

## LONG-TERM CARE IN HAWAII

by Scott Suzuki<sup>1</sup>

In addition to becoming highly probable,<sup>2</sup> long-term care (“LTC”) has become highly regulated and for many, painfully expensive. The labyrinthine regulations applicable to LTC have established a respectable, but not fully acceptable,<sup>3</sup> quality of skilled nursing care. There remains great variety in types and quality of care and services available. As a result, planning for an individual’s LTC may seem an insurmountable task.

Assisting people with LTC planning requires a basic understanding of the development of the LTC system, the types of care that may be available, an approach to selecting appropriate settings and the financial<sup>4</sup> aspects of LTC. This article endeavors to provide a brief overview of these elements of LTC planning.

### I. A Brief History of the Development of Long-Term Care

*Nursing homes as we know them today are a relatively new resource for caring for the elderly. Before public funding for the construction of nursing homes was widely available, and before the Medicaid program provided public funding for long-term institutional care, the only congregate settings for the elderly were the old age homes run by charitable institutions and municipalities for those who were without family resources.*<sup>5</sup>

The above excerpt reveals the all-or-nothing nature of LTC in the United States as it has evolved from its apathetic beginnings to its current highly-regulated, Byzantine status.

The American system of LTC has evolved enormously over the nation’s history. In Colonial America, a relatively small percentage of the population lived into what is now considered to be “old

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<sup>2</sup> See Naomi Freundlich, *Health Policy Snapshot*, Robert Wood Johnson Foundation, February 2014.

<sup>3</sup> For many, LTC simply means “nursing home” or “skilled nursing facility”. Although skilled nursing facilities provide an unparalleled method of providing continuous, comprehensive, cost-effective care, they simply do not fit well into most individuals’ plans for their own care. See Staff Editorial, *Will You Still Feed Me When I’m Eighty-Four?*, HONOLULU ADVERTISER, Nov. 18, 2002 at A8 (People fear the economic burdens of LTC, loss of autonomy, their own physical decline, and the quality of care they may, or may not receive).

<sup>4</sup> See also Christopher R. Dang, Derek T. Kamiya, Scott C. Suzuki, and Eric S.T. Young, *Planning Ahead: Practical Financial and Estate Planning Considerations*, HAWAII BAR JOURNAL, October 2014, for additional information on the financial aspects of LTC.

<sup>5</sup> Margaret M. Flint, *Nursing Homes*, 266 PRACTICING LAW INSTITUTE 559, 561-562 (1998). (“Flint”).

age.”<sup>6</sup> Caregivers for these few were most frequently family members, including a spouse or children.<sup>7</sup> Only the very fortunate could hire additional assistance.<sup>8</sup> The fate for those who had no family or money was more ambiguous.<sup>9</sup> Small colonial communities commonly established care systems for people with disabilities, including older adults.<sup>10</sup> In these systems, community members took turns providing care for those in need. Almost always, colonists provided these services with the expectation of some form of reciprocity.<sup>11</sup> Eventually, the governments had to become more involved.

“Outdoor Relief” was the original form of government-controlled LTC.<sup>12</sup> Generally, “outdoor relief” consisted of a cash payment from the government to a private individual who accepted the duty of caring for poverty-stricken citizens.<sup>13</sup> Local taxpayers bore the burden of this considerable, but necessary expense.<sup>14</sup> Community-based care evolved into a more formal network to accommodate important demographic changes, but this placed substantial financial strains on the government.<sup>15</sup> Thus, a new paradigm emerged.<sup>16</sup>

Western expansion during the 1800s was one of the many factors influencing change in LTC. As young pioneers left their older parents behind in the Colonies to explore the virgin frontier, the family’s role in LTC diminished.<sup>17</sup> While never completely displaced as the primary source of care, the family became less available to care for older relatives. The first major alternative trend to “outdoor relief” was the privately-funded, system of “indoor relief.”<sup>18</sup> This system utilized private institutions such as poorhouses, almshouses, infirmaries, and asylums.<sup>19</sup> Many of these institutions

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<sup>6</sup> See Karen Stevenson Brown, *LTC Backwards and Forwards*, (2002) at <http://www.ElderWeb.com>. (“Brown”)

<sup>7</sup> See SOCIAL SECURITY ADMINISTRATION, *Why Social Security*, SOCIAL SECURITY BOARD PUBLICATION NO. 15, (1937).

<sup>8</sup> See BROWN, *supra* note 5.

<sup>9</sup> See generally Jennifer Gimler Brady, *Long-Term Care Under Fire: A Case for Rational Enforcement*, 18 J.CONTEMP. HEALTH L. & POL’Y 1, 6 (2001)(indicating that prior to Medicare and Medicaid in 1965, local governments imposed regulations of nursing homes and other forms of long-term care).

<sup>10</sup> See Martha Holstein, & Thomas R. Cole, *The Evolution of Long-Term Care in America*, in THE FUTURE OF LONG-TERM CARE: SOCIAL AND POLICY ISSUES, 19-47 (Robert H. Binstock, Ph.D. et al., eds., 1996). (“Holstein”).

<sup>11</sup> CHARLES W. LIDZ ET AL., THE EROSION OF AUTONOMY IN LONG-TERM CARE 24 (1992). (“Lidz”).

<sup>12</sup> See generally David A. Bohm, *Striving for Quality Care in America’s Nursing Homes: Tracing the History of Nursing Homes and Noting the Effect of Recent Federal Government Initiatives to Ensure Quality Care In The Nursing Home Setting*, 4 DEPAUL J. OF HEALTH CARE LAW 317 (2001). (“Bohm”); BROWN, *supra* note 5; see also Holstein, *supra* note 9 at 19. (“Outdoor relief” was based on the English Poor Law of 1601 and was enforced and financed at the community level).

<sup>13</sup> See Holstein, *supra* Note 9.

<sup>14</sup> *Id.*

<sup>15</sup> *Id.*

<sup>16</sup> See Octave Thanet, Secretary of the Board of Charities, *The Indoor Pauper: A Study*, 47 Atlantic Monthly, 284 (1881) (showing that Tennessee at one point even auctioned the care of “paupers” off to the lowest bidder). (“Thanet”).

<sup>17</sup> See generally BROWN, *supra* note 5.

<sup>18</sup> *Id.*; see also BOHM, *supra*, note 11; and HOLSTEIN, *supra* note 9.

<sup>19</sup> *Id.*

were self-sufficient and economical in the eyes of the government and taxpayers.<sup>20</sup> Despite the economic benefits, these facilities had few positive characteristics.

Indoor relief essentially institutionalized older adults, linking old age with disability, insanity, and even criminality.<sup>21</sup> Residents of almshouses and other facilities were referred to as “inmates,” and were frequently clothed in uniforms.<sup>22</sup> Indoor relief created “a deliberately punitive environment” which gave the message that the residents of such facilities had forsaken the predominant faith.<sup>23</sup> The punishment was an attempt to “motivate persons to lead upstanding lives.”<sup>24</sup>

The horrendous conditions in the almshouses are well recognized.<sup>25</sup> The public was aware of the quality of care provided in almshouses, but accepted it as a necessary trade-off.<sup>26</sup> Dissatisfied with the atrocious conditions in LTC facilities, America began to search, yet again, for an alternative method in the new century.<sup>27</sup>

New methods of LTC care became more of an industry, inspiring public nursing institutions.<sup>28</sup> “Ageist”<sup>29</sup> stereotypes dominated the LTC paradigm, convincing people that institutional settings were not only essential and inevitable, they were also the best method of providing care for disadvantaged older adults.<sup>30</sup> Despite the wide-spread public acceptance of the role of nursing homes within American LTC, the government stayed away from long-term care.<sup>31</sup> As a result, institutionalization remained the norm until the emergence of non-profit organizations.<sup>32</sup>

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<sup>20</sup> See generally CHARLES W. LIDZ ET AL., *supra* note 10.

<sup>21</sup> See MICHIGAN STATE MEDICAL SOCIETY, *MEDICAL HISTORY OF MICHIGAN*, (1930) (providing an example that the Black Horse Tavern of Wayne County, MI provided care to “Deaf, dumb, blind, idiots, aged and sick, poor children, unfortunate women, insane...”).

<sup>22</sup> See generally BROWN, *supra* note 5.

<sup>23</sup> See BOHM, *supra* note 11 at 326.

<sup>24</sup> *Id.* See also HOLSTEIN, *supra* note 9 (both indicating that the purpose of almshouses was, in fact, to motivate a person to live righteously, but not to provide care).

<sup>25</sup> See generally, DOROTHEA L. DIX, *ON BEHALF OF THE INSANE POOR: SELECTED REPORTS 1842-1862*, (New York, Ayer Co. Publishers, Inc., 1975) (describing the horrible conditions in some of the almshouses. Some accounts even describe women who were chained up or locked in pens).

<sup>26</sup> See THANET, *supra* note 15. (“The quality is not strained, since it costs [older adults] nothing.”).

<sup>27</sup> See HOLSTEIN, *supra* note 9 at 22-23; BOHM *supra* note **Error! Bookmark not defined.** at 327 (indicating that people tended to revert back to a method of caring for their own in their private homes. BOHM further indicates that only those people who society deemed “worthy” were permitted to stay at the almshouses.).

<sup>28</sup> See BOHM, *supra* note 11 at 328.

<sup>29</sup> See W.A. ACHENBAUM, *SOCIETAL PERCEPTIONS OF AGING AND THE AGED*, (1985) (Robert Butler, M.D. coined the term “ageism” in 1969 as the first director of the National Institute on Aging. The term is defined as “a systematic stereotyping of and discrimination against people because they are old.”).

<sup>30</sup> See generally HOLSTEIN, *supra* note 9; see also BOHM, *supra* note 11.

<sup>31</sup> See BOHM, *supra* note 11; see also LIDZ ET AL., *supra* note 10.

<sup>32</sup> See generally BROWN, *supra* note 5 (Non-profit and charitable organizations such as the Odd Fellows and Benevolent Societies played an essential role in the long-term care system. While facilities were often much better than those of the poor houses, they continued to operate on ageist philosophies that endangered and exploited the “inmates” who resided in them. Because the overall philosophy of these organizations is substantially similar to that of the private nursing home, there were no government regulations for these facilities, and because the private nursing facility currently dominate the industry, this discussion does not focus on the non-profit sector.).

Private organizations carried the costs of most LTC.<sup>33</sup> As demographics and American society itself changed, the nature of nursing homes again began to adapt.<sup>34</sup> The implications of these changes are important in that they created new and unimaginable conditions of poverty.<sup>35</sup> Economic conditions forced many people into an involuntary early retirement.<sup>36</sup> In response, the states and the territories of Hawaii and Alaska began implementing their own old-age assistance programs.<sup>37</sup>

Old-age assistance programs varied greatly.<sup>38</sup> Some states were progressive and liberal, while others were conservative.<sup>39</sup> The Great Depression represented the height of the suffering, and federal old-age assistance programs became the watershed for the development of the modern nursing home.<sup>40</sup>

In 1935, the United States implemented the Social Security Act,<sup>41</sup> which was the impetus of the development of the modern nursing home.<sup>42</sup> Federal funding assisted state welfare and old-age assistance programs to provide better funding for private nursing homes, which became the primary model of care-giving for dependent older adults.<sup>43</sup> Federal programs encouraged private nursing homes to help alleviate the strain on hospitals.<sup>44</sup> Nursing homes developed a medical model in order to provide both care and basic needs to residents.<sup>45</sup> The transition in care paradigms inspired federal action to strengthen the quality of care.

The initial legislative act that began to address the quality of care in medical facilities was arguably the Hill-Burton Act of 1946.<sup>46</sup> The 1950 amendments to the Hill-Burton Act required state

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<sup>33</sup> See BOHM, *supra* note 11 at 328. (“Federal laws mandating the level of care to be administered to public or private institution residents were still nonexistent.”).

<sup>34</sup> See U.S. CENSUS BUREAU CHANGES IN RURAL/URBAN POPULATION 1800-1990. (Census fertility charts show that American demographics changed considerably between 1850 and 1940. For example, the birth rates decreased, indicating that the American family was shrinking. Additionally, society was becoming more urban. In the 1850’s, only 15% of the population was urban. By the 1940’s, nearly 60% of the population lived in urban areas.).

<sup>35</sup> See generally AMERICAN LIFE HISTORIES: MANUSCRIPTS FROM THE FEDERAL WRITERS’ PROJECT, 1936-1940.

<sup>36</sup> See BROWN, *supra* note 5.

<sup>37</sup> See BARBARA NACHTRIED ARMSTRONG AND STAFF, *Final Staff Report: Old Age Security Staff Report, from the UNPUBLISHED STUDIES OF THE STAFF OF THE COMMITTEE ON ECONOMIC SECURITY*, VOL. II (1934).

<sup>38</sup> *Id.*

<sup>39</sup> See *Id.* (Note also that Hawaii was one of the most liberal and progressive. Hawaii was one of only two jurisdictions that made “payments to older people who had children or relatives who could support them.” The assistance programs, however, were not mandatory upon the counties of the Hawaii Territory.).

<sup>40</sup> See generally BOHM, *supra* note 11.

<sup>41</sup> The Social Security Act (Old Age Pension) is codified at 42 U.S.C.A. § 301 (1935).

<sup>42</sup> See LIDZ, *supra* note 10 at 29.

<sup>43</sup> See HOLSTEIN, *supra* note 9 at 29 (the Social Security Act only funded private homes.); see also BOHM, *supra* note 11 at 329 (“Federal government programs to reimburse only particular types of facilities for the care and treatment of qualified elderly persons inadvertently shaped these facilities” into the primary source of care for dependent older adults.).

<sup>44</sup> See generally BOHM, *supra* note 11 at 329; HOLSTEIN, *supra* note 9 at 29, and LIDZ, *supra* note 10 at 23. (all indicating that nursing homes were essential for providing care to patients with chronic conditions when hospitals became unable to do so).

<sup>45</sup> See generally BOHM, *supra* note 11 at 330 and LIDZ, *supra* note 10 at 31.

<sup>46</sup> See generally BOHM, *supra* note 11 at 330 (This Act encouraged private owners to develop more hospitals. As a result, numerous new facilities emerged and existing facilities, such as private mansions and hotels, were converted into care centers for older adults.).

licensure provisions for all nursing home facilities.<sup>47</sup> The preliminary licensure processes and their variability across jurisdictional lines made it almost impossible to impose federal regulations.<sup>48</sup> Market competition among private nursing home owners, and not legal regulation, drove the improvements in nursing home quality between the 1940s and the 1960s.<sup>49</sup>

The 1960s contributed some of the most influential, broad-reaching legislation to the field of LTC.<sup>50</sup> In the early half of the decade, certain legislative solutions caused LTC costs to skyrocket.<sup>51</sup> As taxpayers began to pay more money for LTC, politicians began to reconsider the quality of care.<sup>52</sup> Major changes were inevitable.

Perhaps the most wide-spread changes to the nursing home industry developed in the 1960s with the introduction of Medicare and Medicaid laws.<sup>53</sup> These programs introduced federal enforcement over the quality of care provided by nursing homes.<sup>54</sup> Initially, the Advisory Council on Social Security opposed funding nursing homes.<sup>55</sup> Eventually, however, the federal government was able to earmark public monies under the Medicare and Medicaid programs to those facilities that met minimal standards.<sup>56</sup> Such standards were based on concepts of “substantial compliance” that allowed deficient facilities to continue to receive federal funding on the condition that they fully comply with federal standards within a certain amount of time.<sup>57</sup> Congress periodically made several amendments to the Medicare and Medicaid programs between 1965 and 1987, but the overall impact

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<sup>47</sup> See generally BOHM, *supra* note 11 at Note 67.

<sup>48</sup> *Id.*

<sup>49</sup> See generally Kevin B. Dreher, *Enforcement of Standard of Care in the Long-Term Care Industry: How Far Have We Come and Where Do We Go From Here?*, 10 ELDER L.J. 119, (2002).

<sup>50</sup> See generally Arthur J. Altmeyer, *The Development and Status of Social Security in America*, in LABOR, MANAGEMENT AND SOCIAL POLICY: ESSAYS IN THE JOHN R. COMMONS TRADITION. (Gerald G. Somers, ed., U. Wisc. Press, 1963) (Among the many legislative initiatives were Medicare and Medicaid and the Kerr-Mills Social Security Act (codified at 26 U.S.C. § 3125 and providing for federal government to match the costs of medical care for needy older adults). In addition, the Older Americans Act of 1965, which created the Administration of Aging within the Department of Health and Human Services and established the Aging Network, had considerable impact on the American system of long-term care.).

<sup>51</sup> See BROWN, *supra* note 5. (indicating that Kerr-Mills costs jumped from \$449 million annually to \$2.5 billion annually from 1960 to 1965).

<sup>52</sup> See S.REP NO. 107-158(I), 3 (2002). (Describing the concern of the 1960s that 44% of nursing home beds failed to meet the Hill-Burton fire and health standards. Also note that the Moss Committee hearings of 1965 reported a lack of consistency between the states in terms of quality of care in nursing homes).

<sup>53</sup> Medicare is codified at 42 U.S.C. § 1395 ET SEQ. (1994), and Medicaid is codified at 42 U.S.C. § 1396 ET SEQ. (1994). (Very generally, Medicare provides certain medical insurance benefits to vested adults 65 and older and Medicaid is a needs-based medical insurance package.)

<sup>54</sup> See generally BOHM, *supra* note 11 at 330.

<sup>55</sup> See generally 1965 REPORT OF THE ADVISORY COUNCIL ON SOCIAL SECURITY, *The Status of the Social Security Program and Recommendations for its Improvement, Part II Hospital Insurance for Older People and the Disabled* (stating that “the proposed program is designed primarily to support efforts to cure and rehabilitate, and since “nursing home care”, in many cases, is oriented not to curing or rehabilitating the patient but to giving him custodial care, the Council does not propose the coverage of care in nursing homes general.”)

<sup>56</sup> See generally BOHM, *supra* note 11 at 330 and LIDZ, *supra* note 10 at 32-33.

<sup>57</sup> *Id.*

on quality of care was complicated by the fact that states maintained licensure standards.<sup>58</sup> The nation therefore continued to search for a method to ensure quality of late-life care.

In 1987, Congress enacted the Omnibus Budget Reconciliation Act (“OBRA ‘87”).<sup>59</sup> The purpose of OBRA ‘87 was to force nursing homes to focus on the actual delivery of care and the results of such care.<sup>60</sup> In addition to requiring this focus, OBRA ‘87 also imposed actual penalties for violations of codes, instead of relying on the substantial compliance methods.<sup>61</sup> The result of OBRA ‘87 is that the “federal government has become directly involved in the provision of quality care administered by nursing facilities.”<sup>62</sup> Ultimately, OBRA ‘87 avails nursing homes to the regulations of both federal and state laws, including zoning, state licensure, Medicare and Medicaid financing standards, accreditation, surveyor reviews, as well as other common-law remedies, as applicable.<sup>63</sup> OBRA ‘87 has effectively created the modern nursing home.

LTC is also tied to local culture and custom. The development of LTC in Hawaii provides further context for planning purposes.

Although the literature on long-term care in the traditions of the Hawaiian people is sparse, what does exist tends to show that the Hawaiian culture displays a great deal of respect for elders and that LTC was largely a community duty.<sup>64</sup> Scattered evidence of this reverence for elders comes from a variety of sources. The Hawaiian language itself contains the concepts of *hulukupuna* and *hulumakua*.<sup>65</sup> These terms imply that the elders, of both the parents’ and grandparents’ generations were “as precious and dearly loved as the choice feathers woven into a feather cape.”<sup>66</sup> These values are also, to a certain extent, evidenced in public health policies.

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<sup>58</sup> *Id.* (both indicate that the lack of uniformity in quality standards resulted in large discrepancies between the quality of the services and the quality of the facility delivering services).

<sup>59</sup> Known as “OBRA 87,” or the “Nursing Home Reform Act,” and is codified at 42 U.S.C. §§ 1395i-3(A)-(H) and 1396R(A)-(H) (1994).

<sup>60</sup> See generally GAO LETTER REPORT, *Nursing Homes: Additional Steps Needed to Strengthen Enforcement of Federal Quality Standards*, GAO/HEHS-99-46 (March 18, 1999)(OBRA ‘87 was enacted on the recommendations of the Institute of Medicine, as contracted by the Department of Health and Human Services).

<sup>61</sup> *Id.* (States could enforce civil penalties against deficient facilities in amounts of up to \$10,000 a day). See also H.R. 391, 100th Congress, at 473 (finding that monetary sanctions could help encourage compliance) (Note also that prior to OBRA ‘87, the only “sanctioning powers available to the federal government against the non-compliant nursing homes included: (1) terminating the nursing home’s Medicare participating agreements, and (2) denying payment for services provided to new Medicare or Medicaid qualified residents.” (see BOHM, *supra* note 11 at note 82).)

<sup>62</sup> BOHM, *supra* note 11 at 332.

<sup>63</sup> See BOHM, *supra* note 11 at 334-335.

<sup>64</sup> See generally E.S. CRAIGHILL HANDY & MARY KAWENA PUKUI, *THE POLYNESIAN FAMILY SYSTEM IN KA-‘U, HAWAII*, at 14, (Charles E. Tuttle Co., Rutland, Vermont, 1981). (“Handy & Pukui”).

<sup>65</sup> *Id.* at 14 (*Hulukupuna* is a “term for one of the few remaining of the living blood relatives of the grandparents’ generation.” *Hulumakua* are the precious elders of the parents’ generation).

<sup>66</sup> *Id.* at 45.

Public health policies in Hawaii appeared as early as 1779,<sup>67</sup> and became more formal through the early 1800s.<sup>68</sup> On May 29, 1839, King Kamehameha III instructed the governors of all the islands to create boards of health.<sup>69</sup> In 1850, King Kamehameha III established a Department of Health for the Kingdom.<sup>70</sup> The Department created several regulations pertaining to LTC, including licensure requirements for physicians and *kahunas*.<sup>71</sup> Hawaii's sixth king, William Charles Lunalilo, had perhaps the greatest impact on LTC.<sup>72</sup>

Although King Lunalilo had a short reign,<sup>73</sup> his efforts continue to influence LTC in Hawaii. Known as "Prince Bill" to the common people who loved him, Lunalilo embraced the values and norms of the Hawaiians.<sup>74</sup> King Lunalilo was the first of the Hawaiian Monarchs to establish a charitable trust for the benefit of his people.<sup>75</sup> King Lunalilo's 1874 testamentary trust established the Lunalilo Home, which is for the "use and accommodation of poor, destitute, and infirm people of Hawaiian blood...giving preference to old people."<sup>76</sup> The Lunalilo Home continues to operate as a long-term care facility on Oahu.<sup>77</sup>

In the short time between statehood and the modern era, Hawaii developed a broad and complicated system of LTC consisting of a variety of agencies and facilities.<sup>78</sup> The current Executive

<sup>67</sup> See George Mills, *Hawaiians and Medicine*, 40.10 HAWAII MEDICAL JOURNAL 272, 273 (1981) at 272 (indicating that the young Kamehameha the Great took part of the first off-shore health inspection of Captain Cook's boat and crew upon arrival to Maui in 1779.).

<sup>68</sup> *Id.* at 273 (Indicating that an August 1, 1836 document from members of the Royal Family directed the Honolulu Harbor Pilot to ascertain whether any boat in the harbor carried small pox. If the boat had an infectious disease, the master was to hoist a yellow flag on the main and report to authorities. Penalties for violating these regulations could result in an unspecified severe penalty and the boat could be driven from the harbor.).

<sup>69</sup> *Id.* at 273 (These Boards were not funded and operated poorly).

<sup>70</sup> *Id.* at 274 (This is significant to the culture because Hawaii established public health as a governmental function only three years after England. Further, the first government-operated department of health on the Mainland was in Louisiana, established in 1855.).

<sup>71</sup> *Id.* (Note that in 1856, there were only three licensed physicians and 14 *kahunas*. This indicates the influence native culture maintained.).

<sup>72</sup> King Lunalilo was born in 1835 and died in 1874.

<sup>73</sup> See (2003), <http://www.Hawaiiankingdom.org/national-headsofstate.shtml> (an organization that strives to preserve the Kingdom of Hawaii) (King Lunalilo reigned from January 8, 1873 through February 3, 1874, when he died of consumption.)

<sup>74</sup> See David S. Poepoe, *The Lunalilo Estate and the Betrayal of Trust*, (U. Haw. Special Collections Library, December 14, 1993) (describing that Prince Lunalilo was elected as King by an overwhelming popular vote). ("Poepoe"). See also Mark Twain, *The Sandwich Islands*, NEW YORK TRIBUNE, January 6, 1873, (Describing the Prince as "a splendid fellow, with talent, genius, education, gentlemanly manners, generous instincts, and an intellect that shines as radiantly through floods of whisky as if that fluid but fed a calcium light in his head. All people in the islands know that William -- or "Prince Bill," as they call him, more in affection than otherwise.") This source can be viewed on line at (2002) <http://www.maritimeheritage.org/ports/pacific/Hawaii.html>.

<sup>75</sup> See POEPOE, *supra* note 73.

<sup>76</sup> See Article III of the William Charles Trust. See also POEPOE, *supra* note 73 at 6.

<sup>77</sup> See [lunalilo.org](http://lunalilo.org).

<sup>78</sup> Describing all of the facilities and agencies involved in Hawaii's LTC system is beyond the scope of this paper, but note generally the following governmental agencies:

- A. Department of Health – Licenses specific types of long-term care facilities, such as nursing homes and ARCHs.

Office on Aging for the State of Hawaii now relies on community planners for the development of long-term care policy, but the extent to which community planners have been used in the past is largely unknown.<sup>79</sup>

The Hawaii Department of Health and/or the Hawaii Department of Human Services license or regulate most of the LTC facilities in the state.<sup>80</sup> The majority of formal care takes place in skilled or intermediate nursing facilities or Adult Residential Care Homes (“ARCHs”).<sup>81</sup> The following section will discuss the different types of facilities people may consider in planning for LTC.

## II. TYPES OF FORMAL CARE

Informal, unpaid caregivers provide the vast majority of LTC services in the United States.<sup>82</sup> Evaluating informal care is beyond the scope of this writing. Formal care, provided within regulated industries, is a critical part of the planning process. Planning for long-term care no longer simply means selecting a nursing home. Rather, the “long-term care sector has changed considerably and is arguably evolving into a ‘system’ in which care can be provided in settings that are more appropriate

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- B. Department of Commerce and Consumer Affairs – regulates and licenses certain professions such as physicians, nurses, nurse aids, and nursing home administrators
  - C. Executive Office on Aging – the State Unit on Aging, as established by the Older Americans Act (*codified at 42 U.S.C. 3001 et seq.* (1965)). EOA grants funds to the Area Agencies on Aging for community planning, advocacy, and coordination and development of certain LTC services.
  - D. Long-Term Care Ombudsman Program – Established by the Older Americans Act to identify, investigate, and resolve complaints that are made by, or on behalf of, residents of LTC facilities. (*authorized by 42 U.S.C. 3001 et seq.* (1965)).

<sup>79</sup> The Executive Office on Aging (EOA) for the State of Hawaii is the primary administrative body for the State aging policy. The Older Americans Act mandates such a state office, but the Act did not take effect until well after Statehood. Therefore, the role of planners cannot be adequately measured.

<sup>80</sup> The following are the primary LTC facilities licensed in Hawaii:

- A. Assisted Living Facilities - HAW. ADMIN. RULES § 11-90.
- B. Nursing Facilities - HAW. ADMIN. RULES § 11-94.1.
- C. Freestanding Adult Day Health Centers - HAW. ADMIN. RULES § 11-96.
- D. Home Health Agencies - HAW. ADMIN. RULES § 11-97.
- E. Adult Residential Care Homes - HAW. ADMIN. RULES § 11-100.1.
- F. Home and Community-Base Case Management Agencies and Community Care Foster Family Homes - HAW. ADMIN. RULES § 17-1454.
- G. Adult Day Care Centers - HAW. ADMIN. RULES § 17-1424.
- H. Developmental Disabilities Domiciliary Homes - HAW. ADMIN. RULES § 11-89.
- I. Intermediate Care Facilities for Individuals with Intellectual Disabilities - HAW. ADMIN. RULES § 11-99.

<sup>81</sup> The Hawaii Department of Health Office of Health Care Assurance maintains listings of licensed facilities. Based on these listings, which can be viewed at <http://health.Hawaii.gov/>, there are approximately 2,250 people residing in licensed assisted living facilities, 2,500 people residing in Adult Residential Care Homes and Expanded Adult Residential Care Homes, 1,000 people residing in Community Care Foster Family Homes, and 4,300 people residing in Nursing Facilities. These numbers are estimated and would be constantly changing.

<sup>82</sup> Some estimate that approximately 87% of Americans who need LTC services receive it from informal caregivers. See National Alliance for Caregiving, American Association of Retired Persons (“AARP”). Caregiving in the U.S., 2009.

for consumers' needs."<sup>83</sup> The following summarizes different types of formal care that may be important for an individual to evaluate through the planning process.

#### A. COMMUNITY BASED SERVICES

Community-based services are generally those services that are provided to an individual outside of a formal care institution.<sup>84</sup> These services can be provided through a variety of services and strategies, including but not limited to, in-home care services, adult day health programs, day care, and home health agencies.

##### i. IN-HOME CARE

As used herein, in-home care refers to services provided for an individual in his or her own home. To stay at home, an individual will, at a minimum, need to address the needs for transportation, social interaction and nutrition. Transportation services are the link between the individual's home and any goods and services necessary for the individual to stay at home. Without realistic transportation supports, it may be impossible or impractical for an individual to remain at home. While some individuals are fully and independently mobile, a large number of people do have significant difficulty getting to and from appointments, shopping for groceries and getting to social activities<sup>85</sup>. For individuals who are unable to drive, transportation services may be provided through public transportation, such as a bus pass<sup>86</sup> or taxi services. These services can vary considerably, and should be considered based on the particular needs of each individual. Beyond transportation, it is important to evaluate an individual's needs for social interactions.

Social interactions may be provided through a variety of community services. Social interactions are important to all persons, including older adults who may not have easy access to social opportunities.<sup>87</sup> There are a variety of social opportunities geared specifically to senior citizens in Honolulu, including the Senior Citizens Program through the City and County of Honolulu Department of Parks and Recreation and also Senior and Community Centers. Certain zoning provisions enable social interaction by making it possible to have multiple living accommodations on the same property, thereby allowing people the opportunity to live close to family members or other individuals who may provide supports.<sup>88</sup> An additional benefit of providing for social opportunities is that socialization can also make it possible to meet the nutritional needs of seniors living in their own homes.

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<sup>83</sup> Castle, Nicholas G. and Ferguon, Jamie; What is Nursing Home Quality and How is it Measured, *Gerontologist* Vol.50., August 2010.

<sup>84</sup> See Clark, Robert F.; U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy. Home and Community –Based Care in the USA. October 1991.

<sup>85</sup> See generally Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2012, tables 18, 19.

<sup>86</sup> Note The Bus, provided through the City and County of Honolulu, for example, offers a "Senior Card" for persons 65 years of age or older. The Handi-Van, also provided through the City and County of Honolulu, may be an additional option for individuals who are unable to use standard bus services.

<sup>87</sup> See generally Tomaka, Joe, Thompson, Sharon, and Palacios, Rebecca, *The Relation of Social Isolation, Loneliness, and Social Support to Disease Outcomes Among the Elderly*, *JOURNAL OF AGING AND HEALTH*, Vol. 18, No. 3, 2006.

<sup>88</sup> See, e.g., HAW.REV.STAT. § 46-4 for an overview of zoning.

Nutrition and meal services are often coupled with socialization. Many of the social activities available offer food services. For individuals who are more limited, sometimes the simple delivery of a meal through programs such as Meals on Wheels is the only regular socialization an individual has.

While every individual's needs are unique, in-home care may be an important consideration for long-term care services. As described above, transportation, socialization and nutrition are frequently among the most important needs to address.

## ii. ADULT DAY HEALTH

There are approximately ten adult day health centers ("ADHC") in Hawaii.<sup>89</sup> An ADHC is a physical facility in which medical services, nursing services, dietetic services and planned therapeutic and social activities are available to meet the assessed needs of clients of the ADHC programs.<sup>90</sup> Generally, a client would participate in these services during the day and would return home at the end of each day. ADHCs are staffed with a multidisciplinary team that helps to develop and implement a plan of care for clients. For many participants, a daily curriculum would consist of approximately four to eight hours of services, which is spent doing social activities, physical/occupational therapy and meal services. The individualized plan of care must be authorized by a client's physician. To be admitted for participation, a client must have a referral from a community or health agency, physician or hospital and must have a need for the services provided at an ADHC.<sup>91</sup>

## iii. ADULT DAY CARE CENTERS

Adult Day Care Centers ("ADCC") are unique care settings as they are administered by the Hawaii Department of Human Services, instead of the Hawaii Department of Health. An ADCC is a "licensed facility maintained and operated by an individual, organization, or agency for the purpose of providing regular supportive care to four or more disabled adult participants, without charging a fee."<sup>92</sup> In order to be eligible for ADCC services, an individual must be unable to function independently and be in need of regular protective and supportive care.<sup>93</sup> Within this context, "regular care" means care that occurs at fixed or uniform intervals and excludes temporary, occasional or casual care.<sup>94</sup> Services for ADCC participants include observation and supervision by center staff, proper notification to a primary caregiver of the participant's well-being, counseling and referral to appropriate services, certain limited assistance with medications, meal services, and activities to enhance an individual's well-being. Many of the activities will include therapeutic, social, education, and recreational events, such as arts and crafts, exercise, hobbies, reading, excursions and community activities.<sup>95</sup>

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<sup>89</sup> See <http://health.Hawaii.gov/ohca/medicare-facilities/adult-day-health-centers/>

<sup>90</sup> See Haw.Admin.Rules § 11-96-7.

<sup>91</sup> See Haw.Admin.Rules § 11-96-5.

<sup>92</sup> Haw.Admin.Rules § 17-1424-2.

<sup>93</sup> *Id.*

<sup>94</sup> *Id.*

<sup>95</sup> See Haw.Admin.Rules § 17-1424-16.

#### iv. HOME HEALTH AGENCIES

Individuals may arrange to receive health care provided in his or her own home through a Home Health Agency. A Home Health Agency (“HHA”) is an entity “primarily engaged in providing direct or indirect skilled nursing services and other therapeutic services under a physician’s direction to homebound patients on a part-time or intermittent basis”.<sup>96</sup> These services are provided in a place that is used as the individual’s home.<sup>97</sup> In addition to providing nursing services, a HHA must provide at least one other therapeutic service, including physical therapy, occupational therapy, speech therapy, medical social services or home health aide services.<sup>98</sup> Home health agencies may extend an individual’s ability to comfortably and safely live in the community and delay admission to a LTC institution.

It may be necessary to mix-and-match the above community-based services to address all of the needs of an individual for long-term care purposes. The programs and services summarized above are not necessarily mutually exclusive and frequently complement each other.

#### B. SENIOR HOUSING<sup>99</sup>

Although senior housing is not technically a long-term care service, a basic awareness of senior housing programs is important within the comprehensive LTC spectrum. Proper housing and accommodations can help people maintain independence and prevent reliance on more costly, less-appropriate services or public programs. Senior housing is intended for individuals who are seeking independent living options, and not for those who need a higher level of assistance, which one may find in retirement communities or assisted living facilities. There are a variety of senior housing opportunities, and an in-depth description of the different types of options exceeds the intended scope of this writing. The primary benefits of senior housing programs include the lower or subsidized costs for housing and the opportunity to be in a community of people in the same age cohort. Eligibility and benefits through senior housing projects can vary dramatically based on a number of factors including the developer, owner and management. Senior housing projects usually are available to people over the age of 62, but some programs are available for people as young as 55. At the time of this writing, nearly all senior housing programs have waitlists, which can range from a few months to several years. The bottom line is that senior housing is not for everyone, and planning well in advance of the need is important.

#### C. ADULT RESIDENTIAL CARE HOMES

In or around 2006, two separate chapters of the Hawaii Administrative Rules relating to Adult Residential Care Homes and Extended Care Adult Residential Care Homes were repealed and replaced with a new single chapter governing Adult Residential Care Homes (“ARCH”).<sup>100</sup> This new chapter governs different categories of ARCHs, including Type I, Type II and Expanded

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<sup>96</sup> See Haw.Admin.Rules § 11-97-1.

<sup>97</sup> *Id.*

<sup>98</sup> See Haw.Admin.Rules § 11-97.5(g)(3).

<sup>99</sup> For a more detailed overview of Senior Housing, see the Aging and Disability Resource Center of the City and County of Honolulu Elderly Affairs Division at [http://www.elderlyaffairs.com/site/449/publications.aspx#Oahu Housing](http://www.elderlyaffairs.com/site/449/publications.aspx#Oahu%20Housing). This section is based primarily on information available at this site.

<sup>100</sup> Haw.Admin.Rules § 11-100.1.

ARCH.<sup>101</sup> Generally, Type I homes are licensed to provide care for five or less residents; Type II homes are licensed to care for six or more residents. Residents of both Type I and Type II ARCH facilities require “at least minimal assistance in the activities of daily living, personal care services, protection and health care services, but who do not need the professional health services of an intermediate, skilled nursing, or acute care facility.”<sup>102</sup> On the LTC spectrum, therefore, Type I and Type II ARCHs are better suited for individuals with lower care needs than traditional nursing facilities. For people with greater care needs, an Expanded ARCH facility may be a consideration.

An Expanded ARCH is a facility providing “twenty four hour living accommodations, for a fee, to adults unrelated to the family, who require at least minimal assistance in the activities of daily living, personal care services, protection, and health care services, and who may need the professional health services provided in an intermediate care facility or skilled nursing facility.”<sup>103</sup> To be admitted to any ARCH type of facility, a resident must meet the level of care appropriate for the facility.<sup>104</sup> There is no age restrictions, or other types of restrictions based on race, color, national origin, language, sexual orientation, religion or gender.<sup>105</sup> The care provided in an Expanded ARCH facility includes “personal care, shelter, protection, supervision, assistance, guidance or training, planned activities, food service, laundering of personal clothing, recognition of and provision for changes in health status, and arrangement for transportation to medical and dental offices.”<sup>106</sup> Expanded ARCH facilities may also include “specialized care”.<sup>107</sup>

One attractive characteristic of the ARCH model is that the accommodations are in a community setting and do not appear “institutional” in nature. Costs of ARCH facilities vary, but are generally more affordable than comparable “institutional” level of care. Some considerations in choosing an ARCH facility should include financing and whether a permanent care arrangement is desirable. Some facilities may accept private payments only, so individuals of more limited means may need to make alternative arrangements. ARCH facilities may have limitations on the level or type of care that can be provided. As a result, people with progressive conditions may need to inquire about whether or how long the facility can continue to provide necessary care.

#### D. ASSISTED LIVING<sup>108</sup>

As of the date of this writing, there are approximately 13 licensed Assisted Living Facilities in Hawaii, with a total capacity to service approximately 2,250 people.<sup>109</sup> Assisted living facilities provide a “combination of housing, meal services, health care services and personalized supportive services designed to respond to individual needs.”<sup>110</sup> One of the primary benefits of an assisted living facility is to enable a person to “age in place”, which allows for a person to receive needed services within the ability of the facility without having to move every time the individual’s personal needs

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<sup>101</sup> *Id.*

<sup>102</sup> Haw.Admin.Rules § 11-100.1-2.

<sup>103</sup> *Id.* Further, there are two types of Expanded ARCH facilities. Type I facilities have five or less residents, with no more than two nursing facility level residents. Type II facilities have six or more residents, with no more than twenty per cent of its residents requiring nursing facility level of care.

<sup>104</sup> *See* Haw.Admin.Rules § 11-100.1-10.

<sup>105</sup> *Id.*

<sup>106</sup> *See* Haw.Admin.Rules § 11-100.1-11.

<sup>107</sup> *See* Haw.Admin.Rules § 11-100.1-87(a).

<sup>108</sup> *See* Haw.Admin.Rules §11-90.

<sup>109</sup> *See* <http://health.Hawaii.gov/ohca/state-licensing-section/assisted-living-facilities-in-Hawaii/>

<sup>110</sup> Haw.Admin.Rules § 11-90-1.

change. Assisted Living facilities consist of a building complex that offers dwelling units for individuals with on-site resources necessary to provide round-the-clock services designed to maximize the independence of residents.<sup>111</sup> Each resident must have a service plan that reflects the resident's assessed needs and choices. There may be different requirements for admission in each facility, and each facility may have different limitations as to what levels of care may be provided for residents. For instance, some facilities may provide care through the skilled nursing level, and some may need to discharge residents when the level of care exceeds the facility's particular ability to service the individual's needs.

While Assisted Living appears to be a good model for aging in place and the delivery of services across the care continuum, these services may be inaccessible to individuals who do not have the means to pay for them. Individuals with progressive conditions should inquire about whether or how long the facility can continue to provide necessary care and how the payment structures work.

#### **E. COMMUNITY CARE FOSTER FAMILY HOMES**

Community Care Foster Family Homes ("CCFFH") are licensed by the Hawaii Department of Human Services.<sup>112</sup> A CCFFH must provide twenty-four-hour living accommodations, personal care, and homemaker services for no more than two adults at one time, at least one of whom shall be a Medicaid recipient, and who require a level of care equivalent to those provided in a nursing facility.<sup>113</sup> The level of care requirement limits the use of these facilities to people who are much less independent than those who may utilize other types of community-based programs, such as assisted living or senior housing. Residents in CCFFHs will also have case management services that are frequently billed separately. The case management services include the development of a comprehensive service plan that outlines, among other items, the needs of the resident and establishes realistic measurable goals to be attained to address the resident's needs.<sup>114</sup> Along with the service plan, the case management agency helps in the coordination of services necessary to carry out the service plan.<sup>115</sup>

CCFFHs are unique among the community-based care settings because they may be licensed to provide skilled nursing services and may accept private and public payment sources, including Medicaid. These characteristics make it possible for people to plan for their LTC needs with a little more certainty knowing that they may not need to find alternative care arrangements if their needs increase or if their private funds are exhausted. One planning challenge, however, is that an individual may have difficulty being admitted to a CCFFH prior to exhibiting the medical need for the services.

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<sup>111</sup> See Haw.Admin.Rules § 11-90-2.

<sup>112</sup> See Haw.Admin.Rules § 17-1454.

<sup>113</sup> See Haw.Admin.Rules § 17-1454-2. "Nursing facility level of care" means "the level of care provided at skilled nursing facilities where the resident would require daily skilled nursing services on more than one shift per day or daily restorative skilled rehabilitative services or a combination of skilled nursing and rehabilitative services; or at intermediate care facilities where the resident would require intermittent skilled nursing, a daily skilled nursing assessment, and twenty-four hour supervision." See also Haw.Admin.Rules § 17-1454-42 regarding client eligibility requirements. Appropriate facilities may also be certified to care for up to three clients.

<sup>114</sup> See Haw.Admin.Rules § 17-1454-22(c).

<sup>115</sup> See Haw.Admin.Rules § 17-1454-23.

## F. NURSING FACILITIES

Nursing facilities include skilled nursing and intermediate care facilities.<sup>116</sup> As of the date of this writing, there are 49 facilities licensed in Hawaii.<sup>117</sup> An Intermediate Care Facility (“ICF”) is defined as a “health facility to which a physician has referred individuals who do not need twenty-four hour a day skilled nursing care but who do require... twenty-four hours a day assistance with normal activities of daily living... and care provided by licensed nursing and paramedical personnel on a regular, long-term basis.”<sup>118</sup> A Skilled nursing facility provides “skilled nursing and related services to residents who require twenty-four hour a day medical or nursing care, or rehabilitation services, including but not limited to physical therapy, occupational therapy, and speech therapy services.”<sup>119</sup> Inspections of these facilities shall be unannounced and may be conducted outside of normal business hours.<sup>120</sup> Each facility is required to have a “Medical Director”, who is a physician responsible for developing, implementing and evaluating resident care policies, coordination of medical care and consultation and training to licensed staff.<sup>121</sup> Each facility is required to provide nursing services,<sup>122</sup> dietary services,<sup>123</sup> physician services,<sup>124</sup> rehabilitation services,<sup>125</sup> dental services,<sup>126</sup> pharmaceutical services<sup>127</sup>, and may provide adult day health services.<sup>128</sup>

Nursing facilities may accept both private and public funds. These facilities may also temporarily house individuals recovering from medical conditions during periods of convalescence, as opposed to being a primary residence. Nursing facilities can be considerably larger than other care facilities in this article and tend to the needs of numerous patients.

While nursing home care in Hawaii is generally perceived to be very good,<sup>129</sup> such ratings should be considered carefully.<sup>130</sup> Even if the care is very good, abuse and neglect are still possible. Preventing elder abuse is “complicated,”<sup>131</sup> especially because abuse is not always visible. Risk factors for facility-based abuse include a high percentage of residents with dementia and a low staff ratio and the amount of training.<sup>132</sup> Residents who have dementia and high degrees of social isolation

<sup>116</sup> These facilities are regulated, generally, by Haw.Admin.Rules § 11-94.1.

<sup>117</sup> See <http://health.Hawaii.gov/ohca/medicare-facilities/skilled-nursingintermediate-care-facilities/>

<sup>118</sup> Haw.Admin.Rules § 11-94.1-2.

<sup>119</sup> Haw.Admin.Rules § 11-94.1-2.

<sup>120</sup> Haw.Admin.Rules. § 11-94.1-2.

<sup>121</sup> Haw.Admin.Rules § 11-94.1-18.

<sup>122</sup> See Haw.Admin.Rules § 11-94.1-39.

<sup>123</sup> See Haw.Admin.Rules § 11-94.1-40.

<sup>124</sup> See Haw.Admin.Rules § 11-94.1-42.

<sup>125</sup> See Haw.Admin.Rules § 11-94.1-44.

<sup>126</sup> See Haw.Admin. Rules § 11-94.1-45.

<sup>127</sup> See Haw.Admin.Rules § 11-94.1-46.

<sup>128</sup> See Haw.Admin.Rules § 11-94.1-47.

<sup>129</sup> See Rob Perez & Dana Williams, [Hawaii leads nation in nursing home ratings](#), *Honolulu Star Advertiser*, February 25, 2015.

<sup>130</sup> See Nathan Eagle, [Nursing Home Care in Hawaii the Best in the Nation?](#), *Honolulu Civil Beat*, February 25, 2015. See also Rob Perez, [Dept. of Health fails nursing home inspections](#), *Honolulu Star Advertiser*, June 29, 2014.

<sup>131</sup> See [Nursing Home Abuse Prevention Profile and Checklist](#), National Center on Elder Abuse, July 2005.

<sup>132</sup> See [Nursing Home Abuse Prevention Profile and Checklist](#), National Center on Elder Abuse, July 2005.

are at greater risk of abuse.<sup>133</sup> Care facilities are required to inform residents of their rights<sup>134</sup>, and there are a variety of governmental agencies available to assist.<sup>135</sup>

### G. HOSPICE

Hospice is a consideration for individuals who are terminally ill<sup>136</sup>. Hospice care involves the coordinated interdisciplinary services that provide for the physical, psychosocial, spiritual and emotional needs of a terminally ill patient and/or family members.<sup>137</sup> The health care involved is generally palliative and not curative. In other words, Hospice services tend to address the comfort of a patient, rather than trying to cure the patient from a particular medical condition. Hospice services can be provided in various locations, including a patient's home or in a more formal setting. Certain LTC facilities also allow for residents to receive hospice services within their facilities.

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<sup>133</sup> See Nursing Home Abuse Prevention Profile and Checklist, National Center on Elder Abuse, July 2005.

<sup>134</sup> See Haw.Admin.Rule § 11-94-26 (The nursing home resident's bill of rights must be available to anyone. Generally, the resident has the right to:

1. Be fully informed of his or her rights.
2. Be fully informed of the expenses of care.
3. Understand their medical conditions and treatment methods, unless not medically appropriate, and to participate in devising the care plan. This includes the right to refuse participating in experimental research.
4. Provide an informed refusal of all treatment.
5. Not be discharged or transferred except for medical purposes or for the welfare of self or others. All transfers require advance notice to the resident and must be recorded in the health record.
6. Be encouraged to exercise their rights as residents, voice grievances, and recommend changes free from "restraint, interference, coercion, discrimination, or reprisal."
7. Manage their own money.
8. Be free of humiliation, harassment, injury or threat, including the use of chemical or physical restraints, except under emergency situations. If, however, restraints are used, they must be reported to the physician and closely monitored.
9. Privacy in their personal and medical records.
10. Be treated with consideration, respect, and in full recognition of their dignity and individuality, including privacy in treatment and in care.
11. Refuse to perform services not in the care plan.
12. Freely associate and communicate with anyone they chose, confidentially. Residents also may visit with members of the clergy whenever they wish.
13. Participate in whatever social, religious or community activities they wish.
14. Wear their own clothes and use their own possessions as space and other patients' rights permit.
15. Have private visits or share a room with a spouse.

(Patients must, however, comply with facility rules.)

<sup>135</sup> Government agencies that will assist with the prevention of elder abuse and neglect would include the licensing agency, such as Department of Health and the Department of Human Services. There are additionally certain specific organizations that include the Adult Protective Services the Department of Human Services and the Long-Term Care Ombudsman Program of the Department of Health.

<sup>136</sup> Generally, an individual is "terminally ill" if the individual has a life expectancy of six months or less. See 42 C.F.R. § 418.102.

<sup>137</sup> See 42 C.F.R. § 418.3.

As of the date of this writing, there are ten licensed hospice facilities in Hawaii.<sup>138</sup> In many cases, Medicare is available to cover the majority of hospice services.

### III. CHOOSING THE RIGHT CARE

There is no “one-size-fits-all” guideline to select the right fit for an individual’s long-term care needs. If an individual is in the market for long-term care services, a good place to start looking for the proper care and resources would be through informational services such as the “eldercare locator”<sup>139</sup>. Additionally, nearly all States have Aging and Disability Resource Centers, which are available to help link individuals to different services and programs.<sup>140</sup> These services can help a consumer narrow down a very broad search and provide a helpful overview of the types of services available by location. In further selecting the type of care and options for an individual, at least one study shows that the two most important factors to families are quality of care and location.<sup>141</sup>

Quality of care within the long-term care system is difficult to assess and quantify. The Centers for Medicare and Medicaid Services (“CMS”), through its Nursing Home Quality Initiative, has developed certain quality measures that help consumers assess the care provided within care facilities based on standardized assessment data.<sup>142</sup> Long-stay quality measures include an analysis of falls, self-reported pain, bed sores, vaccinations, urinary tract infections, incontinence, the use of physical restraints, activities of daily living, depression, antipsychotic medication and weight loss.<sup>143</sup> CMS uses this data to assess the over-all quality measures of a particular facility. It is possible to compare multiple facilities within a comparable location through CMS’ “Nursing Home Compare” program.<sup>144</sup> Importantly, this service also shows the general location of the licensed facilities. Comparing nursing homes through the CMS services may be helpful, but is not likely to be the definitive measure or prediction of quality for any particular individual.

In addition to utilizing the Nursing Home Compare tool, individuals and families may utilize other methods of selecting long term care services.<sup>145</sup> Physicians, social workers, family and friends who live in the area may have recommendations more specific to an individual. Most hospitals have a discharge planning service to help place individuals for custodial or convalescent care. People who

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<sup>138</sup> See <http://health.Hawaii.gov/ohca/medicare-facilities/hospice/>. Note that some of the hospices are administered by the same parent company.

<sup>139</sup> [www.eldercare.gov](http://www.eldercare.gov). This service is provided by the Department of Health and Human Services. Although as of the date of this writing the website references that it is operated by the U.S. Administration on Aging, it should be noted that said Administration has merged with another administration to become the Administration for Community Living.

<sup>140</sup> In Honolulu, the City & County of Honolulu Elderly Affairs Division serves as the Aging and Disability Resource Center.

<sup>141</sup> Dillman, J. L., Yeatts, D. E. and Cready, C. M. (2013), Geographic distance, contact and family perceptions of quality nursing home care. *Journal of Clinical Nursing*, 22: 1779–1782.

<sup>142</sup> See also Pub. L. 113-185, Improving Medicare Post-Acute Care Transformation (IMPACT) Act of 2014, H.R. 4994 (113<sup>th</sup>).

<sup>143</sup> Quality measure specifications are available at the MDS 3.0 User’s Manual, available at <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/Downloads/MDS-30-QM-User%E2%80%99s-Manual-V80.pdf>.

<sup>144</sup> The Nursing Home Compare program is available at [Medicare.gov](http://www.Medicare.gov).

<sup>145</sup> See *Care Pathways* at <http://www.carepathways.com/checklist-nh.cfm> for a more detailed checklist for considerations in choosing a nursing home.

have regular connections with the long-term care system may have valuable insights to share. Often, an individual's physician may have a practice that services different long-term care facilities, so it may be convenient to select a facility within the physician's service network. Otherwise, an individual may need to find a new primary care physician in addition to a care facility.

After an individual selects a care facility,<sup>146</sup> making appropriate and safe transitions to the facility may be a challenge. Commonly, residents will ask family and staff if they can go "home" because going home may not be possible, families can help assure the quality of care in a care facility by visiting their loved ones and paying special attention to signs of depression.<sup>147</sup> Although it may be a common perception, various research findings "have helped debunk the myth that families abandon their relatives in nursing homes or similar settings to die in isolation."<sup>148</sup> This is fortunate, as visitation has been associated with lower risk of infection,<sup>149</sup> higher life satisfaction,<sup>150</sup> and the potential for return to the community.<sup>151</sup> Aside from visitation, families should also consider the care facility's attempts to keep residents engaged.<sup>152</sup> Adjusting to a new living arrangement can take time and effort. Social services and staff can help make further recommendations about making the transition as comfortable as possible.

#### IV. FINANCING

Selecting an appropriate type and setting for long-term care cannot be done without considering finances, given the high costs of long-term care.<sup>153</sup> Generally, there are three ways to pay for long-term care: privately, through a third party, and/or through government benefits.<sup>154</sup> Out-

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<sup>146</sup> Selecting a care facility does require a certain level of "legal capacity." If an individual is unable to make this decision on his or her own, a variety of agency authorization formats may enable others to act on behalf of the intended LTC facility resident. Such authorization formats may include powers of attorney, Advance Health Care Directive and Surrogacy (see H.R.S. §327E *et seq.*) or even Guardianship (see H.R.S. § 560:5-301 *et seq.*).

<sup>147</sup> "Depression is the most burdensome and prevalent mental illness among nursing home residents". Levin CA, Wei W, Akincigil A, Lucas JA, Bildre S and Crystal S; Prevalence and Treatment of Diagnosed Depression Among Elderly Nursing Home Residents in Ohio; *J. Am Med Dir Assoc.* 2007 Nov; 8(9): 585-594.

<sup>148</sup> Gaugler, Joseph E, (2005), Family Involvement in Residential Long-Term Care: A Synthesis and Critical Review. *Aging Mental Health*, March 2005; 9(2), 105-118.

<sup>149</sup> See Zimmerman S, Gruber-Baldini AL, Hebel JR, Sloane PD, Magaziner J, Nursing Home Facility Risk Factors for infection and hospitalization: Importance of registered nurse turnover, administration and social factors; *J. Am. Geriatric Society*, 2002 December; 50(12); 1987-1995.

<sup>150</sup> See Noelker L, Harel Z, Predictors of well-being and survival among institutionalized aged; *Gerontologist*, 1978 December; 18(6) 562-7.

<sup>151</sup> See Lewis MA, Kane RL, Cretin S, Clark V; The Immediate and Subsequent Outcomes of Nursing Home Care; *Am.J. Public Health.* 1985, July ; 75(7): 758-62. See also Penrod JD, Kane RA, Kane RL, Effects of post-hospital informal care on nursing home discharge. *Research on Aging*, 2000; 22(1):66-82

<sup>152</sup> Activity has been associated with increased levels of happiness among nursing home residents. One interesting study on point is Dixon, MR, NASTally BL and Waterman A, The Effect of Gambling Activities on Happiness Levels of Nursing Home Residents, *J. APPL BEHAV. ANAL.* 2010, Fall; 43(3); 531-5. This study showed that residents exhibited a higher percentage of happiness levels while engaged in simulated gambling activities compared with baseline.

<sup>153</sup> See Genworth 2014 Cost of Care Survey showing that the median annual rate of nursing home care in Hawaii is \$135,050.

<sup>154</sup> See O'Shaughnessy, Carol V, National Spending for Long-Term Services and Supports, National Health Policy Forum, George Washington University, February 1, 2013. This study shows that in 2011, the national

of-pocket expenses for LTC include deductibles, copayments and amounts not covered by insurance. Traditional health insurance does not cover LTC costs, and as a result, LTC can become too expensive for families to independently cover.

Aside from paying out of pocket, it is possible to pay for private long-term care insurance.<sup>155</sup> Long-term care insurance is designed to cover personal and custodial care in a variety of settings. The costs of long-term care insurance depend on a variety of factors, including how old an insured is at the initiation of the policy, pre-existing conditions, and the amount of benefits an insured is seeking to obtain. The market for LTC insurance is changing and a variety of products are becoming available to consumers. While LTC insurance can offer considerable flexibility and assistance with financing LTC, few people have these policies or have sufficient coverage.<sup>156</sup>

The majority of LTC costs are covered by public funding sources, commonly including Medicare, the Veterans Administration and Medicaid. Medicare is a federal health insurance program administered by the Centers for Medicare and Medicaid Services. General eligibility for Medicare is related to age and work record, without consideration of an individual's resources.<sup>157</sup> There is a limited LTC benefit through Part A of the Medicare program. Skilled nursing benefits may be covered, at least in part, by Medicare Part A if an insured person was discharged from a three-day inpatient hospital stay to a Medicare-certified skilled nursing facility for skilled rehabilitation services.<sup>158</sup> Because Medicare provides limited coverage for long-term care services, consumers should not consider Medicare as a form of insurance for the expenses related to LTC. The Veterans Administration also provides assistance with financing long-term care services for certain Veterans who are financially eligible and who have sufficient service-connected disability status.<sup>159</sup> Even with certain benefits from Medicare and the Veterans Administration, an individual may still need additional assistance in paying for long-term care. Typically, the Medicaid program is the payer of last resorts, but will cover the unmet financial needs of an individual seeking assistance in financing long-term care.

Medicaid is the single largest funding source for LTC services and supports. Medicaid is authorized and partially funded by federal law<sup>160</sup> and administered and partially funded by State rules and regulations. In Hawaii, the Medicaid program is known as "Med-Quest" and is administered by the Department of Human Services.<sup>161</sup> There are many categories under which individuals may qualify for general Medicaid benefits which can cover a range of services and supports. Eligibility

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total spending on Long-Term Care was approximately \$210.9 billion. Of these expenditures, approximately 62% is covered by Medicaid, 21% is covered privately out of pocket, approximately 11% is covered by other private sources and approximately 4% is covered by other public sources, such as Medicare and the Department of Veterans Affairs.

<sup>155</sup> A detailed discussion of long term care insurance exceeds the intent and scope of this writing. For a more detailed description of long term care insurance and products, see Dang, Christopher R., Kamiya, Derek T., Suzuki, Scott C., and Young, Eric S.T., *Planning Ahead: Practical Financial and Estate Planning Considerations*, HAWAII BAR JOURNAL, October 2014; 4-16.

<sup>156</sup> See Freundlich, Naomi; Long-Term Care: What Are the Issues, Health Policy Snapshot, Robert Wood Johnson Foundation (2014), indicating that "less than 8% of Americans have insurance for long-term care."

<sup>157</sup> See generally 42 U.S.C. § 426.

<sup>158</sup> See 42 U.S.C. § 1395.

<sup>159</sup> See generally 38 U.S.C. § 1710.

<sup>160</sup> See 42 U.S.C. § 1396

<sup>161</sup> Regulations for the Med-Quest program are in Title 17 of the Hawaii Administrative Rules, specifically § 17-1700 *et seq.*

for the Medicaid long-term care benefit is linked generally to medical need, and financial eligibility.<sup>162</sup>

Medical need for the long-term care benefit within the Hawaii Medicaid program is assessed with a “Level of Care (LOC) and At Risk Evaluation” form referred to as the DHS Form 1147. This form is used to screen and identify the functional status related to health conditions and significant current diagnosis. Coverage under the Medicaid program must be medically necessary, and DS Form 1147 helps to determine whether an applicant needs the care that would be provided in a LTC facility financed by Medicaid. The assessment covers a wide range of functional and health conditions, including vision/hearing/speech, communication, memory, mental status/behavior, feeding, transferring, mobility/ambulation, bowel function/continence, bladder function, bathing, dressing and personal grooming.<sup>163</sup> If an individual requires the level of care that can be covered by the Medicaid program, the individual’s financial eligibility can be assessed.

Financial eligibility for Hawaii Medicaid-financed long-term care services requires an evaluation of both income and assets. The general rule relating to income is that the income of household members shall be considered available to an applicant.<sup>164</sup> When spouses cease to live together, or one spouse is receiving home and community based waiver services or hospice services, only the income actually contributed from one spouse to the other shall be considered to be available to the applicant spouse.<sup>165</sup> For Hawaii Medicaid purposes, there are two types of income, referred to as “earned income”<sup>166</sup> and “unearned income.”<sup>167</sup>

Earned income includes all “employment-related income received.”<sup>168</sup> Certain deductions for self-employment business expenses<sup>169</sup> and other earned income exemptions<sup>170</sup> may apply. Unearned income can come from a variety of sources, including but not limited to legal settlements, inheritance, insurance and compensation,<sup>171</sup> educational loans, grants scholarships and benefits,<sup>172</sup> and Social Security benefits.<sup>173</sup> Exempt unearned income rules exist, but in the author’s experience, tend to apply infrequently.<sup>174</sup> Once an individual or household’s income is determined, it is possible to assess financial eligibility for the applicant. Although specific and complicated income rules apply, due to the high costs of LTC, an applicant whose income is insufficient to cover the LTC costs will generally satisfy the income test based on being “medically needy.”<sup>175</sup> Individuals who are

<sup>162</sup> See HAW. REV. STAT. Chapter 91 and Haw.Admin.Rules Title 17.

<sup>163</sup> See DHS Form 1147.

<sup>164</sup> Haw.Admin.Rules § 17-1724.1-16.

<sup>165</sup> Haw.Admin.Rules § 17-1724.1-16(b) and (c).

<sup>166</sup> Haw.Admin.Rules § 17-1724.1, Subchapter 4.

<sup>167</sup> Haw.Admin.Rules § 17-1724.1, Subchapter 5.

<sup>168</sup> Haw.Admin.Rules § 17-1724.1-16-23.

<sup>169</sup> Haw.Admin.Rules § 17-1724.1-24.

<sup>170</sup> Haw.Admin.Rules § 17-1724.1-26.

<sup>171</sup> Haw.Admin.Rules § 17-1724.1-34.

<sup>172</sup> Haw.Admin.Rules § 17-1724.1-35.

<sup>173</sup> Haw.Admin.Rules § 17-1724.1-38(1). *Note* this section describes a number of other unearned income sources.

<sup>174</sup> Haw.Admin.Rules § 17-1724.1-39.

<sup>175</sup> For rules relating to the over-all income eligibility, see Haw.Admin.Rules § 17-1719-11. For rules relating to the “medically needy” standard, see Haw.Admin.Rules § 17-1730.1. See specifically Haw.Admin.Rules § 17-1730.1-11(a)(2) which provides that there is no maximum allowable countable income for an aged, blind or disabled individual.

medically needy will essentially use their income to pay for their share of LTC bills, leaving Medicaid to pay the remaining balance.<sup>176</sup> Once eligible for LTC Medicaid, the individual will keep a personal needs allowance of \$50 of income each month<sup>177</sup>, and may contribute certain amounts of income to a community spouse.<sup>178</sup> The rest of the individual's income will be considered a "cost share" and will be applied to the individual's LTC bill.<sup>179</sup> Individuals seeking assistance for LTC Medicaid must also be eligible on the basis of their assets.

Asset eligibility for LTC Medicaid may not be as detailed as income eligibility, but complicated transfer of asset rules may apply. Generally, an individual may be eligible for LTC Medicaid as long as countable assets do not exceed the value of \$2,000.00 as of the first moment of the month.<sup>180</sup> The value of certain assets do not count towards this limit,<sup>181</sup> and certain assets are exempt from being considered<sup>182</sup>. Notably, an individual's principal place of residence is an exempt asset, unless it is placed in a trust.<sup>183</sup> An individual's community spouse who is not applying for or receiving Medicaid benefits, is also allowed to retain funds, known as a "resource allowance", that will not impact the institutionalized spouse's LTC Medicaid eligibility.<sup>184</sup> Transferring assets for less than fair market value within the five-year period immediately prior to applying for LTC Medicaid may result in a "penalty period" during which an applicant will not receive assistance for coverage for LTC services.<sup>185</sup> Given the complexity of the Medicaid eligibility rules and the high costs of LTC, it may be critically important for individuals to plan early enough to maximize flexibility and cost savings. While certain assets may be exempt for eligibility purposes, Medicaid has a right to recover LTC benefits paid from an individual's estate through a process referred to as "medical assistance recovery."<sup>186</sup>

Medicaid has the authority to recover medical care payments from recipients.<sup>187</sup> Recovery may be from a deceased recipient's estate<sup>188</sup> or upon the sale of a property to which the State of Hawaii has attached a lien.<sup>189</sup> The State may place a lien on real property after a determination by the Department of Human Services that the individual cannot reasonably be expected to be

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<sup>176</sup> Haw.Admin.Rules § 17-1724.1-63.

<sup>177</sup> Haw.Admin.Rules § 17-1724.1-63(b)(1)(A).

<sup>178</sup> Haw.Admin.Rules § 17-1724.1-63(b)(2)(A). The current maximum monthly maintenance needs allowance is \$2,980.00.

<sup>179</sup> Haw.Admin.Rules § 17-1724.1-63(c).

<sup>180</sup> Haw.Admin.Rules § 17-1725.1-42(c). *See also* Social Security Programs Operations Manual System at SI 01110.003.A.2. which clarifies that a single individual may have a limit of \$2,000.00 of resources to be eligible for Supplemental Security Income.

<sup>181</sup> *See* Haw.Admin.Rules § 17-1725.1-17.

<sup>182</sup> *See* Haw.Admin.Rules § 17-1725.1-26.

<sup>183</sup> *See* Haw.Admin.Rules § 17-1725.1-26(4). The current equity exemption limit is \$828,000.00.

<sup>184</sup> *See* Haw.Admin.Rules § 17-1725.1-50. The current resource allowance is \$119,220.00.

<sup>185</sup> *See* Haw.Admin.Rules § 17-1725.1-51.

<sup>186</sup> *See* Haw.Admin.Rules § 17-1705.

<sup>187</sup> *See* Haw.Admin.Rules § 17-1705 Subchapter 7,

<sup>188</sup> *See* Haw.Admin.Rules § 17-1700.1-2 defining "Estate" as "the real and personal property included in an estate under the State's probate law and any other real or personal property and other assets in which the individual had any title or interest in at the time of death (to the extent of such interest). This includes assets conveyed to a survivor, heir, or assign of the deceased through joint tenancy, tenancy in common, survivorship, life estate, living trust, or other arrangements."

<sup>189</sup> *See* Haw.Admin.Rules § 17-1705-56(d). Liens are imposed under Haw.Admin.Rules § 17-1705-57.

discharged and return home.<sup>190</sup> The State is precluded from placing a lien on home property if the individual has a spouse residing in the home, dependent child residing in the home, or sibling who has an equity interest in the home and who was residing in the home for a period of at least one year prior to the individual's admission.<sup>191</sup> If the State is able to place a lien, the State may not initiate recovery from the lien as long as the individual has a surviving spouse or surviving dependent child,<sup>192</sup> or in certain circumstances in which a sibling or non-dependent child resides on the property continuously from the individual's date of admission.<sup>193</sup> The estate recovery concept and process can be confusing and should be an important element in analyzing an individual's long-term care plan.

## V. CONCLUSION

Given the increased need for LTC, the enormous financial implications it can have, and the abundance of care options and considerations, planning for LTC has become an essential element of the estate planning process. Analysis of the issues that arise in LTC planning should involve an assessment of care needs, a review of care options, and a detailed plan for financing the care. While there is no one-size-fits-all solution, individuals and advisors have an increasing variety of choices and strategies to address LTC issues.

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<sup>190</sup> See Haw.Admin.Rules § 17-1705-57(a).

<sup>191</sup> See Haw.Admin.Rules § 17-1705-57(b).

<sup>192</sup> See Haw.Admin.Rules § 17-1705-57(c).

<sup>193</sup> See Haw.Admin.Rules § 17-1705-57(d).