25; Barbara Brillhart, “A Study of Spirituality and Life Satisfaction Among Persons with Spinal Cord Injury,” *Rehabilitation Nursing Journal* 30, no. 1 (2005): 31–34, <https://doi.org/10.1002/j.2048-7940.2005.tb00353.x>; Elizabeth N. Matheis, David S. Tulskey, and Robert J. Matheis, “The Relation Between Spirituality and Quality of Life Among Individuals with Spinal Cord Injury,” *Rehabilitation Psychology* 51, no. 3 (August 2006): 265–271, <https://doi.org/10.1037/0090-5550.51.3.265>; Theresa Lorenzo and Madeleine Duncan, “Deep Down in Our Hearts: A Spirituality of Disability that Enables Social Belonging for Economic and Political Inclusion of Women with Disabilities,” *Journal of Disability and Religion* 25, no. 2 (2021): 110–131, <https://doi.org/10.1080/23312521.2020.1816245>; Emily K. Schulz, “Spirituality and Disability: An Analysis of Select Themes,” *Occupational Therapy in Health Care* 18, no. 4 (2005): 57–83, [https://doi.org/10.1080/J003v18n04\\_05](https://doi.org/10.1080/J003v18n04_05).

mortality.<sup>442</sup> The literature shows that spirituality and spiritual care can improve overall wellness.<sup>443</sup>

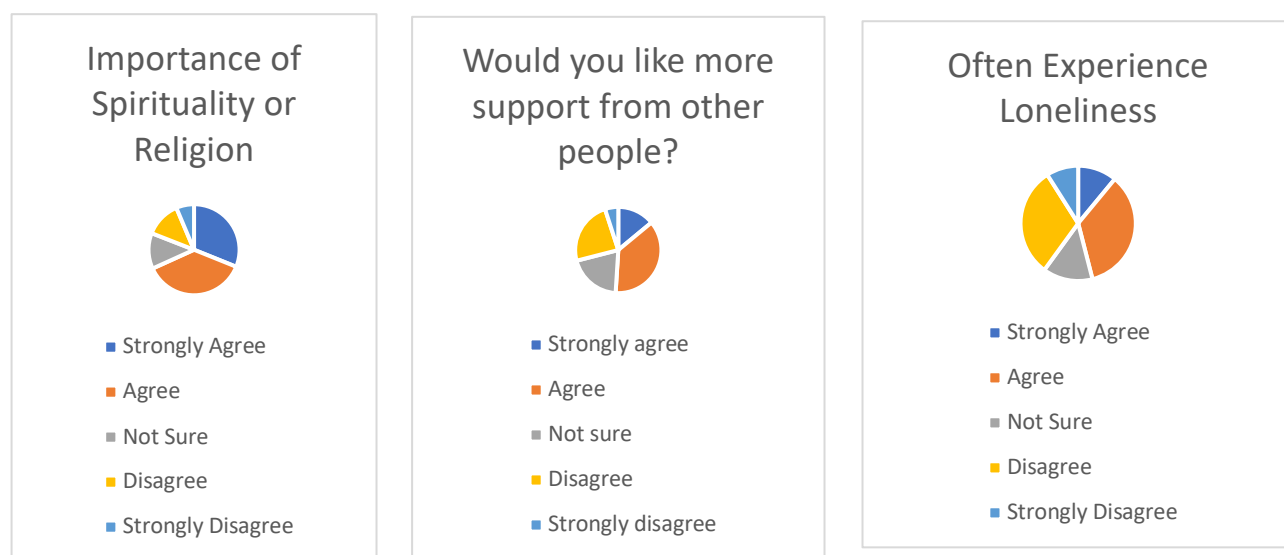


Fig. 2—Findings from the One Care Quality of Life Surveys 2017–2019  
Graphs are from Massachusetts One Care Implementation Council.<sup>444</sup>

<sup>442</sup> Ricardo Pagan, “Gender and Age Differences in Loneliness: Evidence for People without and with Disabilities,” *International Journal of Environmental Research and Public Health* 17, no. 24 (January 2020): 10, 11, <https://doi.org/10.3390/ijerph17249176>; Macdonald, “The Invisible Enemy,” 1138–59; Emerson et al., “Loneliness, Social Support, Social Isolation and Wellbeing,” 5, 6.

<sup>443</sup> Boswell et al., “Disability and Spirituality,” 16; Merja Tarvainen, “Loneliness in Life Stories by People with Disabilities,” *Disability & Society* 36, no. 6 (2021): 865, 879, 880, <https://doi.org/10.1080/09687599.2020.1779034>; William Gaventa, “Disability and Spirituality: Re-Membering Wholeness in Services and Supports,” *Journal of Disability & Religion* 20, no. 4 (October 1, 2016): 307–315, <https://doi.org/10.1080/23312521.2016.1239155>.

<sup>444</sup> “Findings from the One Care Quality of Life Surveys 2017–2019,” Commonwealth Medicine, Commonwealth of Massachusetts, September 2021, <https://www.mass.gov/doc/implementation-council-quality-of-life-survey-report-9-14-21-0/download>.

## **Leveraging Opportunities in the Bureaucracy**

The federal government has been providing spiritual care since 1865, when chaplaincy services became required services available to veterans.<sup>445</sup> Yet, perhaps due to concern over religious freedoms or misunderstandings of the nature of spirituality, chaplains were officially defined as clinical employees in 2020 when CMS approved standardized Healthcare Common Procedure Coding System (HCPCS).<sup>446</sup> The new HCPCS codes call for spiritual care to be provided by Board-certified chaplains to advance integrated care for veterans.<sup>447</sup> To be a Board-certified chaplain, an individual

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<sup>445</sup> “History of the Department of Veterans Affairs Chaplain Service,” U.S. Department of Veteran Affairs, [https://www.patientcare.va.gov/chaplain/docs/History\\_Department\\_Veterans-Affairs\\_Chaplain\\_Service.pdf](https://www.patientcare.va.gov/chaplain/docs/History_Department_Veterans-Affairs_Chaplain_Service.pdf).

<sup>446</sup> “History of the Department of Veterans Affairs Chaplain Service,” U.S. Department of Veteran Affairs; “Centers for Medicare & Medicaid Services (CMS) Agenda for Healthcare Common Procedure Coding System (HCPCS) Public Meeting for Code Applications for Non-Drug and Non-Biological Items and Services Submitted to CMS’ 1st 2021 Biannual HCPCS Coding Cycle,” Centers for Medicare & Medicaid Services, July 7, 2021, <https://www.cms.gov/files/document/hcpcs-public-meeting-agenda-july-7-2021.pdf>; “VA health care first to have Centers for Medicare & Medicaid Services codes for chaplain care,” U.S. Department of Veterans Affairs, July 16, 2020, <https://www.va.gov/opa/pressrel/includes/viewPDF.cfm?id=5488>; “Alpha-Numeric HCPCS,” Centers for Medicare & Medicaid Services, last modified May 9, 2022, <https://www.cms.gov/Medicare/Coding/HCPCSReleaseCodeSets/Alpha-Numeric-HCPCS>; “First Biannual, 2020 Coding Cycle for Durable Medical Equipment (DME) and Accessories; Orthotics, Prosthetics (O & P), and Supplies,” Centers for Medicare & Medicaid Services, 2020, <https://www.cms.gov/files/document/2020-hcpcs-application-summary-bi-annual-1-2020-durable-medical-equipment-dme-and-accessories.pdf>.

<sup>447</sup> “History of the Department of Veterans Affairs Chaplain Service,” U.S. Department of Veterans Affairs; “Centers for Medicare & Medicaid Services (CMS) Agenda for Healthcare Common Procedure Coding System (HCPCS) Public Meeting,” Centers for Medicare & Medicaid Services; “VA health care first to have,” U.S. Department of Veterans Affairs; “Alpha-Numeric HCPCS,” Centers for Medicare & Medicaid Services; “First Biannual, 2020 Coding Cycle,” Centers for Medicare & Medicaid Services.

must have completed a certified training program and must meet established qualifications and competencies required of chaplains.<sup>448</sup>

Spiritual care is a required covered service for veterans and persons in hospice without providing a direct path for payment of chaplains to provide this spiritual care.<sup>449</sup> For example, hospital spiritual care reimbursement is done through complicated bundled payments, such as Medicare pass-through funding for chaplaincy accreditation programs conducted by staff certified chaplains.<sup>450</sup> Similar contracting impediments impact hospice and palliative care healthcare agencies.

CMS identifies spiritual services as an important component of HCBS in its Education to American Indian Alaska natives. CMS describes a variety of person-centered HCBS services available to address the needs of people with functional limitations. In addition to listing services such as bathing and dressing to help people

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<sup>448</sup> “Advocating for Professional Chaplaincy: The Benefits of BCCI Board Certification,” Board of Chaplaincy Certification, Inc., accessed October 3, 2022, [https://bcciprofessionalchaplains.org/Files/benefits\\_of\\_bcc.pdf](https://bcciprofessionalchaplains.org/Files/benefits_of_bcc.pdf).

<sup>449</sup> “Hospice,” Centers for Medicare & Medicaid Services, last modified March 14, 2022, <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice>; “Beyond Certification: Looking At the Future of Chaplaincy,” The Chaplain’s Report, September 24, 2021, <https://chaplainsreport.com/2021/09/24/beyond-certification-looking-at-the-future-of-chaplaincy/>; “Condition of participation: Core Services,” Legal Information Institute, Cornell Law School, <https://www.law.cornell.edu/cfr/text/42/418.64>.

<sup>450</sup> “Medicare Pass-Through,” ACPE, 2020, <https://acpe.edu/news-resources/resources/medicare-pass-through>; “Beyond Certification,” The Chaplain’s Report; “Cost of approved nursing and allied health education activities,” GovInfo, October 1, 2011, <https://www.govinfo.gov/app/details/CFR-2011-title42-vol2/CFR-2011-title42-vol2-sec413-85>.

remain in the community and out of institutions, it includes “spiritual and cultural activities” under the umbrella of health services.<sup>451</sup>

However, CMS has not expanded these codes beyond VHA, leaving hospitals, hospice agencies, and other groups without the codes needed to track chaplaincy services or pay for those services directly. A potential way for CMS to seamlessly integrate direct payment of chaplaincy care is through fully capacitated dual-eligible plans such as Fully Integrated Dual Eligible Special Needs Plan (FIDE SNPs) and Program of All-Inclusive Care for the Elderly (PACE). While different in many respects, both FIDE SNPs and PACE are highly integrated, person-centered, and have some ability offer supplemental services that may include spiritual care to the members.<sup>452</sup>

### **FIDE SNPs and PACE**

The Center for Medicaid and Medicare Innovation (CMMI) is developing and testing new health payment and service delivery models to improve health outcomes and reduce cost. However, it has not yet developed a comprehensive strategy for integrating spiritual care across its portfolio of care plans. For example, PACE plans provide fully

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<sup>451</sup> “Home- and Community-Based Services,” Centers for Medicare & Medicaid Services, last modified June 15, 2022, <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/hcbs>.

<sup>452</sup> Kathryn A. Coleman and Sharon Donovan, “Frequently Asked Questions on Coordinating Medicaid Benefits and Dual Eligible Special Needs Plans Supplemental Benefits,” Centers for Medicare and Medicaid Services, May 27, 2021, accessed October 3, 2022, <https://www.cms.gov/files/document/dsnpmedicaremedicaidcoordbenefitsfaqs.pdf>. “National PACE Association Model State Reporting Framework Project,” National PACE Association, accessed October 3, 2022, [https://www.npaonline.org/sites/default/files/PDFs/NPA%20Model%20State%20Reporting%20Framework%20Project\\_Gap%20Analysis.pdf](https://www.npaonline.org/sites/default/files/PDFs/NPA%20Model%20State%20Reporting%20Framework%20Project_Gap%20Analysis.pdf).

integrated care and have the flexibility to provide non-traditional “flexible ‘value-added’ services including spiritual care/chaplain services outside of hospice . . . and other social services.”<sup>453</sup> In contrast to VHA, services are not captured through encounter or utilization reporting, but are value-added services.<sup>454</sup>

CMMI should require FIDE SNPs and PACE plans to provide enrollees with spiritual assessments and spiritual care as optional services. It is recommended that these codes be included as a contracting requirement for FIDE SNPs to ensure spiritual care is seamlessly integrated into the care plans of enrollees who self-identify or identified as potentially benefiting from spiritual care.

MassHealth should not wait until CMMI expands HCPCs to include FIDE SNPs to provide One Care members access spiritual care by chaplains. There are existing codes that MassHealth can adapt to provide chaplaincy services to One Care members.<sup>455</sup> Medicare “Z codes” already available to provide spiritual care to persons in institutional settings and persons receiving palliative or hospice care could be expanded to include dual eligibles living in community settings.<sup>456</sup> Z codes offer a potential opportunity to expand medical necessity codes to include chaplaincy as a service. Z codes identify

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<sup>453</sup> “2019 PACE Model State Reporting Framework,” National PACE Association, 2019, 8, <https://www.npaonline.org/sites/default/files/PDFs/2019%20PACE%20Model%20State%20Reporting%20Framework.pdf>.

<sup>454</sup> “2019 PACE Model State Reporting Framework,” 8.

<sup>455</sup> “Capitated Model,” Centers for Medicare & Medicaid Services, May 2, 2019, <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/CapitatedModel.html>.

<sup>456</sup> “2021 ICD-10-CM Codes Z5Z65: Persons with Potential Health Hazards Related to Socioeconomic and Psychosocial Circumstances,” ICD10 Data, accessed October 4, 2020, <https://www.icd10data.com/ICD10CM/Codes/Z00-Z99/Z55-Z65>.



issues related to a person’s socioeconomic situation, including education and literacy, employment, housing, lack of adequate food or water or occupational exposure to risk factors like dust, radiation, or toxic agents.<sup>457</sup> It should be possible for EOHHS and health plans to leverage the flexibility within Z codes to apply them to provision of spiritual care in One Care. Z codes serve multiple purposes, for example they can:

- enable providers to offer services that might not otherwise be available to persons.
- assist providers to: increase person-centered care that meets an individual social as well as medical needs; aggregate data to develop strategies to address social determinants of health across populations; pinpoint specific health trends in different populations and communities to support development of community partnerships to address nonmedical factors that can impact a person’s health status.<sup>458</sup>

## **Value-Based Purchasing**

Value-based purchasing is a performance-based financial arrangement between CMS and hospitals, ACOs, and MCOs. Under this arrangement, providers are held accountable for reducing costs and improving health outcomes for their patients.<sup>459</sup>

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<sup>457</sup> “ICD-10-CM Coding for Social Determinants of Health,” American Hospital Association, Accessed November 2019, <https://www.aha.org/system/files/2018-04/value-initiative-icd-10-code-social-determinants-of-health.pdf>.

<sup>458</sup> “ICD-10-CM Coding for Social Determinants of Health,” 1.

<sup>459</sup> Debra J. Lipson et al., “Accelerating the Adoption of Value-Based Payment in Medicaid by Linking Delivery System Reform to Managed Care Payment,” Accessed March 28, 2021, 1, <https://www.medicaid.gov/medicaid/downloads/accel-adoption-vp-pay.pdf>.

Value-based purchasing is becoming increasingly important to increase quality of care and reduce cost.<sup>460</sup>

- a. “They can use state-designed measures, as well as consumer surveys such as NCI, Council on Quality and Leadership Personal Outcome Measures (POMS) or the CAHPS HCBS survey. Advocates should push for quality measures that reflect outcomes that will improve overall quality of life for consumers and urge states to expand use of consumer surveys. States using NCI should increase their survey sample size to retain validity when data is disaggregated for managed care vs FFS, or by MCO, and for demographic characteristics (such as race, gender and disability).<sup>461</sup>
- b. According to the March 2020 U.S. Department of Health & Human Services Office of the Assistant Secretary for Planning and Evaluation (ASPE) Report to Congress: Social Risk Factors and Performance in Medicare’s Value-Based Purchasing Program, when combining all social risk factors, two social risk factors stand out as being most associated with high costs and poor health outcomes.<sup>462</sup> The report findings also indicate increased need to improve performance in addressing health equity.<sup>463</sup>

The Joint Commission statement on spiritual care assessment and home settings states, “It is important that the spiritual needs, beliefs, values and preferences be evaluated for patients receiving psychosocial services to treat alcoholism or other substance use disorders and those receiving end-of-life care. Each organization would determine how

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<sup>460</sup> Lipson, “Accelerating the Adoption of Value-Based Payment,” 2.

<sup>461</sup> “Service Disrupted: Managed Long-Term Services and Supports Falling Short for Adults with Intellectual and Developmental Disabilities,” Community Catalyst, accessed August 26, 2020, [https://www.communitycatalyst.org/resources/publications/Service-Disrupted\\_MLTSS-for-Adults-with-IDD.pdf](https://www.communitycatalyst.org/resources/publications/Service-Disrupted_MLTSS-for-Adults-with-IDD.pdf).

<sup>462</sup> “Report to Congress: Social Risk Factors and Performance in Medicare’s Value-Based Purchasing Program,” Office of the Assistant Secretary for Planning and Evaluation, accessed August 25, 2020, <https://aspe.hhs.gov/system/files/pdf/263676/Social-Risk-in-Medicare%E2%80%99s-VBP-2nd-Report-Executive-Summary.pdf>, 1.

<sup>463</sup> “Report to Congress,” 5.

these needs will be identified as our standards do not define such elements.”<sup>464</sup> The Joint Commission’s statement does not prevent healthcare entities from conducting spiritual assessments for people with conditions beyond substance use or end-of-life. However, the standards do set out an important baseline requirement for determining a person’s spiritual needs and basis for spiritual care plan to be created.

Home and Community-Based Services (HCBS) are types of person-centered care delivered in the home and community. A variety of health and human services can be provided. HCBS programs address the needs of people with functional limitations who need assistance with everyday activities, like getting dressed or bathing. HCBS are often designed to enable people to stay in their homes, rather than moving to a facility for care.<sup>465</sup> New HCBS guidance includes “[h]ealth promotion and disease prevention . . . [h]ospice care (comfort care) for patients likely to die from their medical conditions.”<sup>466</sup> HCBS is another area of services where the integration of chaplaincy and spiritual care should be considered essential.

This project asserts that the need for person-centered planning goes beyond the walls of institutional settings, hospitals, palliative care, and hospices. The failure to make chaplaincy or other spiritual services available in care planning reflects the ongoing binary view of health and wellness solely as physical and psychological. Spiritual care

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<sup>464</sup> “Spiritual Beliefs and Preferences – Evaluating a Patient’s Spiritual Needs,” The Joint Commission, accessed January 10, 2022, <https://www.jointcommission.org/standards/standard-faqs/home-care/provision-of-care-treatment-and-services-pc/000001669/>.

<sup>465</sup> “Home- and Community-Based Services.”

<sup>466</sup> “Home- and Community-Based Services.”

must be integral to a truly patient-centered planning and goal-setting process. Such a planning process requires chaplaincy and other spiritual services be provided to people with complex care enrolled in One Care living in community-based settings.<sup>467</sup>

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<sup>467</sup> “CMS Issues New Guidance on State Implementation of Home and Community Based Services Regulation,” Centers for Medicare & Medicaid Services, March 22, 2019, <https://www.cms.gov/newsroom/press-releases/cms-issues-new-guidance-state-implementation-home-and-community-based-services-regulation>.

## CHAPTER 6—A CALL TO POLICY CHANGE AS PRAXIS

Advancing a legislative campaign requires organization, persistence, and as an act of spiritual praxis a commitment to relationship and a furthering of human rights. Shifting the medical paradigm in One Care to a more person-centered model that includes spiritual care requires committed advocacy by the disability community, allies, and leaders in the chaplaincy field. The advocacy strategy will include robust community engagement to get buy-in from members of the disability community, health plans, MassHealth, and state legislators. The legislative strategy will employ techniques and strategies proven to be successful in the past. The language in the bill will mirror existing language that advocates have successfully passed into law.

The existing statute requires One Care plans to provide members access to A Long-Term Service and Supports (LTSS) coordinator. While the services offered by the LTSS coordinator differ from those of the spiritual care provider, the purpose of both roles is to strengthen the whole-person-centered care provided to members by promoting the individual's dignity and opportunity to live meaningful lives in community settings. However, the exact language contained in the bill must align with the role and purpose of the spiritual care provider.

### **The LTSS Coordinator Role**

As a result of advocacy by the disability community, One Care members have a right to a Long-Term Service and Supports (LTSS) Coordinator. The LTSS coordinator is unique to Massachusetts One Care. The LTSS coordinator is responsible for assisting One Care members to access services to support their ability to live in the community.

These services include nonmedical transportation to help people engage in the community by providing rides to the mall, baseball games, theater, a service at a faith community, etc.<sup>468</sup>

Because of the intersectional nature of barriers to engagement in the community that affect persons with disabilities, the “LTSS coordinator” also assists members in navigating systems to get housing, food, and other resources that impact an individuals’ health and wellness. Advocates pressed for creating the LTSS coordinator on care teams to ensure that LTSS, such as nonmedical transportation, is provided in keeping with the members’ goals and priorities in life. Advocates believe coordination of LTSS by the LTSS coordinator will increase consumer choice, dignity of risk, and control over life decisions free from potential influence by plans intent on maintaining the medical model.

Advocates were adamant that plans buy, not build LTSS coordinators from organizations with governance structures reflective of the populations served by the organizations and with a demonstrated history of investment in independent living principles. One Care plans must contract LTSS coordinator services from Independent Living Centers (ILCs) and Aging Services Access Point (ASAPs). ILCs are consumer-controlled community-based organizations that provide services and advocacy by and for persons with disabilities.<sup>469</sup> ASAPs are nonprofit agencies that provide home and

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<sup>468</sup> “LTSS Overview,” Center for Medicare and Medicaid Services, accessed February 18, 2022, <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/ltss-overview>.

<sup>469</sup> “Independent Living Centers,” Commonwealth of Massachusetts, accessed February 19, 2022, <https://www.mass.gov/service-details/independent-living-centers>.

community-based services with governing boards that serve and represent 51% of people age 60 and older.<sup>470</sup> The law defines the Independent Living and LTSS coordinator in this way:

Independent Living and Long-Term Services and Supports (IL-LTSS) Coordinator—A coordinator contracted by the Contractor from a community-based organization (CBO) to ensure that an independent resource is assigned to and available to the Enrollee to perform the responsibilities described in Section 2.5.C.4., including assisting with the coordination of his/her LTSS needs and providing expertise on community supports to the Enrollee and his/her care team.<sup>471</sup>

The proposed bill can be inserted in this section of the existing law as part of the budget amendment process rather than having to stand up a new law.

### **Advocacy Activities**

In any legislative campaign, it's important to tie action steps with the legislative calendar. From September to December the governor begins the process of creating a budget. During this time the stakeholder group will send letters to the Executive Office of Health and Human Services and the governor's office describing why provision of spiritual care to One Care members is important. Letters should be sent by One Care members, their family members, religious leaders, health policy leaders, and chaplaincy groups. The letters will all share three key messages: the importance of spiritual care in

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<sup>470</sup> "Aging Services Access Points (ASAP)," Mass.gov, accessed February 19, 2022, <https://www.mass.gov/service-details/aging-services-access-points-asap>.

<sup>471</sup> "Contract Between United States Department of Health and Human Services Center for Medicare and Medicaid Services in Partnership with the Commonwealth of Massachusetts and Commonwealth Care Alliance, Fallon Community Health Plan, Network Health," Center for Medicare and Medicaid Services, accessed February 19, 2022, 4, <https://www.cms.gov/medicare-medicare-and-medicare-coordination/medicare-and-medicare-coordination-office/downloads/massachusettscontract.pdf>.

whole-person-centered care (health in mind, body, and spirit), a personal or professional story of how spiritual care or its absence has impacted the person's life, or the specific request of EOHHS to include chaplains in One Care teams.

Early on, we will identify legislators from both the statehouse Senate and House to sponsor the spiritual care bill. These legislators will file the bill at the House and Senate Clerk's offices before the bill filing deadline on the third Friday in January.<sup>472</sup> We will also work with other legislators to build increased support for the bill.

In January copies of the Governor's proposed budget for fiscal year (July 1, 2023 to June 30, 2024) are shared with legislators. During this time legislators in the House and Senate review the governor's proposal. Throughout this time, we will target public budget hearings and arrange to testify at Health Finance committee meetings on the Senate and representative sites. However, the legislation we are seeking will not directly impact the budget. Therefore, what might be most effective is to do targeted outreach to specific legislative allies during budget reconciliation.

Identifying supporters in districts of different legislators will be important for the outreach to be effective. Phone calls, letters, email messages and legislative visits at district offices as well as the State House will be important. While legislators may be responsive to advocacy organizations seeking passage of the bill, unless they hear directly from constituents speaking to the importance of spiritual care in their lives it will be more challenging to testify for the bill's passage.

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<sup>472</sup> "The Legislative Process in Massachusetts: Bill Filing," Massachusetts Legal Services, November 1, 2007, <https://www.masslegalservices.org/content/legislative-process-massachusetts-0#:~:text=Bill%20Filing%3A,in%20the%20even%20numbered%20year.>



Most work will take place between April and June. This is when the House Budget and Senate Ways and Means Committee all hold private meetings to discuss finalization of the budget and legislative actions. Because creating a provision in the law for Spiritual Care included in One Care will more than likely not require new resources, it can be folded into an existing law specific to One Care. It will therefore be addressed during the budget amendment process between April and June.

Legislators are not experts which is why the voice of constituents is so important.<sup>473</sup> The Executive Office of Health and Human Services (EOHHS) will require significant pressure to move the initiative forward. Gaining support from constituents will be of particular importance if there is opposition put forward by The Executive Office of Health and Human Services (EOHHS) or health plans. Based on experience lobbying for a bill opposed by EOHHS, it will be important to maintain open and transparent communication with the Office.

Ten years ago, when seeking passage on a bill to include a service coordinator on care teams, lead legislators supporting the bill requested advocates work directly with the administration to draft the final legislative language. So on one late afternoon several of us sat with leadership from EOHHS and negotiated language that was passed into law the

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<sup>473</sup> “State Legislators: Who They Are and How to Work With Them: A Guide for Oral Health Professionals,” National Conference of State Legislators, March 2018, [https://www.ncsl.org/Portals/1/HTML\\_LargeReports/OralHealth\\_3.htm](https://www.ncsl.org/Portals/1/HTML_LargeReports/OralHealth_3.htm).

next day. This negotiation was possible only because we already had a standing relationship anchored in trust and cooperation, essential to any successful negotiation.<sup>474</sup>

The primary activities undertaken will lead to statutory language making access to spiritual care a requirement in One Care. Obtaining statutory language is important because once an activity of the state becomes law, it is difficult to undo. This is in contrast to a state regulation which can be easily overturned or altered as state administrations change. For example, a governor has the right to change regulations and could easily weaken the required spiritual care requirements. The governor does not have this right with the law. This stated, obtaining regulatory change can be far easier to obtain than statutory. That is why this thesis sets out as its primary goal statutory language, but also includes a request for changes in regulatory language or a piloting of spiritual care.

### **Timeline of the Project**

The scope of the populations to be provided chaplaincy services will be dependent on priorities of the state and health plans. The project identifies people with mental health diagnoses and people with high level community service needs as the priorities to be included in the pilot. The project includes short, intermediate, and long-term goals. Because of the multi-year nature of the project, Year 1 will be viewed as the project being implemented to meet the DMin qualification requirements.

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<sup>474</sup> Jeswald Salacuse, “The Importance of a Relationship in Negotiation,” Program on Negotiation at Harvard Law School, December 21, 2021, <https://www.pon.harvard.edu/daily/negotiation-training-daily/negotiate-relationships/>.

Most legislation requires up to three sessions for passage with continued refinement of the legislative request. Recognizing this, the timeline contains a multi-prong strategy.

1. The project will be put forward as an unfunded pilot and so an alternative approach requires seeking funding from external foundations.
2. Foundation funding scope and “defined ask” will be contingent on the receptivity of Mass Health to including spiritual care as an unfunded requirement of plans.
  - a. If Mass Health does not support the initiative without external funding, the proposal will request funding for the pilot project.
  - b. If Mass Health approves the pilot project, the funding request from foundations will be for evaluation purposes to assess the value of the intervention.

#### Year 1 – 2022

May – July: Identify a stakeholder team to drive the advocacy effort.

July – September: Finalize strategy and priorities based on project thesis.

May – September: Submit an article to an open-source public health or disability publication.

September – October: Present legislative ideas to key members of the State House; Present to the One Care Implementation Council; Conduct an assessment of the capacity of certified chaplains in Massachusetts to engage in the pilot.

October – January: Identify and submit a grant proposal to fund the pilot project.

Year 2 – 2023

Contingent on deliverables met in Year 1.

Year 3 – 2024

Contingent on deliverables met in Years 1 and 2.

## CHAPTER 7—LIMITATIONS

### Limitations

In this paper, I posit the value of spiritual care provided by chaplains in healthcare from a Christian, Catholic perspective based on my experience as a Catholic and trained chaplain. This paper does not deal with the complexity of human experience of suffering or relation with the transcendent from the perspective of non-Christian traditions. A major limitation to this paper is the lack of prior research on the effectiveness of primary care chaplaincy in the American context. For this reason, I have put forward an outline for researching the effectiveness of spiritual care provided to enrollees in One Care.

Because of the practical nature of this paper, I do not give adequate attention to questions of theodicy or different theological understandings of embodiment. The paper also focuses on physical disability, particularly acquired disability that results from a spinal cord injury. In this respect, the paper does not give proper attention to the opportunity and I would argue the obligation One Care plans have to make spiritual care available to persons with substance use disorder.

Professional healthcare chaplaincy lacks a clear definition or articulation of a chaplain's added value or impact.<sup>475</sup> Spirituality and the spiritual care process are distinct and qualitative in nature, not lending themselves to generalizable quantitative analysis.<sup>476</sup>

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<sup>475</sup> Kevin Adams, "Defining and Operationalizing Chaplain Presence: A Review," *Journal of Religion and Health* 58, no. 4 (August 1, 2019): 1246, <https://doi.org/10.1007/s10943-018-00746-x>.

<sup>476</sup> Ramakrishnan Parameshwaran, "Theory and Practice of Chaplain's Spiritual Care Process: A Psychiatrist's Experiences of Chaplaincy and Conceptualizing Trans-Personal Model of Mindfulness," *Indian Journal of Psychiatry* 57, no. 1 (2015): 26, <https://doi.org/10.4103/0019-5545.148511>.

Distinct from other practices, chaplains are discouraged from writing physical notes and usually write verbatims (reflections of their visit with a person). Such a practice is imperfect and may lead to flawed recollections of the pastoral visit.

Advancing chaplaincy services for the One Care population is not without challenges that must be addressed as plans develop policies, practices, and procedures to provide services to their enrollees. These barriers include:

- Care provider resistance: Healthcare providers are wary of addressing the spiritual needs of patients. Implementing person-centered care that includes chaplains on care teams may face resistance from providers. To increase provider comfort and competency in valuing spiritual care as an essential aspect of whole person care requires ongoing training and research.<sup>477</sup>
- Shifts in American Culture: Culture in the United States is increasingly shifting away from institutional religious practice. Therefore, a patient may prefer speaking to a physician or nurse instead of a trained chaplain or pastoral counselor.<sup>478</sup> If this is the case, physicians, nurses, and other care providers need training to address patients' spiritual and existential needs, if not their religious needs.
- Patient expectations and chaplain competency: A review of empirical studies identified two barriers to interfaith spiritual care. The first is the

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<sup>477</sup> Jones, "The Content, Teaching Methods and Effectiveness of Spiritual Care Training," conclusion.

<sup>478</sup> Büssing and Koenig, "Spiritual Needs of Patients with Chronic Diseases," 24–25.

“normativity”<sup>479</sup> factor. Some patients, because of expectations rooted in tradition or other factors may not value the role of an interfaith chaplain. The second category is competency.<sup>480</sup> There may be constraints to interfaith spiritual care due to the level of competency needed for chaplains to provide truly person-centered spiritual care e.g., depth of knowledge of multiple spiritual traditions.<sup>481</sup>

- The fee-for-service (FFS) payment structure: This payment method restricts coding for provision of chaplaincy services outside of institutional settings or home-based end-of-life care provided by hospice services.<sup>482</sup>
- Narrow definition of medically necessary services: There is opportunity for providing chaplaincy services beyond the narrow cohort of persons in inpatient settings or hospice care. The greater challenge is to demonstrate that the services provided by a chaplain are medically necessary and ensure that a qualified individual provides the chaplaincy services with the skills required for that benefit category.<sup>483</sup>

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<sup>479</sup> Anke I. Liefbroer et al., “Interfaith Spiritual Care: A Systematic Review,” *Journal of Religion and Health* 56, no. 5 (2017): 1790, <https://doi.org/10.1007/s10943-017-0369-1>.

<sup>480</sup> Liefbroer et al., 1790.

<sup>481</sup> Liefbroer et al., 1790.

<sup>482</sup> “Fee for Service -HealthCare.Gov Glossary,” HealthCare.gov, accessed July 13, 2019, <https://www.healthcare.gov/glossary/fee-for-service/>.

<sup>483</sup> Jean Acevedo, “Documentation & Coding Handbook: Palliative Care,” 2019, 1.

- Newly chartered territory: Provision of community-based chaplain services is in its preliminary stage of development.
- Discrimination: Explicit bias against persons with disabilities that permeate the healthcare delivery system.
- Religious/Institutional Bias: Paternalistic and negative perceptions of disability in organized religion.

## **Conclusion**

This thesis outlines a cogent argument for including chaplains on care teams. It is action-oriented and outcome directed, outlining steps to advance inclusion of chaplains on care teams in the Massachusetts One Care. One Care was chosen for several reasons. First, the plan was specifically designed to meet the needs of persons with disabilities age 21–64. This population includes those of the highest need and highest cost in the state (and nationally). Second, the plan was created through collaborative efforts between the disability community and the state. Third, One Care contracts require health plans to offer services not covered by Medicare or Medicaid to promote wellness and meaningful integration into the community.

The thesis also provides a clear objective: statutory language requiring One Care plans to offer spiritual care provided by certified chaplains as an optional service to members. This objective is accompanied by a strategy for attaining passage of the law within a year. In addition, it offers other ways of advancing inclusion within One Care while recognizing constraints within the legislative process, including separation of church and state. The backup strategy is to advocate for a pilot program requiring One



Care plans to offer spiritual care to a subset of the One Care membership. In tandem, the project includes a community-based participatory action research project that will provide a clearer understanding of the spiritual care needs of One Care members.

Persons with disabilities are subject to injustices that impact determinants of health such as inequity in education, income, and health.<sup>484</sup> At question is the normative understanding of human identity. Insistence on defining health as complete physical and mental health completely free of disease or disability relegates persons with disabilities to nonnormative status. Reducing human identity and health to physical or mental status is incompatible with the lived experiences of people with chronic illness or disability across the lifespan.

This reductionistic definition devalues and underestimates the human capacity to live full lives while adapting to physical, emotional, and social challenges that impact their ability to carry out activities of daily living. In the West, focus is placed entirely on autonomy. Whether it be the ICF or World Health Organization definition, the emphasis is on the ability of the individual to control his or her environment.<sup>485</sup> The insistence on defining wholeness as autonomy and the ability to carry out activities of daily living either by oneself or with the assistance of others remains an obstacle to understanding the human condition as one of interdependence connected to spiritual wholeness.

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<sup>484</sup> “Disability and Justice,” Stanford Encyclopedia of Philosophy, July 2, 2019, <https://plato.stanford.edu/entries/disability-justice/>

<sup>485</sup> Juan E Mezzich et. al. “Introduction to Conceptual Explorations on Person-Centered Medicine,” *International Journal of Integrated Care* 10 (2010): 1–2, <https://doi.org/10.5334/ijic.472>.

The World Health Organization has stated that policymakers must promote health in all sectors of society using diverse approaches including legislative, fiscal changes and organizational innovations to foster greater equity by identifying barriers to health and doing away with those barriers.<sup>486</sup> For these shift to occur, policymakers and the healthcare system must reorient their priorities toward an equitable person-centered health system.

Health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members.<sup>487</sup>

Spirituality is central to human identity when understood as a search for existence, meaning, and relationship with oneself and others.<sup>488</sup> A positive spiritual outlook is correlated with improved overall wellness and life expectancy. At the same time spiritual and religious coping can be either a resiliency factor or barrier to wellness. Spiritual values are important to members for engagement in social justice activities. This thesis seeks to harness spiritual based social justice values to shift the biomedical or biosocial model of One Care toward the direction of a bio-social-spiritual model of care.

Members of One Care should have the legal right to access spiritual care as part of their overall care experience. The healthcare delivery system's relationship with

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<sup>486</sup> "Health Promotion," World Health Organization, accessed April 3, 2022, <https://www.who.int/teams/health-promotion/enhanced-wellbeing/first-global-conference/actions>.

<sup>487</sup> Marcelo Saad, Roberta de Medeiros, and Amanda Cristina Mosini, "Are We Ready for a True Biopsychosocial-Spiritual Model? The Many Meanings of "Spiritual," *Medicines* 4, no. 79 (2017): 2, <https://doi.org/10.3390/medicines4040079>.

<sup>488</sup> Saad, Medeiros, and Mosini, 2.

spiritual care is fractured, which leaves gaps in care for people who most need spiritual support. A high percentage of persons involved in One Care would be eligible for chaplaincy services if they were officially designated to be under the care of a palliative care team or in a nursing facility. For example, I am both nursing home eligible and receive palliative-level care but because of restrictions in how Medicare and Medicaid code spiritual care, I and others in my situation cannot access chaplaincy services in One Care.

Ample evidence has been provided on the potential value of spiritual care and its positive impact on health. As social determinants, spirituality and religious beliefs and values can either support a person or communities' resiliency or increase their vulnerability. Adequate and appropriate chaplaincy care can support resiliency for many people, improving their health outcomes and building a greater sense of existential meaning, while countering negative religious and cultural messages that can lead to poorer health outcomes. From a Christian perspective, this resiliency is reflected in the dynamic image of God as relational *imago Dei*. Evidence of such resiliency could be found in reduced isolation and loneliness, and an increased sense of agency.

There is also increasing awareness within a number of disciplines of the importance of healthcare professionals engaging in spiritual care as social justice praxis, including nursing, counseling, and social work. In social work for example, some research points to the need for increased embrace of the Christian concept of community and "koinonia, a sense of communion, commitment, unanimity, and "brethren bond" and

movement towards agape or unconditional love.<sup>489</sup> It also points to embracing the Buddhist concept of universal respect and of compassion for other people and the Confucian concept of ren, meaning recognition of the oneness of humanity and the need for increased altruism and selflessness.<sup>490</sup> Nursing in the United States from its inception has been engaged in “social moral action” that is increasingly calling for “sacred activism,” bringing together both spiritual and caring action at a global level.<sup>491</sup> There is a call within nursing for greater attention to be focused on advancing nursing leadership characteristics that include “justice-seeking behaviors.”<sup>492</sup>

In Judaism there are a number of parables that speak to disability and interdependence. The midrash provides a beautiful parable that describes interdependence. In the parable, a blind man and a sighted man are walking down the road with the seeing man acting as guide to the blind man. When the two men came to house, the sighted man asked the blind man to enter the house first and light a candle that he might see.<sup>493</sup> Judaism also speaks of interdependence as a pursuit of justice

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<sup>489</sup> Michael K. Prior and Andrew S. Quinn, “The Relationship Between Spirituality and Social Justice Advocacy: Attitudes of Social Work Students,” *Journal of Religion and Spirituality in Social Work: Social Thought* 31, no. 2 (2012): 174–175, <https://doi.org/10.1080/15426432.2012.647965>.

<sup>490</sup> Prior and Quinn, “The Relationship Between Spirituality and Social Justice Advocacy,” 175.

<sup>491</sup> Jean Watson, “Social Justice and Human Caring: A Model of Caring Science as a Hopeful Paradigm for Moral Justice for Humanity,” *Creative Nursing* 24, no. 1 (2018): 56, <https://doi.org/10.1891/1078-4535.14.2.54>.

<sup>492</sup> Fariba Hosseinzadegan, Madineh Jasemi, and Hosein Habibzadeh, “Factors Affecting Nurses’ Impact on Social Justice in the Health System,” *Nursing Ethics* 28, no. 1 (2020): 128, <https://doi.org/10.1177/0969733020948123>.

<sup>493</sup> “Bamidbar Rabbah 15,” Sefaria, accessed April 3, 2022, [https://www.sefaria.org/Bamidbar\\_Rabbah.15.5?vhe=Midrash\\_Rabbah\\_--](https://www.sefaria.org/Bamidbar_Rabbah.15.5?vhe=Midrash_Rabbah_--)

commanding the Jewish community to be inclusive of persons with disabilities. The midrash also speaks of a blind person walking in darkness holding up a torch. A sighted person tells the individual the torch is not needed, the blind person responds, “as long as I have a torch in my hand, people see me and save me from the pits and thorns and the thistles.”<sup>494</sup> this blind person indirectly benefits from the light and is therefore able to bless the heavenly luminaries *and* in holding the torch provide light to others on the road.<sup>495</sup>

Both of these stories provide a wonderful metaphor for chaplaincy engagement with persons with disabilities. At one moment, the chaplain is the guide, at the next moment the chaplain is being guided. Spiritual accompaniment in general is about mutual accompaniment, but with persons with disabilities there is a command that this accompaniment be grounded in relationship moving towards liberation. Liberation on the part of the chaplain begins with valuing disability as a normative reflection of human identity and, from a Christian perspective, identity as *imago Dei*.

When chaplains are oriented towards the theological and spiritual North star of justice, they engage in a ministry of healing not of disability, but of oppression and restoration of the rightful place of persons with disabilities in the community.<sup>496</sup> For all chaplains, this means addressing hypocrisies that lead to the dehumanization and

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\_TE&lang=bi&with=all&lang2=en; “The Light that Brings Us Closer to God,” ReformJudaism, February 2016, <https://reformjudaism.org/learning/torah-study/torah-commentary/light-brings-us-closer-god>.

<sup>494</sup> “Megillah 24b,” Chabad, [https://www.chabad.org/library/article\\_cdo/aid/5448052/jewish/24b.htm](https://www.chabad.org/library/article_cdo/aid/5448052/jewish/24b.htm).

<sup>495</sup> “Megillah 24b,” Chabad.

<sup>496</sup> Kujawa-Holbrook, *Injustice and the Care of Souls*, 222.

subsequent marginalization, isolation, depression, and reduced life expectancy of persons with disabilities.<sup>497</sup> Chaplains are conflict-free and as such play an important role in disrupting the status quo. It is important that they work with members in a manner that supports increased community engagement and fuller realization of their imago Dei.

Chaplains must, like social justice counselors seek to develop a “socially just world, in which all people perceive equitable opportunities to access resources and participate in policy and law development and affect them, ultimately resulting in a society that embodies harmony between the needs of individuals in the needs of the whole.”<sup>498</sup> It is important that chaplains value social justice as “both a goal and the process” that will lead to a “socially just world.” As social justice praxis, chaplaincy seeks to empower people devalued by society. Therefore, chaplains must stand by and advocate with One Care members on their behalf to address the injustices they experience in One Care.

Chaplains unaware that they are engaged in a social justice activity are at risk of facilitating injustice.<sup>499</sup> Gaining competency as a social justice advocate requires experiential learning. Therefore, it is critical that chaplains providing care to persons with disabilities have the experiential learning and understanding of persons with disabilities as a population subjected to oppression.<sup>500</sup>

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<sup>497</sup> Kujawa-Holbrook, *Injustice*, 222.

<sup>498</sup> Hugh C. Crethar and Carrie L. Winterowd, “Values and Social Justice in Counseling,” *Counseling and Values* 57, no. 1 (2012): 3, <https://doi.org/10.1002/j.2161-007X.2012.00001.x>.

<sup>499</sup> Crethar and Winterowd, 6.

<sup>500</sup> Crethar and Winterowd, 7.

Social justice as praxis undergirds the activities, actions, and reflection processes which this thesis advocates. The goal of legislative change is to ensure persons with disabilities enrolled in One Care have a right to access spiritual care. However, spiritual care is not an object to be obtained at the end of the undertaking. As a theologically grounded social justice praxis, the actions to be undertaken will be guided by spiritual praxis committed to systemic transformation achieved through relationship.

I will be engaging with other advocates in social action activities. We will be engaging in social action that will amplify the voice of persons with disabilities through legislative advocacy and research to advance spiritual care for One Care members as a right.<sup>501</sup> These efforts will be guided by a consensus model to ensure the need, goals, and outcomes are representative of the whole, and not a subset of individuals. My role in this process will be to facilitate activities, and following the Freirean model of praxis, to apply analysis, action, and reflection to support the advancement of spiritual care in One Care as a means of transformation and emancipation.<sup>502</sup>

One final note. Chaplains are not skills for any one religious framework. Chaplains are providing care in the postmodern era which is marked by increased secularism and existential anxiety.<sup>503</sup> Chaplains are called to stand against dominant visions of disability at the organizational and interpersonal levels that oppress and

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<sup>501</sup> Marie Weil, Michael S. Reisch, and Mary L. Ohmer, *The Handbook of Community Practice* (Thousand Oaks, CA: Sage Publications, 2013), 347.

<sup>502</sup> Weil, Reisch, and Ohmer, *The Handbook of Community Practice*, 148.

<sup>503</sup> Carmen Schuhmann and Annelieke Damen, "Representing the Good: Pastoral Care in a Secular Age," *Pastoral Psychology* 67 (2018): 408, <https://doi.org/10.1007/s11089-018-0826-0>.

dehumanize.<sup>504</sup> Therefore, chaplains must take ethical stances and speak out against oppression and injustice, whether at the care team level, the organizational level, or higher.

If chaplains engaging in this work do not hold these values, then they will become nothing more than another layer of oppressors who will alienate and further isolate persons in desperate need of spiritual care. It is therefore essential that there be ongoing oversight of the quality of services provided by chaplains not just by the health plan, but by the disability community. If it is discovered that chaplains are not living up to the goals of this thesis, then a new model will need to be created, one that reflection embraces the wholeness of persons with disability.

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<sup>504</sup> Schuhmann and Damen, “Representing the Good,” 413.



## **Appendix I: Legislative Policy Statement**

This legislation requires the Massachusetts Executive Office of Health and Human Services (EOHHS) to establish standards and guidelines in the provision of spiritual care as a covered service available to Massachusetts residents enrolled in the Massachusetts One Care plan. EOHHS guidelines must include regulations that require OneCare plans to contract with professional chaplains certified by The Association for Clinical Pastoral Education (ACPE) and other certifying bodies such as the National Association of Catholic Chaplains (NACC) and the Neshama: Association of Jewish Chaplains (NAJC) or seminarians or if appropriate, volunteers.<sup>505</sup> EOHHS will be responsible for writing contract requirements and guidelines that ensure spiritual care is provided in a manner culturally appropriate to persons with disabilities and the diverse populations enrolled in OneCare. EOHHS regulations, contract requirements and guidelines must also set minimum standards of spiritual care.

These minimum standards include the following requirements. Professional chaplains will conduct a spiritual assessment during the enrollee annual assessment or as requested by enrollee. This spiritual assessment information and spiritual care needs identified by the enrollee will be included in the enrollee's care plan. At the request of enrollees or guardians as appropriate, chaplains are to be engaged as full members of an

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<sup>505</sup> "Association for Clinical Pastoral Education," ACPE, accessed October 14, 2021, [acpe.edu](http://acpe.edu); "The National Association of Catholic Chaplains," NACC, accessed October 14, 2021, [nacc.org](http://nacc.org); "Welcome to Neshama: Association of Jewish Chaplains," accessed October 14, 2021, [najc.org](http://najc.org).

enrollee's care team to provide direct spiritual care to enrollees. Care team members will be trained to identify spiritual distress in enrollees.

Chaplains will also connect enrollees to spiritual resources including assisting enrollees with participating in meditation groups and faith communities and other community resources. At the request of enrollees, chaplains are to provide supports to enrollee family members or other nonpaid members of an enrollee's care team. The amount, frequency and duration of services are to be determined by the enrollee in consultation with their chaplain and care team. As necessary, chaplains are also to coordinate and supervise care provided to enrollees by students in chaplaincy training programs, seminarians, and volunteers.

### **Partnership Overview**

Disability Advocates Advancing Our Healthcare Rights (DAAHR) is a statewide health justice coalition that promotes health equity for persons with disabilities in Massachusetts. DAAHR was spearheaded by the Disability Policy Consortium (DPC) and Boston Center for Independent Living (BCIL). DAAHR will collaborate with seminaries, chaplaincy certification organizations, and healthcare chaplains to ensure enrollees in Massachusetts One Care receive spiritual care as an essential element of integrated person-centered care. A more complete list of supporters will be developed as part of the advocacy strategy. The list will include advocacy groups, legislative co-signers, and supporters.

### **Background**

Spirituality is fundamental to the human experience and overall wellness.<sup>506</sup>

Spirituality is a social determinant of health that with spiritual care can become a facilitator for health and wellbeing. “Spirituality is significant in healthcare because it promotes coping strategies for stress, promotes recovery and resilience and prevents burnout.”<sup>507</sup> Spiritual care is available to people with complex needs in facilities such as hospitals but not available to persons with similar needs living in community settings.<sup>508</sup>

## Research Findings

University of Massachusetts (UMass) recently reported out findings from its 2017 to 2019 surveys of One Care member self-reported quality of life indicators. Most survey respondents reported spirituality or religion is important to their life. The UMass findings are in line with other research on disability and spirituality.<sup>509</sup> Most respondents also

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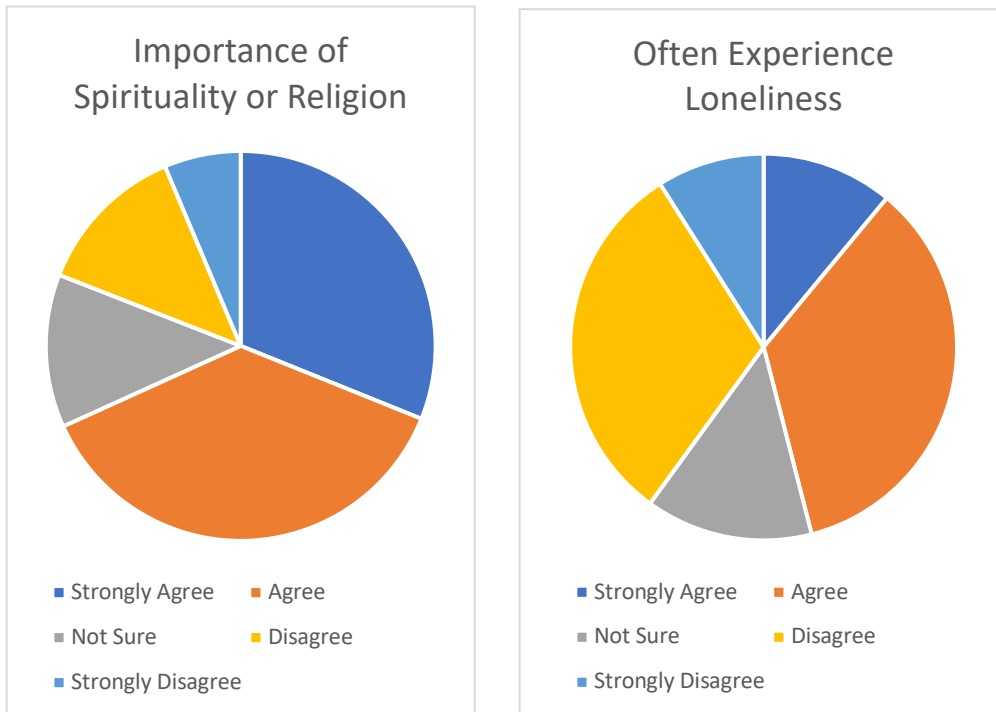
<sup>506</sup> Hvidt et al., “What Is Spiritual Care? Professional Perspectives on the Concept of Spiritual Care Identified through Group Concept Mapping,” *BMJ Open*, Accessed September 26, 2021, <https://bmjopen.bmj.com/content/bmjopen/10/12/e042142.full.pdf>.

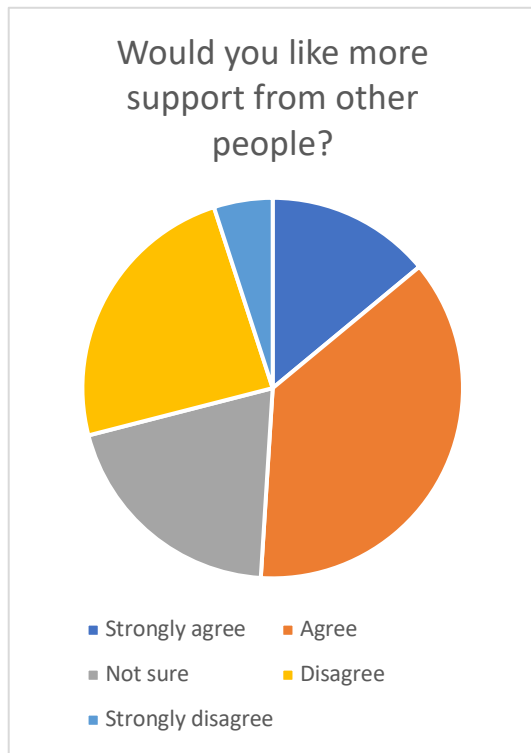
<sup>507</sup> Nicolette V. Roman, Thuli G. Mthembu, and Mujeeb Hoosen, “Spiritual care—‘A Deeper Immunity’—A Response to Covid-19 Pandemic,” *African Journal of Primary Health Care and Family Medicine* 12, no. 1 (2020): 2.

<sup>508</sup> “OCR Resolves Religious Discrimination Complaints after Maryland and Virginia Hospitals Ensure Patients Can Receive Safe Religious Visitations During COVID-19,” U.S. Department of Health and Human Services, accessed September 26, 2021, <https://public3.pagefreezer.com/content/HHS.gov/31-12-2020T08:51/https://www.hhs.gov/about/news/2020/10/20/ocr-resolves-religious-discrimination-complaints-after-maryland-and-virginia-hospitals-ensure.html>; Marcelo Saad and Roberta de Medeiros, “Programs of Religious/Spiritual Support in Hospitals - Five ‘Whies’ and Five ‘Hows,’” *Philosophy, Ethics, and Humanities in Medicine : PEHM* 11, no. 1 (August 22, 2016): 1–4, <https://doi.org/10.1186/s13010-016-0039-z>.

<sup>509</sup> Kaye and Raghavan, “Spirituality in Disability and Illness,” 231–242; Carlos A Reyes-Ortiz, “Spirituality, Disability and Chronic Illness,” *Southern Medical Journal* 99, no. 10 (2006): 1172–1173, <https://doi.org/10.1097/01.smj.0000242805.02180.63>; Boswell et al., “Disability and Spirituality,” 20–25; Brillhart, “A Study of Spirituality and Life Satisfaction,” 31–34; Matheis, “The Relation Between Spirituality and Quality of Life,” 265–271; Lorenzo, “Deep Down in Our Hearts,” 110–131; Schulz, “Spirituality and Disability,” 57–83.

reported that they wanted more support from other people. In 2019 University of Massachusetts (UMass) included a question on feelings of loneliness. Almost half of the respondents reported they often experience loneliness.





Responses of One Care enrollees are also consistent with the literature on the intersection of loneliness, isolation, and disability status. Offering spiritual care to this population is necessary for three reasons: A review of the literature shows a direct correlation between loneliness, isolation and depression that can result in preventable morbidity and mortality.<sup>510</sup> The literature shows that spirituality and spiritual care can

improve overall wellness.<sup>511</sup>

Spiritual care is standard practice in the United Kingdom. Primary Care Chaplains (PCCs) are integrated into the UK health care system, with the literature showing the positive impact of PCCs on the lives of people and palliative care beneficial to persons with chronic conditions in the community.<sup>512</sup>

<sup>510</sup> Pagan, “Gender and Age Differences in Loneliness,” 10, 11; Macdonald et al., ““The Invisible Enemy;”” Emerson et al., “Loneliness, Social Support, Social Isolation and Wellbeing,” 5, 6.

<sup>511</sup> Boswell et al., “Disability and Spirituality,” 16; Tarvainen, “Loneliness in Life Stories by People with Disabilities,” 865, 879, 880.

<sup>512</sup> Pagan, “Gender and Age Differences in Loneliness,” 9176; Macdonald et al., ““The Invisible Enemy,”” 1–22; Emerson et al., “Loneliness, Social Support, Social Isolation and Wellbeing,” 1–7; Tarvainen. “Loneliness in life stories by people with disabilities,” 864–882; Boswell et al., “Disability and Spirituality,” 20–25; Tiffany N. Ricks, Angela Frederick, and Tracie Harrison, “Health and Disability Among Young Black Men,” *Nursing Research* 69, no. 1 (2020): 13–21,

## YESHEALTH: RESEARCH AS PRAXIS

### Background

Participatory Action Research (PAR) is rooted in social justice and emerges from distinct contexts, namely the systemic political oppression permeating Latin America and the systemic racism of the United States. Because of its connection with social justice, there is fear that PAR will destabilize the existing power structure that values

American sociologist Kurt Lewin developed principles of PAR as a way to increase the voice of people impacted by research to counteract the existing system of research that perpetuated the status quo.<sup>513</sup> As such, social science, and with that, action research faces opposition from dominant powers such as politicians and other policymakers. Opposition by social scientists can arise from fear that action research could destabilize the existing power structure.<sup>514</sup>

“A second threat to social science comes from “groups in power.” These people can be found in management on any level, among labor leaders, among politicians, some branches of the government, and among members of Congress. Somehow or other they all seem to be possessed by the fear that they could not do what they want to do if they,

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<https://doi.org/10.1097/nnr.0000000000000396>; Gaventa, “Disability and Spirituality,” 307–316; Macdonald, “Primary care chaplaincy,” 1–12; Julia Strupp, Raymond Voltz, Heidrun Golla. “Opening Locked Doors; Integrating a Palliative Care Approach into the Management of Patients with Severe Multiple Sclerosis,” *Multiple Sclerosis Journal* 22, no. 1 (October 7, 2015): 13–18, <https://doi.org/10.1177/1352458515608262>; McSherry, Boughey, and Kevern, “‘Chaplains for Wellbeing’ in Primary Care,” 2, 8–10.

<sup>513</sup> Kurt Lewin, “Action Research and Minority Problems,” *Journal of Social Issues* 2, no. 4 (1946): 34–46, <https://doi.org/10.1111/j.1540-4560.1946.tb02295.x>.

<sup>514</sup> Lewin, “Action Research and Minority Problems,” 34–46.

and others, would really know the facts.”<sup>515</sup> The greatest source of fear; will and commitment to social sciences a means of promoting dignity among oppressed groups.<sup>516</sup> The purpose of PAR is to locate the source of inequities e.g. hegemonic systems of power. “Race” is not the source of health inequities facing black people, racism is the cause of inequities. Inequities in health are not inherent in disability, health disparities result from ableist bias.<sup>517</sup> By locating inequities at their hegemonic source, PAR empowers oppressed groups to name specific causes of inequities. For example, redlining is a primary cause of inequities in housing faced by African Americans.

Persons with disabilities as outlined in this paper face ongoing threats to their identities as whole persons created in the image and likeness of God. Bias and discrimination within the healthcare delivery system in larger society. The purpose of participatory action research is to ensure persons with disabilities, traditionally treated as objects of research are actively engaged in designing, conducting and analyzing the research and defining the action steps to follow.<sup>518</sup> In taking this approach, I am, along with other disability rights researchers, challenging traditional research approaches that exclude or objectify persons with disabilities and our experiences.<sup>519</sup>

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<sup>515</sup> Lewin, “Action Research and Minority Problems,” 43–44.

<sup>516</sup> Lewin, 45.

<sup>517</sup> Lewin, 44.

<sup>518</sup> John Swinton and Harriet Mowat, *Practical Theology and Qualitative Research - Second Edition* (London, UK: SCM Press, 2016), chapter 8, “Participatory Action Research: Researching with Marginalized People.”

<sup>519</sup> Swinton and Mowat, chapter 8, “The Situation.”

Seeking to be true to Swinton’s principles of practical theological reflection in his book, *Practical Theology and Qualitative Research*, I began this undertaking with a contextual analysis of spiritual care praxis in the current healthcare delivery system. This was followed by a rich and thick analysis of the relationship between spirituality and wellness in healthcare looking specifically at the potential positive impact of spiritual care for persons with disabilities living in community settings. While integrated into both the first and second stages of research as a practical theological reflection, I am at the stage of engaging more deeply in theological reflection with persons with disabilities and other stakeholders to explore what Swinton describes as “authentic revelation in a spirit of critical faithfulness and chastened optimism.”<sup>520</sup>

With these steps taken, I am ready to take on qualitative research with other persons with disabilities to understand better how spiritual care may or may not benefit persons with complex care needs between 21 and 64. This qualitative research will bring to light: the spiritual wisdom of persons with disabilities; the negative impact that hegemonic powers have had on their spiritual identities; and, potential opportunities for spiritual and religious healing through engagement with community-based healthcare chaplains. In alignment with Swinton and the principles of “nothing about us without us,” DPC will engage with in Community-Based Participatory Action Research.

YESHealth is committed to engaging in research that enhances the ability of the disability community to identify and take action that will restore the humanity of not only

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<sup>520</sup> Swinton and Mowat, *Practical Theology*, chapter 8, “The Situation.”



the disability community, but those who are responsible for the ongoing discriminatory practices that lead to increased preventable morbidity and mortality in the disability community.<sup>521</sup>

YESHealth has been engaged in Community-Based Participatory Action Research (CBPAR) and PAR research activities for fifteen years. I lead the YESHealth team of researchers. Under the umbrella of YESHealth, DPC has conducted research with Harvard University and Brandeis University in addition to carrying out its own research projects. These state-wide projects have been carried out by and for persons with disabilities to ensure fidelity to Paulo Freire's model of action research as a means of liberation. In this same vein, we will make every effort to conduct research in a culturally humbled manner that supports the intersectional needs identified by persons with disabilities of different racial, ethnic, and other backgrounds.

The YESHealth team will engage in a use a mixed methodology mixing qualitative and quantitative methods and data collection and analysis.

1. To persons with disabilities aged 21–64 to work as part of the research team.

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<sup>521</sup> “WHO Global Disability Action Plan 2014–2021,” World Health Organization, accessed April 3, 2022, <https://apps.who.int/iris/rest/bitstreams/887498/retrieve>.

- a. The team will include persons with disabilities with expertise in research methods to conduct focus groups with persons with disabilities in the cohort.
2. The team will use information gathered in the focus groups to create survey questions and interview guides.
3. We will outsource cognitive testing and data collection with an entity such as Mathematica.
  - a. The entity contacted to conduct the surveys and interviews will also do the initial analysis of the results.
4. YESHealth staff will do the final analysis and development and dissemination of reports to appropriate stakeholders, including state legislators, faith leaders, and disability organizations.

### Scope

The Disability Policy Consortium (DPC) will engage in a Participatory Action Research (PAR) project with a local university to be identified. I have already had initial conversations with Chaplaincy Innovation Lab at Brandeis University.<sup>522</sup> The Lab supports chaplains working in all fields to name and address changes taking place in religious and spiritual life in the United States. The lab provides a site for dialogue,

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<sup>522</sup> “Chaplaincy Innovation Lab,” Brandeis University, accessed March 22, 2022, <https://chaplaincyinnovation.org/>.

experimentation, and promotion of best practices in spiritual care as the needs of those served by the chaplains evolve.<sup>523</sup> In addition to Brandeis, active engagement is also taking place with Harvard University School of Public Health and a larger group of medical professionals and chaplains.

The research project will include persons with lived experience of disability between the ages 21–64 who have no research experience. The team will use information gathered from key informant interviews to create interview and focus group guides. We will outsource cognitive testing and data collection with an entity such as Mathematica. The analytical entity contacted to conduct the surveys and interviews will also do the initial analysis of the results.

### **Capacity and Competency**

I have been engaged in Community-Based Participatory Action Research (CBPR) and PAR research activities for nearly twenty-one years. I currently lead a small team of researchers at DPC in Massachusetts. Under the umbrella of Your Experience: Speak up for better health care (YESHealth), DPC has conducted research with Harvard University and Brandeis University in addition to carrying out its own research projects. These state-wide projects have been carried out by and for persons with disabilities to ensure fidelity to Paulo Freire’s model of action research as a means of liberation. In this same vein, we will make every effort to conduct research in a culturally humbled manner that

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<sup>523</sup> “Chaplaincy Innovation Lab.”

supports the intersectional needs identified by persons with disabilities of different racial, ethnic, and other backgrounds.

### **Scope**

The scope of the research will depend on funding. Therefore, the proposal includes two phases. The proposed scope of phase one: I will conduct interviews with three pastoral care providers who self-identify as persons with physical disabilities. Based on these interviews I will develop a guide to be used in listening sessions with three groups. The three groups of persons with disabilities are persons age 21–64 with amyotrophic lateral sclerosis (ALS), spinal cord injuries (SCI), and multiple sclerosis (MS). I will analyze and synthesize the results to produce a concise issue brief that will inform next steps.

## **Appendix II: Legislative Amendment Draft Language**

The goal is not to create new legislation but to amend existing legislation that will require Integrated Care Organizations (ICOs), now called Managed Care Organizations (MCOs), to provide spiritual support by chaplains as a covered service available to One Care members. The amendment structure of existing legislative language requesting One Care members have access to a long-term service and support coordinator (LTSS Coordinator). The amendment reads as follows:

We seek to have the following language added to Part One Title XVII 118E Section 9F:

(b) Members of the MassHealth dual-eligible pilot program in ICOs or any successor program integrating care for dual-eligible persons shall be provided an independent spiritual care provider by the ICO or successor organization, who shall be contracted by the ICO or successor and be a full participant in the member's care team. The spiritual support provider shall assist in the development of the member's a local comprehensive care assessment and care planning process.

(c) The spiritual care provider shall:

(1) be appropriately seminary educated with at least one unit of CPE.

(2) Contracted by the plan from a community-based organization (CBO) with experience in providing community-based chaplaincy services to persons with high level medical, behavioral health, social and other needs

(3) keep records, e.g., notes recorded in the members care plan, simple records to refresh the memory of the chaplain on members seen, and detailed notes on more difficult situations for the chaplain's learning

(4) track member satisfaction

(5) Demonstrate competency in providing care that maintains integrity of an interfaith model of care and supports member agency, choice, control, dignity of risk and recovery goals.

(6) participate in initial and ongoing assessments of the health and functional status of the member, including determining appropriateness of spiritual care and provide spiritual guidance and pastoral care to members and as directed by the member, a family member or other person identified by the member in consultation with the members care team;

(7) at the member's discretion,

- annually, or as requested by the member, carrying out a comprehensive spiritual assessment and in consultation with the member develop a plan of care that contributes to the overall care of the member that is measurable and documented;
- coordinating member engagement spiritual communities and activities of their choosing and as they define;
- participating as a full member in interdisciplinary teamwork and

collaboration of members requesting spiritual care;

(8) and monitor the appropriate provision and functional outcomes of community long-term care services, according to the service plan as deemed appropriate by the member and the care team; and

(9) the appropriate provision and functional outcomes of community long-term care services, according to the service plan as deemed appropriate by the member and the care team.

(d) The ICO or successor organization shall not have a direct or indirect financial ownership interest in an entity that serves as a provider of chaplain services in institutional or community based long-term services and supports on a compensated basis shall not function as an independent care coordinator.

### **After Law is Passed**

Legislative language is purposefully broad to allow for entities, in this case EOHHS latitude to implement the law in addition to legislative language, regulatory recommendations will be put forward to MassHealth. These recommendations will include the following requirements for chaplain responsibilities:

- (1) Providing spiritual/religious resources, e.g., sacred texts, Shabbat candles, music, prayer rugs, rosaries, etc.;
- (2) Offering rituals, prayer, and sacraments;

- (3) Helping interpret and broker cultures and faith traditions that impact health care practice and decisions of members and their care team members and direct home and community-based care providers;
- (4) Building relationships with local faith communities, spiritual groups, and their leaders on behalf of members and the health care organizations;
- (5) At the member's discretion, offering care and counsel regarding dynamic issues, e.g., loss/grief, spiritual/religious;
- (6) communication or interpersonal dynamic situations; with member agreement, conduct a comprehensive spiritual assessment, provide spiritual direct spiritual support, and coordinate opportunities to participate in religious and spiritual communities of their choosing, and as they self-define. (Meditation groups, ecotherapy)
- (7) track member satisfaction milestones in achieving desired spiritual wellness goals and track barriers impeding achievement of those milestones;
- (8) work collaboratively with other care team members to support the member to achieve the identified goals.



### **Appendix III: One-Page Handout for Legislators**

#### **Legislative Policy Statement**

This legislation requires the Massachusetts Executive Office of Health and Human Services (EOHHS) to establish standards and guidelines in providing spiritual care as a covered service available to Massachusetts residents enrolled in the Massachusetts One Care plan.

#### **Partnership overview**

Disability Advocates Advancing Our Healthcare Rights (DAAHR) is a statewide health justice coalition that promotes health equity for persons with disabilities in Massachusetts. DAAHR was spearheaded by the Disability Policy Consortium (DPC) and Boston Center for Independent Living (BCIL). We are united in our goal working in partnership with seminaries, chaplaincy certification organizations and medical chaplains.

#### **Background**

Spirituality is fundamental to the human experience and overall wellness.<sup>524</sup> Spiritual care is available to people with complex needs in facilities such as hospitals and tired of care or hospice centers, but not available to persons with similar needs living in community settings.<sup>525</sup> One Care is a demonstration project designed to provide whole person-centered care to Massachusetts residents with Medicaid and (dual eligibles)

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<sup>524</sup> Hvidt et al., “What Is Spiritual Care?” 7, 8.

<sup>525</sup> “OCR Resolves Religious Discrimination Complaints,” U.S. Department of Health and Human Services; Saad, “Programs of Religious/Spiritual Support in Hospitals,” 1–4.

between the ages of 21–64.<sup>526</sup> The majority of dual eligibles under the age of 65 are eligible for Medicare based on disability status.

One Care is mandated to offer flexible services to assist enrollees get their individual healthcare needs met and achieve their personal wellness goals.<sup>527</sup> Wellness includes the opportunity for meaningful engagement in the community.<sup>528</sup> By requiring One Care to offer spiritual care to enrollees, policymakers will be ensuring increased availability of resources and services that support health and wellness they are not receiving right now.

Dual eligibles in this age group experience high levels of substance use disorder, mental health diagnoses, complex medical diagnoses, and social need.<sup>529</sup> In addition, dual eligible people are at increased risk of loneliness, isolation and other factors that lead to poor health outcomes.<sup>530</sup>

### **Research findings**

University of Massachusetts (UMass) recently reported out findings from its 2017 to 2019 surveys of One Care member self-reported quality of life indicators. The majority

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<sup>526</sup> “OneCare Report,” Blue Cross Blue Shield of Massachusetts Foundation, 1–3.

<sup>527</sup> Barry, “Early Insights from One Care.”

<sup>528</sup> “One Care,” Boston Center for Independent Living.

<sup>529</sup> “The CBHSQ,” 2.

<sup>530</sup> Victor, “The Prevalence of Loneliness Among Adults”; Lee, “High Prevalence and Adverse Health Effects of Loneliness”; Soest, “Development of Loneliness in Midlife and Old Age”; Holt-Lunstad, “Loneliness and Social Isolation as Risk Factors for Mortality.”

of survey respondents reported spirituality or religion is important to their life. The UMass findings are in line with other research on disability and spirituality.<sup>531</sup>

In 2019 UMass included a question on feelings loneliness. Almost half of the respondents reported they often experience loneliness. These responses are also consistent with the literature on the intersection of loneliness, isolation and disability status. Offering spiritual care to this population is necessary for three reasons: A review of the literature shows a direct correlation between loneliness, isolation and depression that can result in preventable morbidity and mortality.<sup>532</sup> The literature shows that spirituality and spiritual care can improve overall wellness.<sup>533</sup> Spiritual care is standard practice in the United Kingdom. Primary Care Chaplains (PCCs) with the literature showing the positive impact of PCCs on the lives of people and palliative care beneficial to persons with chronic conditions in the community.<sup>534</sup>

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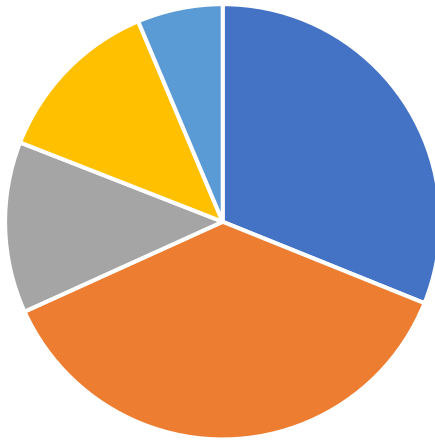
<sup>531</sup> Kaye and Raghavan, "Spirituality in Disability and Illness," 237–39; Brillhart, "A Study of Spirituality and Life Satisfaction Among Persons with Spinal Cord Injury," 33; Matheis, "The Relation between Spirituality and Quality of Life among Individuals with Spinal Cord Injury," 266, 269; Lorenzo, "*Deep Down in Our Hearts*," 120–22; Schulz, "Spirituality and Disability," 61–70.

<sup>532</sup> Pagan, "Gender and Age Differences in Loneliness," 10, 11; Macdonald et al., "'The Invisible Enemy'"; Emerson et al., "Loneliness, Social Support, Social Isolation and Wellbeing among Working Age Adults with and without Disability," 5, 6.

<sup>533</sup> Boswell et al., "Disability and Spirituality: A Reciprocal Relationship with Implications for the Rehabilitation Process," 16; Tarvainen, "Loneliness in Life Stories by People with Disabilities," 865, 879, 880.

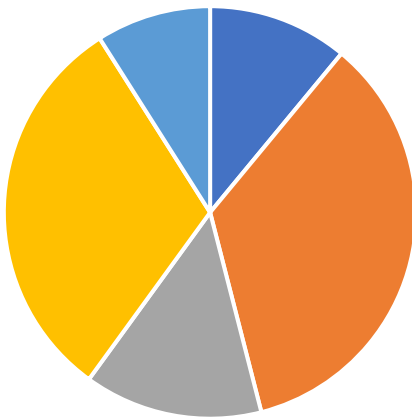
<sup>534</sup> McSherry, Boughey, and Kevern, "'Chaplains for Wellbeing' in Primary Care," 2, 8–10.

### Importance of Spirituality or Religion



■ Strongly Agree   ■ Agree  
■ Not Sure   ■ Disagree  
■ Strongly Disagree

### Often Experience Loneliness



■ Strongly Agree   ■ Agree  
■ Not Sure   ■ Disagree  
■ Strongly Disagree

Would you like more support from other people?



- Strongly agree
- Agree
- Not sure
- Disagree
- Strongly disagree

#### **Appendix IV: Sample Spiritual Self-Assessment Guide**

<b>Write a narrative addressing each of the following areas of Assessment:</b>
<b><u>I. Family of Origin</u></b> Discuss the spirituality of your family of origin. What is your spiritual and religious background? What importance did faith play in your home, and in generations past?
<b><u>II. Influences on your Spirituality</u></b> Discuss the people (friends, mentors, extended family members, authors) who have had significant impact on your spiritual formation.
<b><u>III. Life Events</u></b> Discuss events in your life that have shaped/influenced your spirituality and what kind of impact they have made.
<b><u>IV. Your current spiritual state</u></b> Discuss key spiritual <b>Beliefs</b> that you hold about the god of your understanding.  Discuss spiritual <b>Activities and/or Rituals</b> that you practice currently. What significance do they hold for you?  What <b>Impact/Meaning</b> does your faith have on your daily life?  What are <b>spiritual struggles/strengths/questions</b> that you identify in your life?
<b><u>V. Graphic Assessment Tool</u></b>  Create a <b>Genogram or Life Map</b> (whichever you find more important and insightful with your spiritual journey) and include it with your narrative assessment.

Taken from: Julie Hunt. "Bio-Psycho-Social-Spiritual Assessment? Teaching the Skill of Spiritual Assessment," *Journal of the North American Association of Christians in Social Work* 41, no. 4 (2014): 379.

## **Appendix V: Evolving Definitions of Disability**

### **World Health Organization, 2001**

“Umbrella term for impairments, activity limitations or participation restrictions,”  
conceiving “a person’s functioning and disability . . . as a dynamic interaction between  
health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors,”  
including the social, attitudinal, and physical environments and personal attributes.”<sup>535</sup>

### **Americans with Disabilities Act (ADA), 1990**

“The term ‘disability’ means, with respect to an individual—(A) a physical or mental  
impairment that substantially limits one or more of the major life activities of such  
individual; (B) a record of such an impairment; or (C) being regarded as having such an  
impairment.”

### **ADA Regulations (28 CFR Part 36, §36.104)**

“Major life activities include such things as caring for oneself, performing manual tasks,  
walking, seeing, hearing, speaking, breathing, learning, and working.” To be substantially  
limited, an individual’s important life activities must be “restricted as to the conditions,  
manner, or duration under which they can be performed in comparison to most people.”

### **Social Security Administration, 2003**

“Inability to engage in any substantial gainful activity by reason of any medically  
determinable physical or mental impairment(s) which can be expected to result in death

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<sup>535</sup> “Towards a Common Language for Functioning, Disability and Health,” *World Health Organization*, 2002, <https://www.who.int/classifications/icf/icfbeginnersguide.pdf>; Lisa I. Iezzoni and Vicki A. Freedman, “Turning the Disability Tide: The Importance of Definitions,” *Journal of American Medical Association* 299, no. 3 (2008): 332–334, <https://doi.org/10.1001/jama.299.3.332>.

or which has lasted or can be expected to last for a continuous period of not less than 12 months.”<sup>536</sup>

American Medical Association, 2001

“An alteration of an individual’s capacity to meet personal, social, or occupational demands because of an impairment.”<sup>537</sup>

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<sup>536</sup> “Disability Evaluation Under Social Security,” United States Social Security Administration, 2003, <https://www.ok.gov/odc/documents/Blue%20Book.pdf>; Iezzoni and Freedman, “Turning the Disability Tide,” 332–334.

<sup>537</sup> Linda Cocchiarella and Gunnar Andersson, *Guides to the Evaluation of Permanent Impairment* (Mishawaka, IN: American Medical Association, 2001); Iezzoni and Freedman, 332–334.



## **Appendix VI: Chaplaincy Qualifications Draft Language**

### **Chaplaincy Qualifications**

Chaplains must be certified by the Board of Chaplaincy Certification Inc. (BCCI) or be an associate certified chaplains (ACC) according to established national qualifications including a code of ethics.<sup>538</sup> The chaplain must demonstrate cultural humility and working knowledge of independent living and recovery principles necessary to advance personal agency, meaning and hope. The spiritual assessment should include elements needed to help the chaplain better understand the enrollee's:

- belief or faith system (what gives the enrollee meaning), and ways that belief system may impact the enrollee's health and wellness;
- current or past connection with spiritual, religious, or other community that provide that may have negatively impacted or supported individual meaning;
- health and wellness goals with particular emphasis on spiritual, religious, or other activities needed;
- expectations of the chaplain and other care team members to integrate spiritual or religious goals into their overall care plan.

The chaplain, in partnership with the enrollee and other members of the care team develops and implements an individualized care plan that promotes enrollee identified

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<sup>538</sup> "Common Standards for Professional Chaplaincy," Association of Professional Chaplains, accessed February 18, 2020, [https://www.professionalchaplains.org/files/professional\\_standards/common\\_standards/common\\_standards\\_professional\\_chaplaincy.pdf](https://www.professionalchaplains.org/files/professional_standards/common_standards/common_standards_professional_chaplaincy.pdf).

spiritual/religious goals that support enrollee's health and wellness. The chaplain actively collaborates with other members of the enrollee's interdisciplinary care team, including as appropriate the enrollee's family to support the achievement of these goals. The chaplain is responsible for:

- enrollee goals, barriers to achieving these goals
- that support these aspects of a sense of personal meaning and hope as well as barriers the goals and the services and activities attain promoting the integration of spiritual and religious goals identified by the enrollee into the enrollee's care plan.
- coordinating activities necessary for the enrollee to achieve these goals including, but not limited to:
  - acting as a liaison between the enrollee and CBOs and FBOs;
  - assisting the enrollee and the CBO/FBO to identify and address potential barriers to active engagement by the enrollee e.g., transportation barriers or attitudinal barriers
- Building partnerships with Community-Based Organizations (CBOs) and Faith-Based Organizations (FBOs) to increase enrollee choice of CBOs and FBOs with the competency and capacity to:
  - provide the enrollee with a welcoming environment and activities that support the opportunity for the enrollee to meet identified spiritual/religious goals;
  - offer clinical treatment and recovery support services to persons with behavioral health needs.

In addition to the above, chaplains shall be held accountable to the following standards adapted from the Association for Professional Chaplains Standard of Practice for Professional Chaplains in Hospice and Palliative Care:

#### Section 1: Chaplaincy Care with Members and Families

Standard 1, Assessment: The chaplain gathers and evaluates relevant data pertinent to the member's situation and/or bio-psycho-social-spiritual/religious health.

Standard 2, Delivery of Care: The chaplain develops and implements a plan of care to promote member well-being and continuity of care.

Standard 3, Access to Information and Documentation of Care: The chaplain, as a participant in the member's care team, updates the care plan regularly. Information provided in consultation with the member includes progress towards spiritual, religious, community, and wellness goals. Barriers to achieving goals and new opportunities should also be included as appropriate.

Standard 4, Teamwork and Collaboration: Team is an essential component of the One Care model and the chaplain is a fully integrated member of the interdisciplinary team.

Standard 5, Ethical Practice: The chaplain will adhere to the Common Code of Ethics, which guides decision making and professional behavior.

Standard 6, Confidentiality: The chaplain respects the confidentiality of information from all sources, including the member/family members, medical record, interdisciplinary team members, larger health care team and local faith community members, in accordance with federal and state laws, regulations, and rules.

Standard 7, Cultural Humility: The chaplain models and collaborates with the member and their interdisciplinary team in respecting and providing cultural, psycho-social and spiritual/religious support

1. Providing spiritual/religious resources, e.g., sacred texts, Shabbat candles, music, prayer rugs, rosaries, etc.
2. Offering rituals, prayer, and sacraments;
3. Helping interpret and broker cultures and faith traditions that impact health care practice and decisions of members and their care team members and direct home and community-based care providers;
4. Building relationships with local faith communities, spiritual groups, and their leaders on behalf of members and the health care organization to promote culturally competent welcoming communities for persons with disabilities.
5. At the member's discretion, offering care and counsel regarding

dynamic issues, e.g., loss/grief, spiritual/religious

6. Communication or interpersonal dynamic situations; with member agreement, conduct a comprehensive spiritual assessment, provide spiritual direct spiritual support, and coordinate opportunities to participate in religious and spiritual communities of their choosing, and as they self-define.  
(Meditation groups, ecotherapy, dance, cultural events, as well as religious services).

Standard 8, Disability Culture: The chaplain models and supports consumer choice, control, and dignity of risk for persons as appropriate.

Standard 9, Recovery: The chaplain accompanies as requested persons identified as having a history of a mental health diagnosis or trauma and persons in recovery from substance use disorder.

## Section 2: Maintaining Competent Chaplaincy Care

Standard 11, Continuous Quality Improvement: The chaplain seeks and creates opportunities to enhance the quality of chaplaincy practice.

Standard 12, Research: The chaplain practices evidence-based care, including ongoing evaluation of new practices, and, when appropriate, contributes to or conducts research.

Standard 13, Knowledge and Continuing Education: The chaplain takes responsibility for continued professional development. The chaplain

demonstrates a working knowledge of current theory and practice.

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