Groves Monographs on Marriage and Family

Series Editor
Kevin P. Lyness

Volume 8

Caring for Each Other:
Family Caregiving Across the Generations

Editors
Christine A. Readdick
Sharon M. Ballard

Groves Conference on Marriage and Family • www.grovesconference.org

Groves Monographs on Marriage and Family

Series Editor: Kevin P. Lyness

Groves Monographs on Marriage and Family

Groves Monographs on Marriage and Family is an edited book series based on the annual meetings of the Groves Conference on Marriage and Family, an interdisciplinary, interprofessional organization of limited membership founded in 1934. Groves Monographs publishes work on the leading edges of theory development and empirical research in the field of family studies. Individual volumes are edited by the chairs of the annual Groves Conferences and include peer-reviewed chapters by the conference presenters and invited authors. Topics are timely and provocative with diverse themes.

Groves Monographs on Marriage and Family

Volume 8

Caring for Each Other: Family Caregiving Across the Generations

Christine A. Readdick
Forida State University

Sharon M. Ballard
East Carolina University

Volume Editors

Michigan Publishing
University of Michigan Library
Ann Arbor, Michigan
2023

For information:
Groves Conference on Marriage and Family
P.O. Box 1011, Forest Lake, MN 55025
grovesmanager@yahoo.com
www.grovesconference.org

Groves Monographs on Marriage & Family, Volume 8
Caring for Each Other: Family Caregiving Across the Generations
[edited by] Christine A. Readdick & Sharon M. Ballard

ISBN (paper): 978-1-60785-831-7
ISBN (open access): 978-1-60785-832-4

Michigan Publishing
University of Michigan Library
Ann Arbor, Michigan
2023

Caring for Each Other: Family Caregiving Across the Generations

Contents

One rhythmic moment preserved as Atlantic Ocean pounds Maine granite shoreline

Volume Figure 1: Homer, W. (1894). *Weatherbeaten* [oil on canvas]. Portland Museum of Art, Portland, Maine.

Winslow Homer (United States, 1836 - 1910)
Weatherbeaten, 1894
Oil on canvas, 28 1/2 x 48 3/8 inches
Portland Museum of Art, Maine. Bequest of Charles Shipman Payson
1988.55.1.
Image courtesy of Luc Demers
Reproduced with permission.

Preface

*Christine (Coco) A. Readdick**

Florida State University

Sharon M. Ballard

East Carolina University

The idea for a Groves conference centered around family caregiving grew out of a convergence of professional and personal experiences by members of our Board over several years. Sharon is from Maine and wanted to showcase just a little of what Maine has to offer. She was new to conference planning, but Coco had experienced having planned a successful Groves conference in Ireland in 2008. Although Coco and Sharon did not really know each other prior to the conference, a wonderful partnership emerged resulting in a successful conference held in Portland, Maine in June 2018. This monograph echoes that conference and, in Groves tradition, the location is integral to the conference and thus front and center throughout the monograph.

Maine has a strong tradition of caregiving and Sharon's own family story reflects this. Sharon's great, great, great, great, great grandmother, Martha Ballard, was a midwife in central Maine (what is now Kennebec County) during the 1700's. Martha meticulously kept a diary which provides insight into the daily life of women during 18th century Maine. Her diary began when she was 50 years old (1785) and continued for 27 years until her death at age 77 (1812). During that time, she attended 816 births, often in very harsh conditions. Maine people are often no-nonsense in their approach to care and are very resilient. Martha

---

* Correspondence concerning this article should be addressed to: Christine A. Readdick, Professor Emerita, Florida State University; creaddick@fsu.edu

certainly showed these qualities and you continue to see them in Maine people today. You may learn more about Martha Ballard in the 1990 Pulitzer Prize winning book *A Midwifes Tale* by Laurel Thatcher Ulrich.

Local voices and experiences were central to the success of this conference and have been infused throughout this volume. Poet Laureate of Portland, Marcia F. Brown read poems capturing the privilege and challenge of loving caregiving (see chapter 2). Meghan Pomelow and Nicholas Viti introduced us to intergenerational programs with young adults bringing art to the elderly in a residential home and children and young children interacting daily with their elder friends in another residential setting that includes its own preschool, serving the children of employees and others from the community (chapter 6). Ben Chin from the People's Alliance of Maine presented policy initiatives to build toward universal child and elder care (chapter 13). And John Babin, visitor services director for the Maine Historical Society and author, welcomed us to the home of poet Henry Wadsworth Longfellow (see chapter 8 for the story of Anne Longfellow Pierce, the poet's sister). Walks along cobblestone streets, a lobster dinner at DiMillos, a generations-old family-run restaurant in a former ferry tethered to the pier at Long Wharf, and a working mail boat run from island to island on Casco Bay, added to our understanding of family caregiving in Maine.

Throughout this volume, we have inserted images of artwork from the Portland Museum of Art that represent the culture of care that is somewhat unique to Maine—mother and daughter sharing quiet reverie in a hayloft, three siblings cradling a new kitten, a family in the kitchen for breakfast in the morning sun. Upon a visit to the Museum while in Portland and studying these images, Coco wanted to share these for their evocation of family caregiving over time in Maine.

Coco further situates this monograph in Maine with her opening essay Maine: Opportunities and Challenges for Children Learning to Care (chapter 1) and gives thoughtful context to the complexity of Maine as a state. Sharon, having spent the first 28 years of her life in Maine, could relate to the questions asked and the points made; yet, Coco's analysis also gave her new perspective on her home state and the environment in which she grew up.

The enduringness of and dedication to Groves were captured in a lively opening panel discussion at the conference and now in the essays written by several Groves Academy and Lifetime members (chapter 4). These essays reflect the Groves tradition of weaving the personal with the scholarly as they share reflections on giving and receiving care. Though it is impossible to recapture the energy and lively conversation, we have tried to include selections that reflect the traditional Groves style.

Speakers from throughout the country complimented our programming efforts. While we were not able to include articles from all conference presenters, we have included a full list of the presentation titles and authors in the order in which they were presented in Appendix A at the end of this volume for your reference and use.

In addition to the conference presenters and contributors to this volume, Coco and Sharon especially thank First Lady Rosalyn Carter and the Rosalyn Carter Institute for Caregiving (RCI) for the generous support of our 2018 conference. How did this come to be? Earlier in 2018 Coco attended the 30th Anniversary RCI Conference just up the road in Americus, Georgia. Staying in Plains, she was invited by the innkeeper to attend Maranantha Baptist Church, the Carters' own church. Sitting with Jackie Lyden, journalist and NPR contributor, in walked the Carters and sat behind them.

Jackie, a journalism fellow at the Carter Institute in Atlanta, at the time, and conference participant, turned around to greet the Carters, introducing Coco. In whispers Jackie shared that Coco was part of a professional organization addressing family caregiving. "Write me a letter", the First Lady sweetly encouraged. This always to be remembered moment and exchange is preserved in RCI's sponsorship of Leisa Easom, then Executive Director of RCI and now associate dean and professor in the College of Nursing and Health Sciences at Georgia Southwestern State University, as a plenary speaker at our Portland meeting. In this volume (chapter 11), Leisa addresses education of professional "care managers" to help families navigate an increasingly complex medical environment with aging and disabled loved ones.

This monograph remains a reflection of the point in time of the conference--June 2018. Much has happened since then and many of these events, such as COVID-19, certainly are impacting family caregiving in enduring and unique ways. However, we have attempted to stay true to the conference and capture that time, 2018, in this place, Maine.

The giving and receiving of care cuts across every aspect of family life—from parenting to spousal relations to self-care and is embedded in and impacted by our social institutions—from law to finance to education. Invited contributions to this monograph probe family caregiving from these and other vital perspectives, including Tessa leRoux's feminist critique of caregiving (chapter 3) and Jean Pearson Scott's consideration of the influence of faith traditions on giving and receiving care (chapter 10). So central is caring to family life that Groves composed an official statement on family caregiving, included in this volume in Appendix B.

Just like the actual conference, this monograph has something for everyone ranging from poetry and artwork, to personal reflections, to an historical analysis of US policy that directly affects family caregiving. The multidisciplinary and lifespan approach results in a unique compilation that can provide insight into the important role of family caregiving. Come read with us, think with us, and work with us.

Chapter 1

Maine: Opportunities and Challenges for Children Learning to Care

*Christine A. Readdick**

Florida State University

Maine, glacier-sculpted and tree-covered from its highest Appalachian peak of Mt. Katahdin to its islet-edged eastern coastline, is home to families performing the essential human tasks of giving and receiving care. Here, as elsewhere, it is assumed that family members gracefully, generously, and successfully assume their respective and revolving roles—as children, as parents, as siblings, as partners, as grandparents--giving and receiving care as required throughout life.

And, while we know there are junctures in family life, anticipated and unanticipated, in which the developing individual will be at the receiving end of care and others in which giving care is required, we also are aware that there are events and influences, outside the family, at work to affect caring. Admittedly, different individuals develop as more or less sensitive to the needs of others, more or less capable of meeting the needs of others for care, more of less able to receive care themselves, more or less able to engage in self-care—that is, more or less able to perform these central, essential, and evolving human functions.

The question posed in this essay is how do children today learn to give and receive care, within their own families and communities, and what are the particular opportunities and challenges to acquiring this essential human capacity at home and in the wider world. What are representative examples of opportunities for the acquisition of both learning an ethic of caring and practicing its associated skills? Let's look at this

---

* Correspondence concerning this article should be addressed to: Christine A. Readdick, Professor Emerita, Florida State University; creaddick@fsu.edu

through the lens of life in Maine in 2018, when the Groves Conference on Marriage and Family addressed the topic "Caring for Each Other: Family Caregiving across the Generations" in Portland, Maine.

I will illustrate, with selected data, illustrative rather than exhaustive, the potentialities of family caregiving, including its challenges, from the perspective of the developing individual, in this case, the child. I will use the prism of one organized explanatory framework, the sociobiological theory of human development (see Bronfenbrenner, 1979, 1994) to view and discuss these data, for reflection. This commentary will be italicized throughout this chapter.

The structure of the sociobiological theory provides a means of assembling and making sense of the disparate bits of data available at a point in time. This theory demands recognition of the centrality of the developing child to his or her own developmental outcomes while identifying affordances, interactions, and impacts within nested, ever widening, and often remote, social and physical spheres.

I will begin my presentation of data from Maine and discussion at the level of the geosystem, the outermost influential system containing the child. In turn, I will define each system, present illustrative data, and offer a theoretically derived discussion of opportunities and challenges for the developing child learning and practicing an ethic of care. I will conclude this essay with a letter to children and families in Maine.

The **geosystem** "is the natural physical environment that contains individuals, families, and communities. It is comprised of the living and non-living elements of the natural world and includes land, water, and air" (Christopherson, 2011). The geosystem offers a physical place in which each individual--child, youth, and adult--develops. The relationship between each system and geosystem is reciprocal, and risk and opportunity flow bi-directionally" (Readdick, 2014, p. 2). How might the geosystem impact the growing child, learning to give and receive care? How might actions of the child impact the physical environment and contribute to its capacity to support an ethic of care and family caregiving?

Maine is our most northeastern state, framed by the Canadian provinces of New Brunswick and Quebec to the northeast, north, and northwest, by New Hampshire to the southwest and south, and the Atlantic Ocean to the east. It is situated at latitude similar to that of northern Italy or southern France with a humid continental climate of short, warm summers and long, cold winters (National Oceanic and Atmospheric Administration, n.d.) This, then, is the physical stage on which the child lives, plays, loves, and learns to care, on which Maine family life is performed.

"The geologic history that is recorded in Maine's bedrock covers more than half a billion years. Over this period of time a variety of geologic processes including erosion and sedimentation, mountain-building, deformation (folding and faulting), metamorphism, and igneous activity have acted to produce the complex bedrock geology" that is observed today (Marvinney, 2012, September 24). Bedrock sculpted--carved, scraped, and distributed--during the retreat of glacier at the end of the last ice age, some 12,000 to 14,000 years ago, its mountains were formed by colliding tectonic plates, its arcs of islands by one section of oceanic crust sliding beneath another.

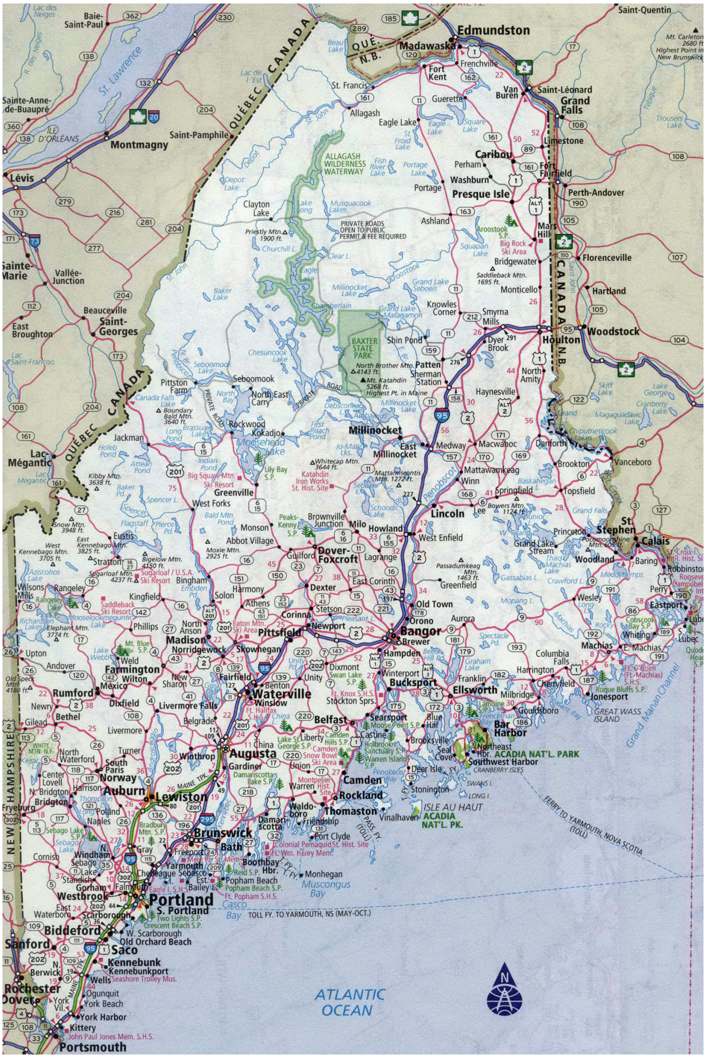


Figure 1. Large detailed map of Maine with cities and towns

As a result, there are three distinct *physical regions* of Maine—the mountains, including its highest peak, Mt. Katahdin, its fertile uplands, and its coastal lowlands [Bayley (2018, July 14); McCaskill et al., 2011, May)]. Most of Maine is tree-covered (83%) and includes 4,000 islands on the Atlantic, from single rocks to 15 landforms sufficient to support year-round habitation (Hawley et al., 2014). Its glacier-tilled soils allow for the production of what have become iconic crops, including potatoes of the fertile uplands and wild blueberries of the coastal lowlands (Bertone, 2017, July 2), and its plentiful growth of conifers and hardwoods.

The historical settlement patterns of Maine residents have followed the sculptured contours of the land. Sequentially, from its first people, to its early European settlers and later immigrants from other regions of the U.S. and world, up to and including today's residents, immigrants, retirees, and tourists, most have chosen to inhabit its transportation-accessible, agriculture-suitable, and seafood-rich coastal lowlands with seasonal mountain-ward treks for hunting, logging, and now recreation (see Figure 1, large detailed map of Maine with cities and towns). "These varied strains—old and new, immigrant and long-term denizen, native and Euro-American—entwine and root Maine's past to its present" (Maine Memory Network, 2010).

Figure 2. Photos (this page and next) representing Maine geosystems: Portland Head Lighthouse; Mt Katahdin and treed surrounds; Augusta, ME in fall; wild blueberry harvesting

According to the 2010 Maine census (U.S. Census Bureau, 2012, August), 61.3% of the population of 1,328,361 lives in rural areas. "Maine has three urbanized areas—Portland, Bangor, and Lewiston—and 24 urban clusters, ranging in size from Calais (population 2,504 according to the 2010 Census) to Brunswick (population 29,159). The state's most rural counties are Piscataquis and Lincoln, where 100 percent of the population lives in rural areas" (Wickenheiser, 2012, March 26). Note that I have included four photos that are representative of Maine's geosystem. These include ME Portland Head Lighthouse; Mt. Katahdin and treed surrounds; the capital of Maine, Augusta, in fall; and wild blueberry harvesting, coastal barrens of Knox County.

The riches of Maine's physical environment are vast. Woodlands offer carbon-sequestering trees contributing clean air for children to breathe; 119 different soil series store carbon and afford opportunities for production and consumption of healthy foods and contribution to commerce (Bailey, 2018, July 14); its rivers, lakes, streams, and ocean provide children worlds to explore and learn about and protect; wind and water affords alternative power sources (see 2014 Maine State Energy Profile); lakes, mountains, and coast laced by streams and rivers, by trails and roadways, offer recreational opportunities for children and their families and for the joy and development of physical skill and right use of and care for their natural environment.

Allowing and encouraging children's actions and interactions in this rich environment itself engenders children's love of their physical world and increases likelihood of their caring for it throughout their lives. Little acts, such as turning off the water in the sink while brushing teeth, composting fruit and vegetable scraps for re-use as enrichment of soil in a spring garden, consuming locally produced foods all contribute to an ethic of caring for the earth and are gifts of care that even very young children can extend.

The **chronosystem**, according to Bronfenbrenner (1979; 1994) is comprised of unique, life-altering events that, from point of occurrence forward, impact the developing person. Two such impactful events can be identified as posing challenges to the abilities of the developing child and family to give and receive care today in Maine: climate change and the Great Recession of 2007-2009.

Climate change effects can be seen in warmer summers and winters, warmer waters, increased drought, increased precipitation, greater storm frequency and intensity, ocean acidification, and rising sea levels, as well as more extreme weather including coastal floods, flash floods, heavy rains, and tropical storms. Evidence of warming waters has been identified in the Gulf of Maine, with temperature warming by 3 degrees since the 1990's (National Aeronautic and Space Administration, 2018). Water quality monitoring for over a decade in Casco Bay documents increasing coastal and oceanic acidification as seawater mixes with carbon dioxide to form carbonic acid, creating less hospitable conditions for marine life such as mollusks and lobster (Frignoca, 2018).

The Maine Geological Survey reports a 1.9 mm sea level rise a year, with the prediction of 2-4 foot rise for Casco Bay by century's end. In Portland alone, sea levels have risen 7.5 inches in the last century (Casco Bay Estuary Partnership, Taylor & Schauffler, 2017, August 1); and, as evidence of more precipitation and greater storm occurrence, Cumberland County (home to residents of 3 cities including Portland and 25 towns including Freeport), has witnessed an increase to 55 days of extreme precipitation events from 2004 to 2014. The Cumberland County Hazard Modification Plan (Cumberland County, 2017) identifies flooding, both coastal (due to sea level rise) and land-based (from the Presumpscot River and other sources), associated with increased precipitation in the Northeast, as its number one hazard.

Other climate change impacts can be observed in the production of Maine's iconic crops—the wild blueberry and the potato. In 2017, in the southeastern coastal barrens, the wild blueberry harvest was marked by fewer berries of smaller size, attributed to seasonal weather changes including a cold, windy, moist winter with poor pollination by bees and a summer drought before harvest (Hauptman, 2018, July 5; Whittle, 2018, September 4). In the potato-growing tier of northern Maine extreme weather events have washed away existing crops and topsoil (Natural Resources Council of Maine, 2014, June 15).

Together these measurable changes pose threats to the natural environment, damage to infrastructure, disruption of economic activity and of families' ways of life, including threats to public health, such as incursion of salt water into the aquifer and rising incidences of Lyme disease, and loss of life. Large Cumberland employers potentially impacted include LL Bean and the Maine Medical Center. Large employers, towns and cities, no less children and families are confronting these gradual and now often abrupt climactic events. Forestall-

ing or reversing these effects of climate change place developing children at risk as they struggle to understand, much less deal with these events, and actively engage in environmental action and care. How are growing children in Maine, commensurate with their understanding and ability, being extended developmentally appropriate opportunities to help address climate change?

The Great Recession--2007-2009--catapulted more children into poverty and more parents into unemployment or underemployment than before the recession (UNICEF, 2014; The Annie E. Casey Foundation, 2017). In 2016 there were 82,000 more children in Maine living in poverty than before the recession (Children's Defense Fund, 2020) and, in one of three households, parents lacked secure employment (The Annie E. Casey Foundation, 2016, June 21). This recession was nationwide with high household debt and real-estate bubbles set in motion by increased liquidity in the economy (fed-lowered interest rates), trade imbalance, and lax lending institutional standards.

In Maine, like other areas of the country, "counties with high proportions of historically disadvantaged racial/ethnic populations, low educational attainment and dependence on pro-cyclical industries (that is, industries responding to elevating or declining product demand by employing more or fewer workers) fared significantly worse during the recession than others" (Thiede & Monnat, 2016, p. 918). Figures of gross domestic production (GDP) provide one means of considering enduring effects of economic downturn on individual children and their families.

When looking at Maine's GDP as a measure of large-scale economic performance, "over the past decade (sic 2007-2017) Maine's GDP grew by 3%, while New England's grew by 9% and the U.S. average grew by 16%" (Maine Economic Growth Council, 2019, April, p.3; Fanjul, 2014). But on the personal and local level of children and families, in 2016 there were 82,000 more children living in poverty than before the recession, out of 64,282 children under 5 years and 250,404 children under 18 years (Children's Defense Fund, 2020), and in 1 of 3 houses parents lacked secure employment (The Annie E. Casey Foundation, 2016).

For Maine families, these intertwining effects of recession and rurality, as depicted in the map of counties above, indicate (according to The Maine Center for Economic Policy, State of Working Maine 2017, Executive Summary, p. 1) that:

- Rural Maine is struggling to recover and is still in deep depression.
- Unable to find a good job and struggling with declining health, too many Mainers are giving up on work.
- Maine's middle class is disappearing.
- Unequal income gains worsen income inequality.

- Economic inequality persists among women and Mainers of color.
- "Deaths of despair" accompany long-term unemployment and poverty.

How does a child/a family respond to these economic circumstances? Already observed Great Recession effects on adults are out-migration, joblessness, homelessness, death-by-despair, as the Maine Center for Economic Policy suggests. Reported child effects in 2017 included elevated anxiety rates, teen suicide, increase in special education services (Maine Children's Alliance, 2019). These severe impacts on children and their families are evidence of more risk than opportunities for development accruing from a single chronosystem event. Beyond despair and family out-migration what solutions are being proposed for buoying the many children and families still most affected? What policies, recognizing special vulnerabilities to economic downturn within Maine's rural counties, might better promote child and family resilience?

Bronfenbrenner defines the **macrosystem** as "the overarching pattern of micro-, meso-, and exosystems characteristic of a given culture or subculture, with particular reference to the belief systems, bodies of knowledge, material resources, customs, life-styles, opportunity structures, hazards, and life course options that are embedded in each of these broader systems" (1994, p. 40). The stories we tell ourselves about our history, our traditions, the lens through which we view our world are the cultural foundation upon which we form and reform our institutions—government, business, worship, health care, social services, our families, too.

If we believe that "things we cherish define us", then one mode by which Mainers express their values is through their state symbols, songs, and emblems, each identified and adopted by the state legislature over time. These convey simply and directly what Mainers have held dear, still treasure, and wish to remind themselves about and convey to others about their state (Netstate, 2017, July 27). In Table 1 below, symbols are arranged by date of adoption by the legislature.

That cultural life should be devoted to the "Common Good" appears to be another Maine core value (Routhier, 2015). Routhier argues that a "mission to serve the common good has characterized Maine cultural life since the earliest years of the nineteenth century (p. 105)." The author quotes the following (a statement declared two years after statehood was established):

> *"It ought always to be remembered, that literary institutions are founded and endowed for the common good, and not for the private advantage of those who resort to them for education…. If it is true, that no man should live to himself, we may safely assert that every man who has been aided*

Table 1

Maine State Symbols and Songs

Designation	Symbol / Emblem	Date Adopted
Floral Emblem	Pine cone and tassel	1895
Flag	State coat of arms on blue field*	1909
Great Seal	**	1919
Bird	Chickadee	1927
Song	"State of Maine Song"***	1937
Tree	White pine	1945
Fish	Landlocked salmon	1969
Mineral	Tourmaline	1971
Insect	Honeybee	1975
Animal	Moose	1979
Fossil	*Pertica quadrifaria*	1985
Cat	Maine coon cat	1985
Vessel	Schooner "Bowdoin"	1987
Berry	Wild blueberry	1991
Language of the Deaf Community	American Sign Language	1991
Soil	Chesuncook Soil Series	1999
Herb	Wintergreen	1999
Heritage Fish	Eastern brook trout	2005
Soft Drink	Moxie	2005
Heritage Fish	Blueback charr	2007
Dessert	Blueberry pie	2010
Treat	Whoopie pie	2010
Sweetener	Pure Maine maple syrup	2015
Crustacean	Maine lobster	2016

Notes: *On a blue field under the North Star is a shield with a moose resting under a tall pine tree and flanked by a farmer on one side and a seaman on the other. A banner unfurls below, reading "Dirigo" ("I Lead" in Latin).

**The Great Seal is an adaptation of the flag design. Here the banner "Dirigo" unfurls under the North Star, and the name of Maine is emblazoned on a banner underneath the moose, pine, farmer, and sailor.

***The State Song praises "the land" of Maine—its woods, fields, hills, lakes, streams, rock-bound coast, its scent of fragrant pines, and tang of salty sea.

> *by a public institution to acquire an education, and to qualify himself for usefulness, is under peculiar obligation to exert his talents for the public good,", this part of the inaugural address of Joseph McKeen, President of Bowdoin College, 1822.*

The Portland Museum of Art, an exemplar of this ethic of service to the common good, has provided six pieces of art from its vast collection to share in this monograph. Each reflects a single moment of family caregiving, a story to tell and tell again. See in this monograph: *Sampler* by Narcissa *Stone* (1810), *Weatherbeaten* by Winslow Homer (1894), *The Ryul Family* by Gertrude Kasebier (1913), *The Quiet Hour* by Eastman Johnson (circa 1877), *Dark Harbor Fisherman* by Newell Convers Wyeth (1943), and *Portrait of the Dearborn Children* by Henry Williams (n.d.).

In Maine one expects these images of family caregiving yesterday to be echoed in the daily living activities of many of today's children and families caring for one another. And beyond museum and gallery walls, the work of poets and writers and sculptors and painters and potters is being shared for the "common good" today along roadsides, in shops and cafes and taverns, in city parks, reminds Routhier.

Aside from an examination of the literature, one can also simply ask those who live in Maine what they value. A psychographic survey sponsored by Commission of Maine's Future (Market Decisions, Inc., 1989) was designed to identify the "bedrock" values of Mainers. From personal conversations, the Commission identified the following: unique feeling for the land and its natural beauty; optimism about <u>quality of life</u> (life is simpler in Maine) but concerns about changes in <u>way of life</u> (sub-cultural and lifestyle); appreciation that traditional values (self-reliance and faith) co-exist with a tolerance of alternative ways of life; recognition/acceptance that some Mainers are alienated from government while others feel actively a part; and value of education for self and children with focus on job preparation.

A direct and powerful explication of an ethic of care, as a fundamental value and social expectation, can be found in Maine Law, 1821, written a year after statehood. Here a litany of virtues/ideals are identified as important for guiding the socialization and education of the new state's young, quoted in a contemporary report *"Taking Responsibility: Standards for Ethical and Responsible Behavior in Maine Schools and Communities"* (The Commission of Ethical and Responsible School Behavior, 2001).

> Instructors of youth in public and private institutions shall use their best endeavors to impress on the minds of the children and youth committed to their care and instructions the principles of morality and justice and a sacred regard for truth; love of country, humanity and a universal benevolence; the great principles

> of humanity as illustrated by kindness to birds and animals and regard for all factors with contribute to the well-being of man; industry and frugality; chastity, moderation and temperance; and all other virtues which ornament human society; and to lead those under their care, as their ages and capacities admit, into a particular understanding of the tendency of such virtues to preserve and perfect a republican constitution, secure the blessings of liberty and to promote their future happiness.
> Maine Law, 1821, as amended
> (Currently Title 20, Section 1221)

"A Song for Machigonne" by poet Mikhu Paul-Anderson (2013), a member of the Maliseet, one of the five groups comprising the Wabanaki Confederacy, addresses yet another emerging value, the need to address and redress the loss of lives and lands of Maine's first people, its "people of the dawn". This powerful poem presents an opportunity for today's Maine, along with other existing social efforts, to come to mutual understanding, to come to terms with yesterday, today. Paul-Anderson concludes her "song", reminding:

> "Machigonne, just one of many, first become Casco, then Old Falmouth,
> Years wore on and Portland Maine became the name.
> The Massacre you blame us for is but the story of your shame,
> those sins for which you must atone.
> Machigonne was not your own." (p. 39)

"Can it be? Should it be that the people of the dawn are reduced to pinpricks of lands on a GPS map of Maine? How are amends made?" the poet seems to prod. (Today there are 4 federally recognized Indian tribes in Maine with a total estimated membership of 9,491 including: the Houlton Band of Maliseet Indians with 1700 members in Littleton; Aroostook Band of Micmacs with 1489 members in Aroostook County; Passamaquoddy Tribe of Indian Township, with 1364 members in Princeton (Sipayik) and 2005 members at Pleasant Point Reservation in Perry; and Penobscot Nation with 610 members in Penobscot, near Old Town, altogether comprising now .6% of Maine's population (Bureau of Indian Affairs, 2014, January 16).

Another emerging value may be seen in work to revive the French-Canadian identity in Maine, perhaps bolstered by enduring prominence of Catholicism (Pelletier, L., 2010, April 8). Today the University of Maine, located in Orono, offers the singular interdisciplinary undergraduate Franco American studies program and French language degree program in the state. It is to be remembered that tight Catholic extended family groups from Quebec and New Brunswick came to enjoy job opportunities in lumber and textiles at the turn of the 19th century (Bridges, L., 2010, April 18) and that in 1919 children were no longer allowed to speak French in school. Today those of French heritage comprise about 20% of Maine's population, most residing in northern areas of the state, particularly Aroostook County (Murphy, A., 2014, March 13).

Finally, religious values reflected in religious institution participation might be viewed as yet another source of inspiration and opportunity to learn and practice an ethic of care. Yet, Maine has been termed the least religious of the 50 states (Reaves, P., 2015, May 12) with declining religious participation and membership. In 2014 membership rates were 37% protestant, 31% no religion, 21% Catholic, 5% other, 2% Mormon, 2% Jewish, 2% don't know, 1% other Christian, 1% Buddhist. Of these affiliations, in 2010, the Catholic Church retained the highest membership with 190,00 members. Might this reflect a trend toward secularization and shift toward "humanitarian spirituality", reflecting efforts "to be good human beings" in everyday life, as opposed to participation in a structured religious institution, as one theologian conjectured for another report (Harrison, J., 2012, May 18)?

In summary, perhaps Maine's values today are best expressed in this simple aspirational sentence, composed in anticipation of Maine's 2020 bi-centennial celebration. It reads:

> Maine's path to statehood mirrored and advanced many issues that resonate through to the present: relationships among different societies, the struggle for civil justice, the use of natural resource, and the idea of responsible stewardship of our land, air, and water (Maine200Bicentennial Commission, 2020, *Commemorating 200 years of statehood*, p. 1).

The consonance/alignment of these values suggest a solid foundation of an ethic of care for guiding how Maine folk see one another and work to bolster and reinforce institutional structures via everyday interactions and intentional development of public policy supporting a truly caring community statewide. How might these values serve as touchstones for the growing child? Can these values be used as a measuring stick against which to evaluate today's institutions in Maine (home, church, school, government, business, family) efforts to assure that each child adopts an ethic of care and grows assuredly as "carer" within family and community, if not the wider world? Are there other values that demand embrace for family life in changing times?

The **exosystem**, according to Bronfenbrenner (1979, 1994), includes social contexts that are influential on the developing child but exist outside of the developing individual's/child's direct everyday experience (e.g., family work environments). An exosystem is viewed as creating opportunity for child development by simply making it easier for the

Table 2.
Maine 2017 State Occupational Employment and Wages

Employment Category	# Employed	Median Hourly Wage
All occupations	599,180	$17.41
Management	34,690	$39.76
Business & Financial Operations	23,390	$29.01
Computer/mathematics	11,370	$33.60
Architecture/engineering	9,700	$34.52
Life, physical, food science	3,990	$26.97
Community/social service	10,250	$20.86
Legal	3,590	$28.32
Education/training/library	40,350	$21.62
Arts/design/entertainment/sports /media	8,060	$16.22
Healthcare practitioners/technical	40,770	$30.08
Healthcare support	20,760	$13.93
Protective services	11,960	$17.63
Food preparation & service related	56,000	$10.53
Building & grounds/cleaning & maintenance	21,660	$13.15
Personal care & service	26,290	$11.49
Sales & related occupations	58,140	$12.33
Office & administrative support	92,610	$16.32
Farming, fishing, forestry	1,770	$16.71
Construction/extraction	25,260	$19.11
Installation, maintenance, repair	26,140	$20.15
Production	35,940	$17.54
Transportation/material	36,518	$15.13

parent/the caregiving adult to parent/care. Risk emerges, alternatively, when an exosytem makes it more difficult for parents to successfully parent. For most children and families, the most influential exosystem is the work environment of the parent/parents.

When parents are employed full-time in jobs they enjoy, in which their skillsets allow a meaningful contribution to others and for which they receive compensation commensurate with their skills and contribution, benefits indirectly accrue to their children. One measure of the distribution of this opportunity can be found in "Maine 2017 State Employment Statistics" published by the U.S. Bureau of Labor Statistics (2017, May). Table 2, above, allows us to see how many people are working in each employment node and at what median wage.

Another way to look at jobs that parents may perform among all workers in the Maine economy and to surmise the risk or benefit it may afford the children of those parents is to examine the real value added to GDP by each employment category, demonstrating contribution of each sector to the economic output of the state, that is, its wealth and likely relative status afforded working parents within each. This provides also another representation of the changing complexion of work in Maine from fishing, agriculture, and industry to service and tourism, increasingly seasonal employment, often marked by employment instability (Maine Center for Economic Policy, 2018). The State of Working Maine Report 2018 also notes other occupation sectors, marked by part-time or seasonal work, include retail/wholesale, delivery/warehouse, education, health care, and natural resource industries.

Table 3 allows us, within the structure of the sociobiological theory, to infer opportunities and risks conveyed to the children of employees via their employers in each sector—perhaps conveyed by one or any combination of perceived job status, wages, and benefits including health care, parental leave, child care, medical family leave, vacation time. To the extent that these benefits accrue to parents, it is more likely that children will experience additional opportunities such as parental free time and availability, resources sufficient for daily living, secure and stable housing, as well as resources to share with others.

Table 3.
Gross Domestic Product (GDP) of Maine, by Industry 2019 (in billion chained 2012 U.S. dollars)

Industry	Value
Finance, insurance, rental and leasing	11.45
Educational services, health care, and social assistance	7.99
Government and government enterprises	7.76
Professional and business services	6.77
Manufacturing	5.59
Retail trade	5.16
Wholesale trade	3.27
Arts, entertainment, recreation, accommodation, and food services	3.03
Construction	1.84
Information	1.38
Transportation and warehousing	1.25
Agriculture, forestry, fishing, and hunting	.88
Mining	.05

An up-close view of a particular node of economic production reflecting continuing change in the economic workplace can be gleaned from Maine agriculture figures (United States Department of Agriculture, National Agricultural Statistics Service, 2018, May), noting a 10% loss of farmland over a period of years. For example, the census of agriculture in Maine (USDA, 2017) shows 766 farms in Aroostook County, down 14% from 2012; retirements and sales of smaller farms to larger producers accounted for this decline. Of total producers recorded, 867 were male and 460 female. Sales by agricultural product type were crops including potatoes, broccoli, and other vegetables at 93% and livestock at 7%, primarily cattle and calves, layers and broilers. As methods of production have changed with machine harvesting replacing hands, most Maine potatoes today are raised for seeds or frozen as fries rather than fresh picked for the tabletop.

Further, overarching bits of economic evidence (Maine Center for Economic Policy, (2017, September 18) indicate:

- The wealthiest 5% of Maine households secured nearly one-third of all income growth since 2012
- Middle class jobs, mostly in manufacturing, were replaced by low-wage jobs largely in service, retail, and tourism
- Mainers of color earned 85 cents to the dollar of non-Hispanic whites
- On average Maine women who worked full-time, year-round, earned 79 cents for every dollar earned by male peers
- Rural Maine economy was in "freefall" from 2006-2013 as large manufacturers downsized or closed
- From 2012 to 2015 there was an annual net influx of 1000 Mainers from rural Maine to the greater Portland area; and others left the state entirely.

Using Bronfenbrenner's theory as a means of understanding the potential effects of parent work on child development (opportunity or risk) – the preceding overlay of evidence cited about work in Maine allows one to ask the following questions:

- *Do we think about or expect or demand that all work environments help employees do their jobs at work well, but also to do their work as parents at home well?*
- *Is it reasonable to assume that fair wages, time for vacation, retirement savings, increased social status elevate working parents' abilities on the job and in the home? Presumably, as developing human beings themselves, parents by doing more and better work and providing more and better care of their children will contribute more to a stronger social fabric in their own workplace, home, and community.*
- *When there is a disproportionate distribution and flow of resources*

flowing to certain families and not to others, based on wages paid for parental work, how are children disproportionately affected?

- *Might provision of a supplemental income for parents doing the good and necessary work of care and personal service or essential seasonal work in tourism be a worthy social goal?*
- *When more and more work is seasonal and part-time, how are the many employees with children compensated in ways that support parents being better parents?*
- *How does access to quality childcare, for example, in rural, as well as town and city environments, influence parental employment patterns and parenting outcomes?*

In the meantime, when jobs diminish in any locale or occupation, what do children and families do? Where do they go? We know there are still family repercussions from the loss of textiles, shoe, and paper manufacturing (Ballard, 2020). How do families and communities deal with ways of life that are diminishing? Is there a structure for assisting families in transition? How can jobs be brought to people, rather than people to jobs, as a means of preserving community and sustaining a culture of care?

In sum, from a theoretical perspective, a good job and work environment helps parents garner the resources necessary for the support and care of their children, as well as time to spend with their children – actively caring for them. Teaching and modeling the value of work and its contribution to the common good while reinforcing an ethic of care with opportunities for real work and family contribution/care at home, engagement in the care of others, and care of the earth. The data speak: financial capital is foundational to building human capital.

A **mesosystem** relationship refers to "linkages and processes taking place between two or more settings containing the developing person (e.g., the relationships between home and school, school and workplace, etc.). In other words, a mesosytem is a system of microsystems" (Bronfenbrenner, 1994, p. 40) or relationships between systems containing the developing individual.

In a strongly linked mesosystem, on behalf of the developing child, the parent/ giver of care is a direct participant in that system as well, accompanying, supporting, and helping strengthen and sustain relationships between the two microsystems. In a weakly linked mesosystem, the developing person is the only link between two microsystems of his or her direct participation, such as family and school, and is assumed to be at risk for development, as the only advocate for his or her own development.

A key to strong links between microsystems, e.g., home and school, home and hospital, home and other service or activity sectors, is the ease or difficulty of establishing and maintaining these multiple direct linkages. And ease is often a measure of the physical distance between the two microsystems.

To demonstrate the opportunities for the coordination of care within the mesosystem, within the daily activities of families, I will focus narrowly on one Maine, largely rural, county, Aroostook. Located on the northeast border of the U.S., Aroostook County spans an area the size of the states of Connecticut and Rhode Island combined. What is meant by rural in this conversation? From a 2000 census perspective, *rural* may be defined as area with 2,500 or fewer people (Economic Research Service, n.d.), neither city nor town nor urban area nor urban cluster.

Rurality can also be defined as "a condition of place-based homeliness shared by people with common ancestry or heritage and who inhabit, culturally defined areas or places statutorily recognized to be rural" (Chigbu, 2013, p. 815). This latter definition is helpful in the following discussion about the opportunities for and challenges to social interface of children and their families with other social structures with which they may be engaged, be that school, health care, shopping, recreation, jobs, and other activity settings.

According to the 2010 United States Census (see U.S. Census, 2012, August), there were 71,870 people residing within the 2000 square miles that is Aroostook County. Of 30,961 households and 19,578 families, 80.3% of these were in rural areas. Population density of 10.8 inhabitants per square mile was the lowest per county in Maine. With 39,529 housing units, there was an average density of 5.9 per square mile.

Among Aroostook households, 25.5% had children under the age of 18 living with them; 49.6% were married couples living together; 9.4% had a female householder with no husband present; 36.8% were non-families; and 30.8% of all households, were made up of individuals. The average household size was 2.26, and the average family size was 2.79.

Mapping of population nodes show most of these vital microsystems for direct child involvement/engagement clustered along the shared border with Canada, echoing early settlement patterns in the county. The capital of Houlton, Presque Isles, and Caribou are the county's largest towns and county service centers, each with fewer than 10,000 residents.

In Aroostook there are only two census-designated cities (Caribou and Presque Isle) and 53 incorporated towns. In addition, there are 9 plantations (a municipal designation somewhere between a town and an unincorporated community) and 12 census-designated places (e.g., Houlton, the capital with fewer than 10,000 folk, designated for statistical purposes and community recognition only). Thirteen unincorporated communities (places identified and administered within towns), eight unorganized territories (places with no local, organized government, such as

Oxbow), and two Indian reservations (Aroostook Band of Micmacs and Houlton Maliseet Reservation) complete the list of settlements for families and children (U.S. Census Bureau, 2011, July 17).

As for public services, there were 48 public schools (8 high schools, 7 middle schools, and 24 elementary schools) with an average student-teacher ratio of 11-1 to 13-1, in 27 districts, serving a total of 10,753 students K-12 (Publicschoolsk12.com, 2011) during the 2010-2011 school year. Two universities that are part of the University of Maine system—Fort Kent and Presque Isle—served undergraduate and graduate students from Aroostook County and beyond.

In 2007 families relied on 29 grocery stores and one supercenter (along with 16 convenience stores without gas stations and 56 convenience stores with gas stations) (City-data, 2020). Fourteen public libraries served the county (My Public Libraries, 2010-2021). Finally, there were 8 hospitals from Cary south to Houlton and 62 primary care providers meeting needs for urgent, primary, and most critical care medical needs for children and families (Maine.gov, 2004, December 31).

Not only distance, but also the number and complexity of mesosytem relationships, operate to create opportunities and challenges for the child learning and practicing an ethic of care. Two examples of these complex mesosystem relationships within daily family life are shared now. As noted earlier, Aroostook County has been defined over time by agriculture and remains associated with its iconic agricultural product, the potato. Sentiment tied to the potato is strong. Corey Park, a Presque Isle High School graduate and former potato farmer, says, in an opinion piece first published in the *Bangor Daily News,* "for three short weeks, we race to uncover a year's worth of labor and toil, waiting with anticipation to see what the dirt holds" (Natural Resources Council of Maine, (2014, June 25).

Today, a century's old tradition of closing school during potato harvest in the fall, and allowing older children (before mechanization when all children worked the harvest) to participate and make a little money themselves while supporting agriculture, the economic centerpiece of their county, is still practiced in many areas of the County [Eno, D. (2017, August 7).] Many schools start their year a couple of weeks early so, that during harvest (two to three weeks during the end of September, beginning October), older children can do the real work of harvest.

But, in areas adhering to this honored tradition, school is often closed for all children, potentially leaving some working parents to seek additional child care for their younger children who cannot participate in harvest work or to leave those younger children home alone during those several weeks. Furthermore, given that mechanization has eliminated most need for helping hands during harvest, many older children, while eligible from harvest and excused from school, will have no work to perform and, presumably, no supervision.

Complexity can also be seen in the tribal structures within Aroostook County. Both the Aroostook Band of Micmacs and the Houlton Band of Maliseets comprise an additional and discrete microsystem for members of each tribe. As children and parents participate together in the governance, education, health and social services, and cultural events of their tribe, their comings and goings back and forth, comprise a mesosystem. In some instances, the tribe may supplant and in others supplement other available community linkages. For example, a family may choose to send their young child to the tribe's federally funded Head Start program instead of pre-k at a local public school or use the local tribal health care clinic for basic preventive health care for their children as opposed to using a primary care physician who might practice at a distance further from a family's home.

It is our comings and goings back and forth, from this place called home to another, that help us build and preserve community. From a theoretical perspective, when the child and other family members share experiences in the same community settings, benefits accrue to the child. Yet, coordination of shared experience and care can be compromised by the stretching of distance, time, and attention associated with rurality. Seemingly, better correspondence between parent work schedules and children's school schedules would allow more parents to have greater and more supportive presence and impact in their children's community engagement activities, forging community bonds of caring for each other. And for children and families of the dawn, seeking to re-establish long-deserved communities of care of all living things according to cultural traditions, surely these tribal structures serve as overdue mesosytems of opportunity.

The **microsystem** is defined as the "pattern of activities, social roles, and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical, social, and symbolic features that invite, permit, or inhibit engagement in sustained, progressively more complex interaction with, and activity in the immediate environment. Examples include such settings as family, school, peer group, and workplace" (Bronfenbrenner, 1994, p. 39).

The microsystem can be considered an environment for the developing child or individual to "do more" and in which, ideally, the balance of power gradually shifts in favor of the developing child. For most children learning an ethic of care—and practicing the giving and taking of care—is achieved within the family and the school, microsystems in which children spend most of their waking time. How is the child socialized to care in these settings?

We must remind ourselves that people are the source of all social knowledge, and caring is a socially acquired behavior. Therefore, we, as parents and grandparents and siblings at home and teachers and other adult personnel at school, must show children how to care, tell what to do and why, provide them with opportunities to care, and acknowledge and value their attempts at caring, as they grow.

First, let's turn to the family microsystem. Family structure and membership, as well as location, affect the showing and telling and provisioning of opportunities to care. A map demonstrating population density by county according to the 2010 census is a visual reminder of where families raise their children in Maine. Denoted by darker shading, most families live clustered along the southeastern seaboard from Portland to Augusta, echoing historic residential patterns (See Figure 3. Maine population density by county-U.S. Census 2010, by William R. Parrish, 2-19-2015).

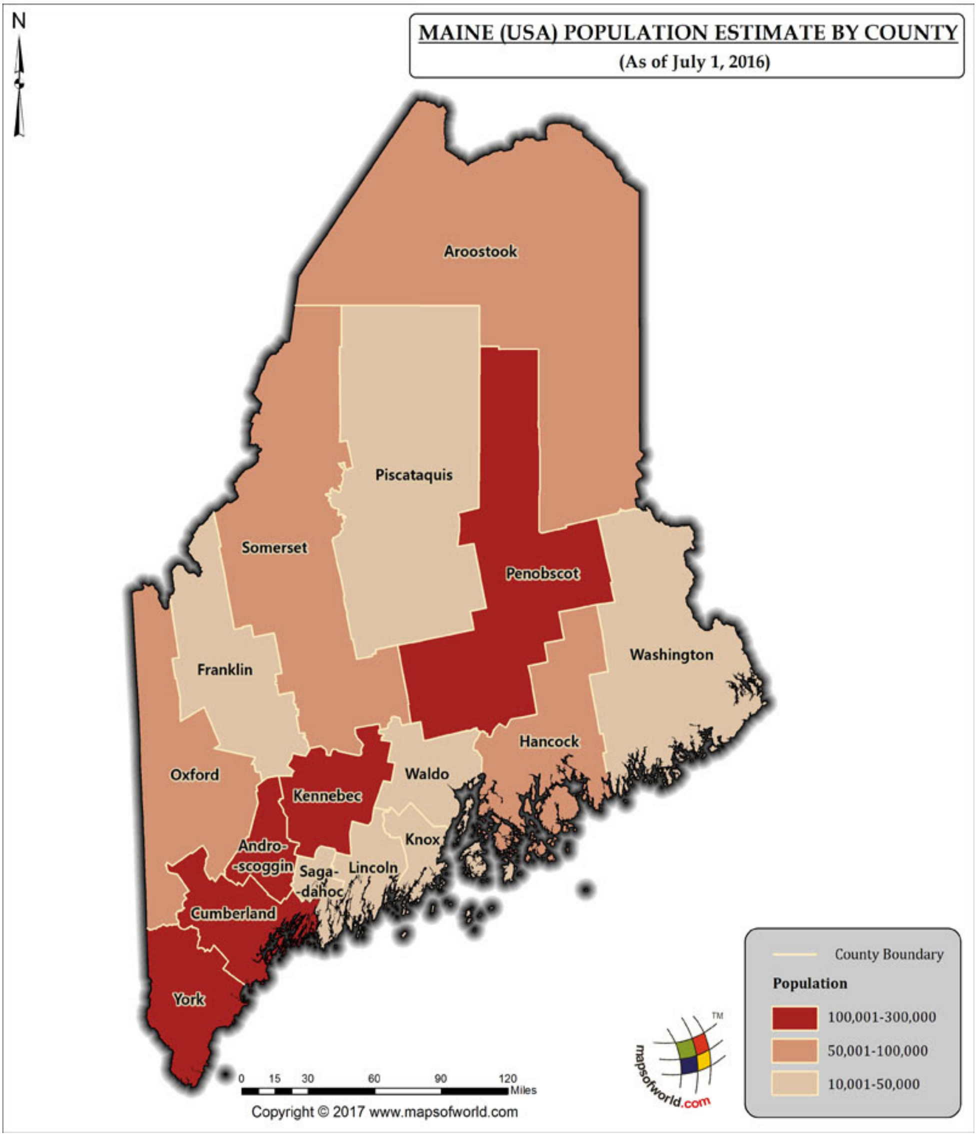
In 2017 there were approximately a third of a million family households (337,607) with children from birth to 17 years of age in Maine (U.S. Census, 2017). Of these, married couples headed 252,402 households. Female householders with no husband present headed another 50,221 households, and male householders with no wife present headed 24,984 households. Most families with children lived in owner-occupied housing (73.2%) with the remainder in renter-occupied housing (26.8%).

The average family size was 2.85, the average number of children 1.7-1.8. Most families (90.4%) were comprised of householder/householders and their own child/children (biological, step, or adopted). Other households contained a householder with grandchild (6.1%), a householder with another relative child (1.2%), and a householder with a foster child (2.3%). In one of 10 (10.7%) of these family households, the household included an unmarried partner of the householder.

Looking at numbers of children, 83,000 children (35%) were living in single-parent families (Annie E. Casey Foundation, 2017b). Some 14,628 children were living with grandparents (Grandfamilies, 2017, May). Other relatives provided care for 3,397 (1.3%) children (Child Trends, 2015). Sixteen percent of children lived in blended families with a stepparent and step-sibs or half-sibs (Pew Research Center, 2015, December).

In 2015, there were 1,873 children living in foster care, most due to neglect, with 666 of these waiting for adoption (Child Welfare League of America, 2017)). During the 2016-2017 school year, there were 2,515 children enrolled in school or Head Start who were homeless or doubled up at any time and 283 homeless families with children and 69 juveniles

Figure 3. Maine population density by county. U.S. Census 2010



in detention in 2017 (Maine Children's Alliance, 2019).

Other relevant family data, at this time in Maine, included:

- 81,000 (33%) children under age 18 lived in low-income families in 2017 (note that from 2016-2017 6400 children were lifted out of poverty in part due to rise in minimum wage, Maine Children's Alliance, 2019);
- 50,000 children under 6 lived in families with all available parents in workforce and likely in need of childcare (The Annie E. Casey Foundation, 2018);
- 11,000 (4%) children lived in families where household head

lacked high school diploma (The Annie E. Casey Foundation, 2017a).

Increasingly, children face "adverse childhood experiences" in their families. These traumatic events, occurring before age 18, include physical abuse, sexual abuse, emotional abuse, neglect, parental mental illness, substance abuse, divorce, incarceration, domestic violence, that includes witnessing violence and having a family member attempt or die from suicide use (Centers for Disease Control and Prevention, 2020, April 5). According to KidsCount data for 2018 (The Annie E. Casey Foundation), one in five (22%) of children in Maine, 17 years old and younger have experienced 2 or more ACE's; this outcome is associated with negative developmental outcomes including depression, drug use and addiction, and brain changes influencing attention, decision-making, learning, and response to stress.

What opportunities and challenges for children learning and practicing an ethic of care in families in Maine today are represented in the selected locational and demographic data just shared? Most Maine children are growing up today with family resources sufficient for helping their children learn and practice an ethic of care. They live in secure housing with two parents. Here children can seek help and information (and be assured of receiving them), enjoy companionship, and practice sharing and other forms of caring. Yet, increasing complexities of family formation for too many children pose challenges for parents trying to muster the time, attention, affection, and resources necessary for fostering an ethic of care in their growing children.

As discussed by Bronfenbrenner (1979) in a single parent family there is simply one less adult available to teach, model, and reward caring. Even children with two working parents may also experience diminished opportunities for caring in the household, particularly when parents must hold more than one job to make ends meet. Finally, when children within a family are fewer and more closely spaced in age, there are diminished chances for one sibling to care for another sibling and, accordingly, for those siblings to become and remain allies with one another throughout life.

Yet, within these changes and constraints of family living, it is still possible for parents, willfully and willingly, to help their growing children acquire and practice an ethic of care. Whispered assurances of enduring care, use of the vocabulary of care (e.g., "help", "please", "need"), provision of small opportunities to take care of another can be still performed. A toddler can pick up a dropped rattle for his baby sister, a school-age child can assume responsibility for putting out fresh food and water daily for a family pet, a teenager can distribute donated picture books to homes of neighbors with young children. The whole family can plant and tend a summer garden together.

Looking at another powerful microsystem of influence, the school, data is available on school organization, student performance, and standards for curriculum that may support or impede children learning to care outside the home and family. One view derived from sociobiological theory is that opportunities for learning an ethic of care at home can be enhanced by additional experiences practicing caring behaviors at school, and vice versa.

School governance in Maine is unique (see www. Maine.gov 2020). The governance structure of Maine school districts ranges in complexity from a municipal school unit in which a city or town assumes individual school supervision to a regional school unit in which two or more municipalities pool their educational resources and educate all students. Four additional governance structures are tailored for the sharing of a variety of administrative and educational services, according to community needs across municipalities and/or districts. Allowances for school choice include opportunities for families and children to select home schooling, charter or private school attendance, and out-of-district attendance.

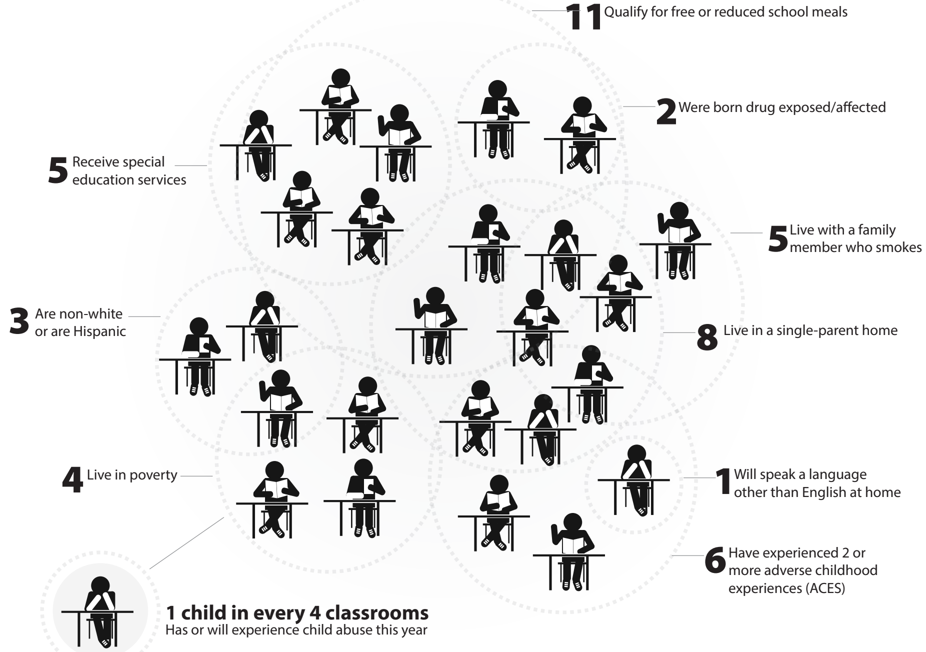
Public school enrollment and staffing. According to Ballotpedia (n.d.), during 2013 Maine had 185,739 students (pre-k through grade 12) enrolled in 617 schools within 255 school districts. (U.S. census data for 2017 shows about 12% of all children in Maine attend private school.) There were 15,222 public school teachers, about one teacher per 12 students. (There was about one administrator per 204 students.)

Most children attended rural schools (54.7%) with 17% in town schools, 16.2% in suburb schools, and 12% in city schools. Figure 4 presents a representative first grade classroom of a Maine school with 25 children enrolled (Maine Children's Alliance, 2019).

Per pupil public expenditure (2013) was $12, 147; and funding sources were: federal (7.5%), state (40.2%), and local (52.3%) (ballotpedia, n.d.). Children in K-12 were expected to attend school for 175 days each year; the minimum length of day was 3 hours but the average over a two-week period was expected to be 5 hours a day (National Center for Education Statistics, 2018).

Enrollment in public preschool is growing with 5,648 or 42% of Maine 4-year-olds enrolled in a program in 2018 for at least a 2-hour day. Operating schedules were dependent on public school, community-based childcare program, or Head Start program partnership. Class size was limited to 16 children with one (Early Childhood Education) ECE certified teacher and one (Child Development Associate) CDA certified assistant teacher. The state investment per child per year was $3,420 (National Institute of Early Education Research, 2019, April).

Figure 4. Representative first grade classroom of Maine school with 25 children enrolled.



A Hypothetical Classroom of 25 First Graders in Maine

Maine Children's Alliance: Maine KIDS Count 2019

School transportation. For approximately 80% of Maine students, the school day begins and ends on the school bus (Maine Department of Education, 2020). Today smaller and more rural districts are spending a greater proportion of their budgets for transportation than more densely populated districts due to statewide increases in school closings and consolidation (Donaldson, 2016, December 8).

Pupil performance. Fourth grade students scoring at or above proficiency on the Maine Educational Assessment (MEA) reading test in 2018 were 51.3% (or 6,650 of all fourth graders taking the test). Eighth grade students scoring at or above proficiency on the MEA math test in 2018 were 38.7% (or 5,108 of all eighth graders taking the test) (Maine Children's Alliance, 2019). Eleventh grade proficiency rates were 59% in reading and 35% in math (EducateMaine, 2018).

Special education enrollment. In the 2016-2017 school year, 29,620 (17%) students ages 6-20 enrolled in Maine public schools had an identified disability. This was out of a total of 174,283 students in that age group (Maine Children's Alliance, 2019).

Chronic absenteeism and school disconnection. For the 2016-2017 school year, the Maine Department of Education (2020) reports among 191,940 students enrolled in public and private schools, 15.94% were chronically absent, that is, absent 10% or more of days enrolled (15.94% among public school administrative districts and 9.2% in private schools).

Visual examination of the DOE data reveals a preponderance of chronic absenteeism in regional school units (RSU's). In 2019, 6% of 16-19 year olds were considered disconnected from school, with no school and no job participation (The Annie E. Casey Foundation, 2018).

High school graduation and college enrollment rates. In 2013, the high school graduation rate was 86.4% (ballotpedia, n.d.). Sixty-three percent of high school graduates enrolled in college within one year of graduation (EducateMaine, 2018). Maine educational goals for its graduates include expectation that each student achieve an academic degree or professional certification leading to employment.

Jobs for Maine graduates. What jobs will be available for Maine high school and college graduates? Valigra (2018, August 7), reviewing Maine Department of Labor forecasts, points to growing demand in the areas of health care and food service with declining demands for office administration and production jobs.

Curriculum standards and student performance expectations. What might an examination of Maine's K-12 curriculum standards and student performance expectations (Maine Department of Education, 2020b) yield for a more focused analysis of opportunities offered children to acquire and practice an ethic of care within their schools? I performed a content analysis of curriculum standards for the following curriculum content areas: careers and education development, English language arts/literacy, mathematics, science and engineering, health and physical education, social studies, visual and performing arts, and world languages, for the purpose of answering this question.

Most notable is the attention given to the promotion of the "common good" as it appears in the following statement from the Introduction of Social Studies K-12 Curriculum Standards:

> According to the National Council for the Social Studies: advocates of citizenship education cross the political spectrum, but they are bound by a common belief that our democratic republic will not sustain unless students are aware of their changing cultural and physical environments; know the past; read, write, and think deeply; and act in ways that promote the common good. (C3 Framework for Social Studies, 2013).

with three derivative student performance expectations to promote the common good at grades 4, 5, and 6-8.

Additionally, under Life and Career Ready Standards, at grades 4 and grades 9 –diploma there is expressed expectation for students "to exhibit ethical behavior". Within Science and Engineering Standards, earth care is fostered when second graders conduct an investigation to see if plants need sunlight and water to grow, and fifth graders gather information about ways "individual communities use science to protect the earth's resources and development". Self-care objectives are evident in Health and Physical education standards with K-2 students expected to choose healthy foods, practice skills of personal hygiene, and express needs, wants, and feelings in healthy ways; students in grades 3-5 additionally develop injury prevention and safety strategies for personal health. Sixth to eighth graders learn about substance abuse prevention, while 9-12th graders learn additionally about prevention of STD's, HIV, and pregnancy.

Maine's small schools with few students and many teachers enjoy a remarkable opportunity to promote an ethic of care and work collaboratively with families in all Maine communities. Here teachers and administrators can more easily model caring behavior and teach the language of care. Expectations for students to give and receive help and information, to share, and to provide opportunities for collaborative work and play can be reinforced within and across classrooms in smaller school environments.

In 2001, the Leave No Child Behind Act was enacted to close the achievement gap for disadvantaged children. How was Maine doing on this? Data cited suggest that early on many children are being left behind. How can parents and teachers work together, to pause and reteach or invite and teach in new ways, so that no matter what the skill that any child has not mastered, we try again?

To this observer, what <u>may</u> be missing, or can be enhanced, is the DOING element of curriculum – baby steps to caring with opportunities in both family and school, not just in one or the other – class pet, garden to tend, plenty of activity outdoors over all seasons, adopt-a-class or "each one helps one", as in holding hands with a younger child while walking to assembly, reading to another child learning English as a second language, healthy food experiences shared, elder volunteer reading stories or coaching multiplication skills, and participating in community service activities tied to and not exclusive of attention to state-generated curriculum standards and expectations for student performance. Real-life experiences in school that captivate attention, allow enduring action and involvement, allow each child to utilize new and old skills with confidence and build a sense of self as capable and caring.

Finally, the **individual**, the developing person, according to Bronfenbrenner, (in this essay, the **child**) is seen as shaping his/her developmental trajectory from birth forward, based on innate physical and social characteristics—gender, race, ethnicity, ability, social and economic status. These givens shape potentialities for the developing person learning to give and receive care throughout life. By virtue of being who he simply is, the developing person "pulls for" certain unique responses in and from those other developing persons around him—parents, siblings, and other relatives, peers, neighbors, teachers. And those responses place her at advantage or disadvantage based on the value or goodness or rightness ascribed to her by those others.

During 2017, 12,290 babies were born in Maine, reflecting a decline in births from 12,951 in 2010 (Maine Division of Public Health Systems, 2020, July; 2019) with 64, 502 children under age 5 and 252,634 under age 18 out of a total state population of 1,335,907. Among babies born in 2017 there were 1,066 (8.1%) babies born pre-term. There were also 603 (15%) babies born to teen mothers and 952 babies (7.8%) born affected by substances (Maine's Children's Alliance, 2019).

Child gender, derived from 2010 census data, would indicate slightly more female than male children, both born and living through first birthday. Birth rates per ethnicity were estimated to be 88.3% white and 11.7% babies of color. Among babies of color, 3.8% were more than one race, 2.9% Black, 2.8% Hispanic, 1.3 Asian, and 0.8 Indian/Alaska Native (Children's Defense Fund, 2020).

An index of disability prevalence among Maine babies born between 2012 and 2013 was 0.70% (Individuals with Disabilities Education Administration, 2013). At this percentage rate, among babies born in Maine during 2017, only 86 babies would have been identified with a disability, most notably vision and hearing. Kraus, Lauer, Coleman, and Houtenville (2018) note that as the population ages, percentages of people with disabilities, including children, increase.

As available measures of socioeconomic status in 2017 (Maine Children's Alliance, 2019), if food insecurity was observed as affecting 50,520 or 19.8% of children birth to age 18, then, it can be assumed that 19.8% or 2,433 of babies were born into families experiencing food insecurity. Or, if 35,045 (14.2%) children were deemed to be living in poverty in 2017, by virtue of household income, it can be assumed that among babies born that year, at least 14.2% or 1,745 babies were born to families living in poverty.

What does the child bring to the table for his own development? Most babies in Maine are born with enduring opportunities for receiving and giving care throughout life. These babies are born healthy into enriched social and economic family environments. Yet, in this data, here are powerful indicators that because of who they are at birth, many babies enter life with abrupt and likely enduring challenges to learning and practicing an ethic of care, for the development of a secure belief in one's value as an individual human being worthy of care.

Through what value lens do we elect to peer--to derive and ascribe value to the developing individual, here, the baby born in Maine? Is a newborn baby merely seen as one new future worker who will pay taxes to replace those of a former worker or someone to fall into place at the necessary time to care for an aging parent or just one more mouth for the "rest of us" to feed?

Or, are there alternate ways of looking at each baby born – perhaps, as one more new person in Maine to abide by an ethic of care – to learn to care for self and to care for family, friends, community, and the earth? If we have not before, how do we learn now to ascribe value to each child born and to tuck each child, figuratively and literally speaking, in a cradle of loving care?

Conclusion. *Sociobiological theory reminds us to look systematically at the developing child in each of his lived environments to derive best practices and policy in fulfillment of the oft-stated goal of educating all children to care for all living things – themselves, their families and communities, this tourmaline green piece of earth named Maine.*

With love, I offer:

"A Maine Child's Bill of Rights to Receive and Give Care"

I am a child. I am good and worthy of care. As I grow, I will help take care of myself.
I live with other people who are good and worthy of care. As I grow, I will help care for my family, for my friends, and for my neighbors.
I live on an earth that is good and worthy of care. As I grow, I will help care for the earth.

References

Bailey, J. (2018, July 14). Maine's soils are a lot of things but don't call them dirt. *Bangor Daily News.* *https://bangordailynews.com/2018/07/14/homestead/maines-soils-are-a-lot-of-things-but-dont-call-them-dirt/*

Ballard, S. (2020, December). Personal communication.

Ballotpedia (n.d.). Public education in Maine. https://www.ballotpedia.org/public_education_in_Maine

Bertone, R. (2017, July 2). Maine's top 10 ag products (infographic). *Farm flavor.* https://www.farmflavor.com/maine/maine-crops-livestock/maines-top-10-ag-products-infographic/

Bridges, L. (2010, April 18). *Trying to revive the Franco identity in Maine.* https://www.bangordailynews.com/2010/0/0/news/trying-to-revive-the-Franco-identity-in-Maine/

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.

Bronfenbrenner, U. (1994). Ecological models of human development. *In M. Gauvain & M.Cole (Eds.), Readings on the development of children (2nd ed.), pp.37-43.* W.H. Freeman. (Reprinted from *International encyclopedia of education.,* 2nd ed., *Vol. 3*, pp. 1643-1647, by T.N. Postlethwaite, &

T. Husen, Eds., Elsevier].

Bureau of Indian Affairs (2014, January 16). *2013 American Indian population and labor force report.* U.S. Department of the Interior, Office of the Secretary Office of the Assistant Secretary—Indian Affairs. *https://www.bia.gov/sites/bia.gov/files/assets/public/pdf/idc1-024782.pdf*

Centers for Disease Control and Prevention (2020, April 3). *Violence prevention-adverse childhood experiences.* https://www.cdc.gov/violenceprevention/aces/fastfact.html

Chigbu, U.E. (2013). *Rurality as a choice: Towards ruralizing rural areas in sub-Saharan Africa, 30(6)* 812-825.

Child Trends (2015). *Kinship caregiving federal fiscal year 2015-Maine*. Available at https://www.childtrends.org/publications/state-level-data-for-understanding-child-welfare-in-the-united-states

Child Welfare League of America (2017, April). *Maine's children 2017.* https://www.cwla.org/wp-content/uploads/2017/04/MAINE-revised-1.pdf

Children's Defense Fund (2020). *The state of America's children in Maine 2020 factsheet.* https://www.childrensdefense.org/wp-content/uploads/2020/02/SOAC-2020_Maine.pdf

City-Data (2020). *Aroostook County Maine-Food environment statistics.* https://www.city-data.com/food/food-Aroostook-Maine.html

Donaldson, G. (2016, December 8). Riding the school bus—Costs and conundrums. *Maine Schools in Focus*. The University of Maine. https://umaine.edu/edhd/2016/12/08/maine-schools-focus-riding-school-bus-costs-conundrums/

Economic Research Service (n.d.). Maine-Rural Definitions: State-Level Maps. *U.S. Department of Agriculture.* https://www.ers.usda.gov/webdocs/DataFiles/53180/25574_ME.pdf?v=0

EducateMaine (2018). Education indicators for Maine 2018. https://www.educatemaine.org/docs/EducateMaine_2018_IndicatorReport-WEB01.pdf

Eno, D. (2017, August 6). Traditional potato harvest break continues at some Aroostook County schools. *Fiddlehead Focus.* https://fiddleheadfocus.com/2017/08/06/news/traditional-potato-harvest-break-continues-at-some-aroostook-county-schools/

Frignoca, I. (2018, March 28). A changing Casco Bay: Beyond the beauty. *Friends of Casco Bay.* https//:www.waterkeeper.org/news/a-changing-casco-bay-beyond-the-beauty/

Grandfamilies (2017, May). *State facts for grandfamilies-Maine.* https://www.grandfamilies.org/Portals/0/State%20Sheets/Grandfamilies-Fact-Sheet-Maine.pdf

Harrison, J. (2012, May 18). Got faith? Maine the least religious state in the nation. *Bangor Daily News.* https://www.bangordailynews.com/2012/05/18/news/got-faith-maine-the-least-religious-state-in-the-nation/

Hauptman, M. (2018, July 5). After a tough 2017, blueberry growers face a shaky start. *The Ellsworth American.* https://www.ellsworthamerican.com/featured/after-a-tough-2017-blueberry-growers-face-a-shaky-start/

Hawley, R., Miller, S., Vargas, M & Whitley C. (2014). The state of Maine's islands. *The State of Maine's Environment 2014, Chap.3.* Colby College, Waterville, ME. https://www.colby.edu/stateofmaine2014/the-state-of-maine-islands/

Homer, W. (1894). *Weatherbeaten* [oil on canvas]. The Portland Museum of Art, Portland, Maine.

Individuals with Disabilities Education Administration (2013). Part C and part B data display; Maine 2012-2013. https://www2.ed.gov/fund/data/report/idea/partcspap/2014/me-acc-statedatadisplay-part-c-12-13-2.pdf

Johnson, E. (circa 1877). *The Quiet Hour* [oil on canvas]. The Portland Museum of Art, Portland, Maine.

Käsebier, G. (1913). *The Ryul Family* [platinum print]. The Portland Museum of Art, Portland, Maine.

Kraus,L., Lauer,E., Coleman, R., & Houtenville, A. (2018). *2017 Disability statistics annual report*. Institute on Disability, University of New Hampshire. https://www.eric.ed.gov/?q=source%3A%22Institute+on+Disability%2C+University+of+New+Hampshire%22&ff1=autLauer%2C+E.

Maine Center for Economic Policy (2017, September 18). *State of working Maine 2017 executive summary.* https://www.mecep.org/news/state-of-working-Maine-2018-examines-job-quality-offers-solutions-to-make-good-jobs-the-norm/

Maine Children's Alliance (2019). 2019 Maine Kids Count. Retrieved from https://www.mekids.org/site/assets/files/1241/kidscount_2019.pdf#:~:text=According%20%to%20the%20state%20populations,1%2c000%20ages

Maine Department of Education (2020). *Transportation.* https://www.Maine.gov/doe/schools/transportation

Maine Division of Public Health Statistics (2020, July). *Historical vital statistics data.* https://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/data/documents/pdf/vs-h1r.pdf

Maine Department of Education (2020a). *Chronic absenteeism.* https://www.maine.gov/doe/data-reporting/reporting/warehouse/chronic-absenteeism

Maine Department of Education (2020b). Content (subject) areas. https://www.maine.gov/doe/learning/content

Maine200Bicentennial Commission (2020). Leading the way. https://Maine200.org/all-about-Maine

Maine Historical Society (2000-2010). Maine's history online—Peopling Maine. *Maine Memory.* https://www.mainememory.net/sitebuilder/site/879/page/1290/display?page=5

Market Decisions, Inc. (1989, April). The people of Maine: A study in values. Vol. 1. *The Commission on Maine's Future. https://digitalmaine.com/cgi/viewcontent.cgi?article=1007&context=commission_onmaines_future*

Marvinney, R.G. (2012, September 24). Bedrock geology of Maine. *Maine Geological Survey. https://www.maine.gov/dacf/mgs/explore/bedrock/facts/geol-hist.htm*

McCaskill, G.L.; McWilliams, W.H.; Barnett, C.J.; Butler, B.J.; Hatfield, M.A; Kurtz, C.M.; Morin, R.S.; Moser, Perry, C.H.; & Woodall, C.W. (2011, May). Maine's forests 2008. *Northern Research Station, Forest Service, United States Department of Agriculture.* https://www.nrs.fs.fed.us/fia/data-tools/state-reports/ME/docs/MaineForests2008.pdf

Murphy, A. (2014, March13, 7:45 PM EDT). In Maine, a little French goes a long **way**. *The World.* https://www.pri.org/stories/2014-03-13/us-english-king-surprising-number-people-maine-also-speak-french

My Public Libraries (2010-2021). My Maine public libraries. http://mypubliclibraries.org/library/maine.php

National Aeronautic and Space Administration (NASA) (2018). Watery heat wave cooks the Gulf of Maine. *Earth Observatory.* https//: www.earthobservatory.nasa.gov/images/92734/watery-heatwave-cooks-the-Gulf-of-Maine

National Center for Education Statistics (2018). *Number of instructional days and hours in the school year by state.* https://www.nces.ed.gov/programs/statereform/tab5_14.asp

National Institute of Early Education Research (2019/04). State of preschool yearbook 2018-Maine. https://nieer.org/wp-content/uploads/2019/04/Maine_YB2018R.pdf

National Oceanic and Atmospheric Administration (n.d.) *1981-2010 U.S. Climate Normals, National Center of Environmental Information.* https://www.ncdc.noaa.gov/data-access/land-based-station-data/land-based-datasets/climate-normals/1981-2010-normals-data

Natural Resources Council of Maine (2014, June 15). Potatoes connect Aroostook county to world; climate change threatens what sets it apart. https://www.nrcm.org?potatoes-connect-aroostook-county-to-world-climate-change-threatens-what-sets-it-apart/

Natural Resources Council of Maine (2013). Maps of communities affected by sea level rise in Maine. https://www.nrcm.org/programs/climate/global-warming-air-pollution/sea-level-rise-maine/sea-level-rise-maps/

Netstate (2017, July 27). *Maine state symbols, songs, and emblems*. https://www.netstate.com/states/symb/me_symb.htm

Parrish, W.R. (2015, February 19). *Maine population density by county-U.S. Census 2010. Geospatial Analytics*. https://www.gis520wrparrish.weebly.com

Paul-Anderson, M. (2013). A song for Machigonne. In *Port City Poems: Contemporary Poets Celebrate Portland, Maine*. Ed. M.F. Brown, Maine Poetry Central.

Pelletier, L. (2010, April 8). Trying to revive the Franco identity in Maine. *Bangor Daily News*. *https://bangordailynews.com/2010/04/08/news/trying-to-revive-the-franco-identity-in-maine/*

Pew Research Center (2015, December). Parenting in America. *Social and Demographic Trends*. https://www.pewresearch.org/social-trends/2015/12/17/1-the-american-family-today/

Readdick, C.A. (2014). The Irish geosystem and family well-being. In C. Readdick (ed.), *Irish families and globalization: Conversations about belonging and identity across space and time. Groves Monographs on Marriage and Family, Vol. 3*, pp. 1-20. Michigan Publishing.

Reaves, P. (2015, May 12). The number of Christians in Maine has dropped dramatically since 2007. *Bangor Daily News*. https://bangordailynews.com/2015/05/12/religion/the-number-christians-in-maine-has-dropped-dramatically-since-2007/

Routhier, J.S. (2015). The common good: Collaboration among cultural institutions in Maine. *Maine Policy Review, 24* (1), 105-110. https://digitalcommons.library.umaine.edu/cgi/viewcontent.cgi?article=1685&context=mpr

Stone, N. (1810). *Sample* [silk on linen]. The Portland Museum of Art, Portland, ME.

The Annie E. Casey Foundation (2016). *Maine 2016 Kids Count Profile*. 2016 Kids Count Data Book. https://www.aecf.org/m/databook/2016KC_profiles_ME.pdf

The Annie E. Casey Foundation (2016, June 21). *2016 Kids count data book*: 2016 *state trends in child well-being* https://www.aecf.org/m/resourcedoc/aecf-the2016kidscountdatabook-2016.pdf

The Annie E. Casey Foundation (2017). *2017 Kids count data book: 2017 state trends in child-well-being*. https://www.aecf.org/m/resourcedoc/aecf-2017kidscountdatabook.pdf

The Annie E. Casey Foundation (2017b). *2017 kids count profiles-Maine*. https://www.aecf.org/m/databook/2017KC_profiles_ME.pdf

The Annie E. Casey Foundation (2018, June 27). *2018 Kids Count Data Book: 2018 state trends in child well-being.* *https://www.aecf.org/m/resourcedoc/aecf-2018kidscountdatabook-2018.pdf*

The Commission of Ethical and Responsible Student Behavior (2001). *Taking responsibility: Standards for ethical and responsible behavior in Maine schools and Communities.* Maine Department of Education. https://www.maine.gov/doe/sites/maine.gov.doe/files/bulk/Behavior/TakingResponsibilityStandardsforEthicalandResponsibleBehaviorinMaineSchoolsandCommunities.pdf

Thiede, B.C. & Monnat, S.M. (2016). *The Great Recession and America's Geography of Unemployment, Demographic Research. 35 (891-928).* https://pubmed.ncbi.nlm.nih.gov

UNICEF Office of Research (2014). *Children of the Recession: The impact of the economic crisis on child well-being in rich countries, Innocenti Report Card* 12, UNICEF Office of Research, Florence.

U.S. Bureau of Labor Statistics (2017, May). May 2017 state occupational employment and wage estimates Maine. *Occupational Employment Statistics.* https://www.bls.gov/oes/2017/may/oes_me.htm

U.S. Census Bureau (2011, July 17). Aroostook County Quick Facts, *State & County Quick Facts.* https://web.archive.org/web/20110717153146/http://quickfacts.census.gov/qfd/states/23/23003.html

U.S. Census Bureau (2012, August). 2010 Census of Population and Housing, *Population and Housing Units Counts,* CHP-2-21, Maine. U.S. Government Printing Office, Washington, D.C. https://usa.ipums.org/usa/resources/voliii/pubdocs/2010/CPH-2.%20Population%20and%20Housing%20Unit%20Counts/cph-2-21.pdf

U.S. Census Bureau (2017a). Selected social characteristics in the United States. *American Community Survey.* https://www.census.gov/acs/www/data/data-tables-and-tools/data-profiles/2017/

U.S. Census Bureau (2017b). American Community Survey. https://www.census.gov/acs/www/data/data-tables-and-tools/data-profiles/2017/

Valigra, L. (2018, August 17). What the '94 jobs in 10 years ' forecast says about the future of Maine's economy. *Bangor Daily News.* https://bangordailynews.com/2018/08/07/news/what-the-latest-forecast-says-about-the-future-of-maines-economy

Whittle, P. (2018, September 4). With industry in decline, wild blueberries sing the blues. *The Associated Press News.* https://apnews.com/article/44593fc9120f466a83c527b715fe7c15

Wickenheiser, M. (2012, March 26). Maine most rural state in 2010 as urban centers grow nationwide. *Bangor Daily News.* https://bangordailynews.com/2012/03/26/news/census-maine-most-rural-state-in-2010-as-urban-centers-grow-nationwide/

Williams, H. (circa 1811). *Portrait of the Dearborn Children: Julia Margaretta Dearborn, William Lee Dearborn, and Henry George Raleigh Dearborn* [oil on canvas]. Portland Museum of Art, Portland, Maine.

Wyeth, N.C. (1943). *Dark Harbor Fisherman* [tempura on hardboard]. The Portland Museum of Art, Portland, Maine.

Chapter 2

Labors of Devotion:
Poetry, the Family & Caregiving

*Marcia F. Brown**
Poet Laureate for the City of Portland, ME

In one way or another, marriage and the family have been fertile ground for poets since the beginning of time. There is an old chestnut told by English professors that a teacher asks his students to write a poem about nature, and they write for a while and then put their pencils down. He then instructs them to write a poem about a place they love. They write for a little longer, and again put their pencils down. Finally he directs them: 'Write a poem about your mother'—and the students never stop writing.

Within the great, mysterious story of the human family, whatever its size or composition, there are few elements more important or at times more challenging, than how we care for, and are cared for by members of our families. We are all born into that give and take—we *will* receive and give care to one another, whether we consciously choose to or not. To be born, to survive as infants, to grow up, someone must care for us. If we become parents, aunts, uncles, grandparents, or extended family, we are immediately handed an honorary life sentence of caregiving. Recall the old adage for parents: *You can only be as happy as your unhappiest child*. However fraught our family ties can at times become, they are invisible bonds that tell each of us who we are, connections that keep us tethered to our unique identities. Throughout the course of our lives, as things

---

* Correspondence concerning this article should be addressed to: Marcia F. Brown; Poet Laureate for the City of Portland, ME, 2013-2015; marciafbrown@aol.com

change—someone gets ill or becomes disabled, someone develops dementia—we discover that with no training for the job, we have suddenly become caregivers. Perhaps we become care receivers. Caring is always in play. So being in caring relationships with family members is not a bond any of us can escape or should wish to. It is how we survive.

For those of us who write, read, and are sustained by poetry, many of the poems we cherish most spring from poets struggling to express to some unseen reader—to the world at large—the love and anguish of being part of a family unit, and caring deeply about those family members and how we travel through life with them. One of the great poems in the canon of twentieth century poetry was written by the native Chicagoan, Robert Hayden. It is a poem of a grown man reflecting on his childhood of Sunday mornings, waking in a cold house as his work-weary father labors to ready the family for church. Here in its brief, breathtaking entirety is his masterpiece, *Those Winter Sundays*:

> Sundays too my father got up early
> and put his clothes on in the blueblack cold,
> then with cracked hands that ached
> from labor in the weekday weather made
> banked fires blaze. No one ever thanked him.
>
> I'd wake and hear the cold splintering, breaking.
> When the rooms were warm, he'd call,
> and slowly I would rise and dress,
> fearing the chronic angers of that house,
>
> Speaking indifferently to him,
> who had driven out the cold
> and polished my good shoes as well.
> What did I know, what did I know
> of love's austere and lonely offices? [1]

Much has been made of the poem's exquisite craft—the countless internal and slant rhymes that in a mere fourteen lines, cohere it in such harmonious compression. It is perhaps Hayden's plaintive final couplet of the poem that most deeply etches itself in our collective memory: the musical repetition of his rhetorical question, *What did I know. What did I know…*; the haunting sonics of *love's austere and lonely offices;* the poignant word pairing of *austere and lonely*; and the elegant use of "offices" meaning obligations, or responsibilities. The lines are moving and masterful. But Hayden's considerable skill as a wordsmith is only the means by which he conveys his story, the vehicle he has built strong enough to bear the emotional weight of his reflections. Here is the adult voice of the long ago child, understanding only years later, the extraordinary tariffs of parental devotion. We feel the house's morning cold, the pain of cracked, stiff fingers building the fire, the sense of pride that calls a worn-down father to polish his son's Sunday shoes, the grown son's rueful regret for thanks unspoken. It is a poem of caring on two levels, by two generations. And when we as readers are drawn in to care about this family, we add still another dimension. The best poetry works in this way. When the poem cares, we, entering it, care too.

Many years ago when I was a college student studying abroad and enrolled in a poetry writing class, the first poem I recall writing was about my family. Specifically, it was about my late grandfather, a retired mill manager with a gift for cultivating roses. I wrote it after a visit to Kew Gardens outside London where the smell of a rose in those famous gardens was enough to pull me back across years and an ocean to his small backyard in Maine. I do not have a copy of the poem, but I do recall some lines from it: *"Where the old man blunts his short cigar, and standing, / takes his clippers from the shelf…"* and: *"Old man, old man, fumbling slow with pale coat sweater buttons…"* What strikes me now about this assignment and my fledgling effort was the primacy of that instinct to write about my family. Three thousand miles from home and asked for the first time to create a poem, I chose not to write about the new sights, new experiences, or the new friends surrounding me, but to write with specificity and detail about the safety and consolation of a summer morning at my grandparents' home. Poets often speak of "emotional veracity" in poems—that is: truth to feelings, not to facts. Nowhere are we on more reliably truthful ground, for better or worse, than in the context of our families. We *know* those emotional truths first hand. I think that standing on the unsteady ground of an entirely new environment all those years ago, I subconsciously sought out familiar emotional territory for my poem--a place where I was secure in writing about my feelings of familial devotion, loss, and a little homesickness.

In 2017 the prestigious Moth Magazine Ballymaloe International Poetry Prize of Ireland was awarded to Maine poet Lee Sharkey for her poem, "Letter to Al" in which she shares the daily emotional journey of her husband's living with Alzheimer's disease. The extraordinary poem travels between the present and the past but explicitly, not to the future. In the poetic conversation of caregiving, when the stakes are so high, there can be only the shared past and the precious present. Sharkey has said that she was hesitant about sharing the poem publicly out of respect for her husband and his illness. But they decided to do so, hoping it would speak to others caring for family members with memory impairment and, as poetry is uniquely able to do, help them feel less alone. Here (excerpts mine) are just a few of the lines I find most poignant from Lee Sharkey's powerful poem, *Letter to Al:*

…a reluctant knowledge
that to do *for* you is to do *to* you...

- a penny/for your thoughts, but you do not speak them. Only
when you draw your bow/across the cello strings do I hear the one
who made my fierce heart/tremble. ..

In whose hands we place ourselves in medicated dreaming,
the voices calling each other's names: *Wake! Emergency!*
I fumbling to you. You fumbling to me. *What can I do? Just stay*
with me. Till the end of shadows. Till the end of end.

To live a routine of catastrophe. Each day radically undetermined.
Will tomorrow be Sunday or Tuesday? Will the heart hold for one
more hour?

It is enough some hours simply to be together, within our walls
among our familiar objects - *refrigerator, toaster, pencil, stepladder,*
jacket, glove - or walking hand in hand. We rest when we're tired.
We eat when we're hungry.

You fill your pillbox, watch Space X rockets land on water.
A hand held, a kiss soft on the lips - there is no future to speak of. [2]

What radiates brilliantly from this poem is not the overriding worry and fear of the disease's progression, though that is certainly the poem's unspoken tension, but the poet's clear voice of commitment, her unflagging devotion to her beloved. We feel that through the process of writing the poem, she is learning anew to honor the familiar comforts of marriage—the household refrigerator, toaster, jackets and gloves. Physical closeness and the elemental acts of sleeping and eating, of being together, walking hand in hand, become gifts again, as they may have been in courtship. Just as anyone who is deeply committed to the poetry life will tell you that it is a labor of devotion—scant fame and scanter fortunes are to be gleaned from the study and creation of poetry—so familial caregiving at its purest and most loving, is a labor of devotion. We give care because it is an intrinsic part of ourselves, of our devotion to our loved ones. Like the need to create poetry, caregiving is not an option we *choose*, but the spontaneous expression of who we are. We write poems about how we live and love within our family units because these are the most emotionally profound experiences we can have and we are moved to express our feelings about them. And despite the demands and hardships such labors of devotion may place on us, poetry can reveal deeper revelations and that there are rich rewards not only for those being cared for, but also for the caregiver.

Portland, Maine's current Poet Laureate, Linda Aldrich, has written movingly of caring for both her late parents through illness and old age. In her poem "Cameo", an adult daughter goes to visit her aged father in her childhood home where her father now lives alone. In her pocket she is fingering a cameo broach carved from a cassis shell, a keepsake left to her by her mother:

> … I rub it nervously whenever I have to
> visit the crumbling house of my father, who doesn't look up
> today because he doesn't hear my key in the lock, sitting calmly
> over his lunch soup, the kitchen filled with smoke, the forgotten
> pot on the stove framing his small head in orange flames?
>
> How likely is it I am here to see death's net
> thrown over him, to feel the growing pressure of letters carving
> into epitaph, to know he's become so light, I could pick him up
> and hold him to my ear to hear the hollow sound of leaving? [3]

Any grown child who has observed evidence of his or her parent's decline, knows too the desire to deny that decline, or at least postpone confronting it—to hope against hope, they are not a danger to themselves or others. In "Cameo" the danger is present—the soup is burning on the stove. How many other times when she is not there, does this happen? The daughter enters this scene of worry, carrying a memento of her late mother—almost willing her mother to somehow share the burden, to tell the daughter how to care for her father. I am particularly struck here by the choice of the word "small" to describe the father's head—a description more usually ascribed to infants. The parent/child relationship is becoming reversed. The father has become seashell-light as the cassis shell from which the cameo was carved. She could imagine picking him up and in her beautiful closing line, holding him to her ear "to hear the hollow sound of leaving."

As with Lee Sharkey's poem of marital caregiving, Aldrich evokes both the very real, physical world of caring for an aged or impaired family member, and its deep emotional resonances. As readers, we sense that the daughter will return to "the crumbling house" as long as her father is there. Unspoken is the inevitability that as family members, we *will* care for one another. The daughter's caring feels instinctive and comes not just from a sense of duty, but love. It accepts that family is in it for the long haul, whatever it takes. "Cameo" quietly offers up that when we are called to it, caretaking will be a lighter assignment if we are in loving relationships with those who now need us.

One of the most demanding roles as caregiver may belong to those who care for family members with special needs. This is not the late in life assignment that falls to grown children, or the constant care required of parents during a child's early and formative years. These are lifelong assignments that have no sunset date. Poet Dennis Camire observes such a relationship in his marvelous poem "Ode to Teenagers' Hairdos in June." The poem opens in what seems to be a public park where the speaker observes the colorful hairdos on teenagers hanging out by the gazebo:

> Today the teens' bouqueting face
> from the gazebo'd railed vase
> have hair shaped into flowers…
>
> … as this girl's blue-highlighted curls
> turn her into a psychedelic tulip
> and this boy's orange and black-dyed spikes
> morph him into the world's tallest marigold…
>
> Nearby a mother and son also look out on the scene:
> Even the mother with
> Down Syndrome child in tow
> slows to marvel
> at this Garden of Eden of Teens
> before sitting by the ocean's magic carpet
> where she thinks her hair, soon,
>
> will be a strange off-gray or blue,
> as she still cares for the son
> who'll never color his hair green
> though, in his fifties, likely
> still seduce her into this world's strange beauty
>
> the way he always blossoms
> that same smile to each unexplained glory

which maybe, she now realizes,
is the only flower any mother could desire
growing over her grave

under the iris blue sky
that too, on our best day,
often feels like the perfect hairdo
though held in place
and fine-tooth-combed by crows… [4]

I love this poem not only for the originality of its subject, but for the unexpected leap into the consciousness of the mother of the boy with Down Syndrome. Through metaphors of flowers and hair—traditional symbols of beauty—the poet takes us into the world of the mother which is one of caregiving that knows no end and must find its own beauty and redemption. While her son will never be able to live like his hair-do-experimenting peers, the poet suggests, the boy's habitual smile at "each unexplained glory" in the world around him, will always be able to "seduce her into this world's strange beauty." It is his way of blossoming and the only reward she will ever know for her motherly devotions. In the poem, that reward is enough: "the only flower any mother could desire."

In his book, *How to Read a Poem and Fall in Love With Poetry*, poet Edward Hirsch suggests that reading poetry is "an act of reciprocity" and "a particular kind of exchange between two people who are not physically present to one another."[5] I believe that one of the great mysteries of poetry is this unique and sacred communion that occurs between a reader and a poem—a relationship that is completely (and happily) independent and out of the hands of the poet. I discovered this first hand when a poem I had written called "Morning Song" was read by Garrison Keillor in National Public Radio's Writers Almanac. For reasons I did not myself understand, the poem connected with a wide range of listeners and was reproduced and shared by members of diverse religious, medical, clinical, and arts communities in publications and on websites. It was read aloud in synagogues and churches. It was annotated in at least one medical journal. The poem speaks of caring for "all things frail and imperiled"—from small birds to the terminally ill. It speaks of the ordinary-extraordinary daily routines of caring such as making coffee and setting out breakfast plates, for our loved ones. I do not know exactly how the poem came to me, or how it came to be written in the form it finally took. I believe it is what poets call "a gift poem," that is, one of those rare poems that seems to find its direction effortlessly, after the hundreds of poems that we have struggled over. I do know that it found communion with readers and listeners beyond any scope I could imagine, and I have been grateful for that. Each of those people who contacted me, and I presume, others unknown to me who saw or heard the poem, found their own meaning and consolations in it, based on their own life experience with family, with caregiving, love and loss. I hope that you, reading it here, will also find communion with "Morning Song."

Morning Song

Here, I place
a blue glazed cup
where the wood
is slightly whitened.
Here, I lay down
two bright spoons,
our breakfast saucers, napkins
white and smooth as milk.

I am stirring at the sink,
I am stirring
the amount of dew
you can gather in two hands,
folding it into the fragile
quiet of the house.

Before the eggs,
before the coffee
heaving like a warm cat,
I step out to the feeder –
one foot, then the other,
alive on wet blades.
Air lifts my gown – I might fly –

This thistle seed I pour
is for the tiny birds.
This ritual,
for all things frail
and imperiled.
Wings surround me, frothing
the air. I am struck
by what becomes holy.

A woman
who lost her teenage child
to an illness without mercy,
said that at the end, her daughter
sat up in her hospital bed
and asked:
What should I do?
What should I do?

Into a white enamel bath
I lower four brown eggs,
You fill the door frame,
warm and rumpled, kiss
the crown of my head.
I know how the topmost leaves
of dusty trees
feel at the advent
of the monsoon rains.

I carry the woman with the lost child
in my pocket, where she murmurs
her love song without end:
Just this, each day:
Bear yourself up on small wings
to receive what is given.
Feed one another
with such tenderness,
it could almost be an answer.

--- Marcia F. Brown [6]

References

[1] "Those Winter Sundays" by Robert Hayden. Copyright © 1966 by Robert Hayden, from *Collected Poems of Robert Hayden,* edited by Frederick Glaysher. Liveright Publishing Corporation.

Hayden, R. (1966). Those winter Sundays. In F. Glaysher (Ed.), *Collected Poems of Robert Hayden.* Liveright Publishing.

[2] Excerpted from "Letter to Al" by Lee Sharkey. Copyright Lee Sharkey. Winner of the the Moth Magazine (Ballymaloe) International Poetry Prize, Ireland 2017. Used by permission of the author.

Sharkey, L. (2017). *Letter to Al.* Winner of the the Moth Magazine (Ballymaloe) International Poetry Prize, Ireland 2017. Used by permission of the author.

[3] Excerpted from “Cameo” by Linda Aldrich. Copyright Linda Aldrich. Published *Portland Press Herald* 2018. Used by permission of the author.

Aldrich, L. (2018). Cameo.

[4] Excerpted from “Ode to Teenagers’ Hairdos in June” by Dennis Camire. Copyright Dennis Camire from *Combed by Crows* by Dennis Camire, copyright 2017, Deerbrook Editions, ME. Used by permission of the author.

[5] Hirsch, Edward. *How to Read a Poem and Fall in Love With Poetry*. Harvest-Harcourt. New York: 1999.

[6] “Morning Song” by Marcia F. Brown. Copyright Marcia F. Brown. From *What On Earth, Poems by Marcia F. Brown*. Moon Pie Press. Westbrook, ME: 2010. Reprinted by permission of the author.

Chapter 3

Dignity, Duty, and Dependence: Feminist Perspectives on Caregiving in a Neoliberal Climate

Tessa le Roux
Lasell College

Opening Plenary

Good morning fellow-Groves members and Groves friends! Today I will define care very broadly. Who in the audience does not consider themselves a carer? Just by virtue of being here I assume that you all have some caring involvement! Yet the year 2018 will probably go down in the history of our country as the year in which close to 700 children of asylum-seekers to the US were separated from their parents and scores held indefinitely – certainly not an image of a caring society.

Let me be clear: When we talk about caregiving, we are not talking about an obscure issue but about a relationship that is at the core of our existence. In a neoliberal era where Ayn Rand is a favorite author of the President of the US (Reich, 2018), and where policies are designed on the principle of little or preferably no government involvement, we have to be very deliberate in countering the marginalization of human relationships across generations, where caregiving is belittled as private (and women's) stuff.

Allow me to share just a few statistics to underline how pervasive the need for care in our society is:

* Correspondence concerning this article should be addressed to: Tessa le Roux,D. Litt. et Phil., Professor, Lasell College; TLEROUX@lasell.edu

- Most young children in the U.S. have parents who work outside the home. Both parents work in 56 percent of married families with children under six. For single mothers raising a young child the employment rate is 65 percent. It is 83 percent for single fathers who are the custodial parent. Childcare is a necessity for these families, which in aggregate constitute 60 percent of families with young children (Whitehurst, 2017).
- About 1 in 6 children in the United States have a developmental disability, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism. According to the Centers for Disease Control (CDC, 2018) one in 59 children has been identified with autism spectrum disorder.
- Every year in the US around 655,000 people survive strokes (CDC, 2018).
- The population 65 years and older in the US is rapidly increasing, "Older people are growing in number and also as a percentage of the population" (Hill, 2015, viii). Over 75% of all help to elderly is given by family and friends (Levine, Halper, Peist & Gould, 2010, cited in Hill, 2015). As we know, so-called "entitlements" are currently under threat so this percentage is likely to increase.
- Around 2.4 million grandparents are raising grandchildren – one fifth of these have incomes below the poverty line. Since 2009 this number has risen by 7 percent (US Census Bureau, 2014). Addiction, mental illness and incarceration of parents play no small role in this.

As far as paid care work is concerned, it is estimated that 24 percent of all employment in the US is in the care industries and that 15 percent of all workers are nurturant care workers. This number has grown sixfold between 1950 and 2007, far outpacing the expansion of the labor market. Home health care and home care are the industries with the first and second-fastest rate of employment growth in the US and long-term care employment in nursing homes and private residences, currently about 3 percent of the total labor force, is expected to account for 10 percent of all new jobs between 2010 and 2020 (Folbre & Nelson, 2012). These are not jobs that generate capital and are largely ignored in the rush to "create jobs" (and ironically these are also not jobs that can be outsourced either).

But I don't have to convince this audience of how important it is to talk about caregiving! Allow me, instead, to share my story with you.

My husband Johann has a PhD in Chemical Engineering, he also holds a law degree and is qualified as a patent attorney. On September 8 of 2002 we were rock-climbing in Franconia Notch in New Hampshire when he fell about 40 feet. He was taken by helicopter to Dartmouth Hitchcock hospital. In that most beautiful of hospitals he underwent emergency surgery for a traumatic brain injury, and gradually emerged from his coma. This was the beginning of my long, complicated journey as a caregiver. The injuries left him with anomic aphasia so that he has great difficulty communicating, he is unable to read or write, and has significant cognitive disabilities including limited short-term memory.

As we at Groves start our three-day journey talking about caregiving across generations I want to share with you some of the trail maps I have been exploring on the academic part of my own journey. I do not have the definitive GPS, but want to offer the signposts along the way that I have found useful.

My caregiving identity has been shaped by my other identities—including my academic identity as a sociologist, and, importantly, my identity as a feminist—hence my talk today. I believe it is important for us to not lose sight of the forest for the trees as we examine caregiving. Of course, we have to stop to examine the nourishment that fortifies us for the journey, like support groups, or religious beliefs and practices, the importance of not traveling alone, but with a family or other primary group, the signposts (or policies) that determine the route, and the boulders of exploitation that make the journey so difficult for many. But as environmentalists keep reminding us, everything is interconnected. What kind of trail are we making? How can we avoid slash and burn and preserve the integrity of the forest? In order to answer these questions, we have to understand what kind of forest we are in. In this talk I want to propose a feminist view of the forest—or a feminist worldview.

Feminist epistemology demands that the researcher or theorist is firmly located in the activities of her research. As Stanley (1990) put it, "the known are also knowers, research objects are their own subjects, objectivity is a set of intellectual practices for separating people from the knowledge of their own subjectivity" (pp. 10-11). Feminists reject the positivist epistemology with an emphasis on objectivity. It is the very assumption that an objectivity can be achieved that privileges a certain way of conducting research—a split between the knower and the known. Other ways of learning and knowing may rely upon or conjure networks of relationship, community knowledges, and subjective experiences. Scientific "neutrality" and "objectivity" serve to mystify the inherently ideological nature of research in human sciences and legitimate privilege based on class, race, gender, sexuality and more. We have to guard against what Dorothy Smith called an androcentric approach to sociology that privileges a white, middle-class, and heterosexual point of view (Hesse-Bieber, 2014, p. 19).

In light of these assumptions it is important that I position myself. So, let tell you about a particular trail on my journey and share with you how my experience was shaped by some feminist insights. This trail is titled "dignity".

In the days and months following the accident, I kept hearing about dignity. For example:

- "Tessa, you are dealing with all of this with such dignity".
- "In order to protect the dignity and privacy of the family, we will no longer send e-mail updates to the community".
- And when about six months into "life after" I kind of complained about the stresses of my life, a colleague said, "Oh, Tessa, don't lose your dignity".

Because I was not only a caregiver but also an academic, and because I was involved in creating a minor in human rights at our campus, the word dignity, which lies at the core of the concept of human rights, resonated with me.

It seemed important to read more about this elusive concept. Even though I discovered that one can get quite lost in the philosophical world, teasing out all the different possible dimensions of dignity, to my not so deeply trained in philosophy mind, the different but related uses of the concept provide a useful framework for looking at caregiving through different feminist lenses.

My journey therefore took me through some of the literature on dignity – in philosophy, medical ethics and the allied health professions and finally the world of caregiving. It became clear to me that the different meanings attached to the concept dignity, especially as applied to caregiving, broadly correspond to different feminist perspectives. Of course, I am taking some liberties with these connections, but I think they provide an interesting framework for discussing the different questions different feminists ask. The four uses of the concept dignity that I will discuss are Dignity as Worth, Dignity as Autonomy, Dignity as Meaning, and Dignity as Equality.

Dignity as Worth

The word dignity comes to us from Latin comes from Latin *dignitas* (worthiness) by way of French *dignité* (Oxford Living Dictionaries). Its contemporary application in morality, ethics, law and politics has its roots in the enlightenment, based on the idea of the inherent, alienable rights of the individual – we ALL have dignity (or worth) by virtue of being human – not because of any specific attributes.

This same humanistic enlightenment brought us liberal feminism, where the attribute of being female should not limit our options. This is a feminism which focuses on equal opportunities. The arguments of liberal feminists are that women have the same capabilities as men and should be allowed the same opportunities including political rights, participation in the public life and work or paid employment without discrimination based on gender. In practice, however, liberal feminism focuses mainly on the ability of women to participate in the (traditionally male) role of work and public life.

I want to highlight two issues with the liberal feminist approach to dignity and care. The first is the work-home split which affects mainly unpaid care work and the second relates to the devaluation of care when it does become a commodity. First: the issue of work-home (or private-public). Liberal feminists ask: How do we balance work-life? Lean-in, says Sheryl Sandberg (2013). Leaning in requires that women demand and transform their workplace to be more flexible and accommodating—this way they can achieve success in a career while juggling family responsibilities (caregiving). But ultimately the goal is that women be able to “do it all”.

One critic calls it a "self-help movement, which accepts our turbo-capitalist, what's-in-it-for-me world as a given and offers us a roadmap to navigate it all by our lonesome self" (Olin, 2018, para. 6). My main concern with this solution is that it does not really shift the paradigm. It simply provides a map for how women can be successful in the (male) marketplace and it does not elevate the status of care.

This brings us to the second issue, namely the commodification of care: Managing work-life for women often means paying someone else to do the "life" part of the work, that is, the caring. Hence caregiving becomes commodified and brought into the market.

But note, caregiving work is regarded as unskilled work (any woman can do it!) and it is therefore devalued. Those who enter the low-paid care market are, as happens in the capitalist market economy, the most marginalized poor women, often women of color and immigrants. No surprise that the wage gap between women and men disproportionately affects the care sector (Dodson & Dickert, 2004).

The paid care world functions according to the rules of the rational bureaucratic, market-driven society where outcomes have to be quantified. Intimacy and emotional work cannot be quantified and furthermore, it is no secret that care workers are underpaid and overworked. Power over the caring process becomes concentrated in the hands of (mostly male) policymakers with higher earning power (Fisher & Tronto, 1990). In practice politics is driven by numbers (mainly of dollars) - it is not about client needs but the political process. The way agencies work is shaped by the demands of funders, and they have to comply in order to survive.

In addition, Dodson and Dickert (2004) found that the family labor of children (mostly girls) is a critical source of support in cases of low wages and absent adult caregivers – they end up taking over essential, complex and time-consuming family demands. The result is an intergenerational transfer of poverty. Middle class teenagers are paid for babysitting but not those in low-income families. The result is what they call "lost opportunities" for girls – educationally, extra-curricular and life course.

In short, in the neoliberal market power is taken away from both carer and caregiver. Ironically, in Stacey's research (2015) with low-paid care workers, she finds that the practical autonomy experienced by the workers helps mediate constraints of poor pay, job insecurity and the emotional and physical strain that accompany paid care work. This leads us to a focus on autonomy.

Dignity as Autonomy

In ethics of health care and in the applied health sciences, the concept of dignity is very closely tied to the concept of autonomy. Much of the literature in especially the health sciences is based on this view of dignity.

- Death with dignity gives the individual power to decide about their time of death.
- Maximum independence is the goal in care.
- Accessibility and community-engagement are intended to provide a sense of autonomy.

I want to emphasize that there is much to be lauded about a focus on independence and autonomy. But in a neoliberal climate where our economic and social policies are informed by minimum government involvement and maximum self-reliance, where work becomes a prerequisite for health care or welfare support, we have to be cautious of the ways in which the focus on individual strengths can be co-opted by a market-driven system. Autonomy can easily translate into "making a valuable contribution to society", which is often shorthand for "not be a financial burden."

All too often, the notes made by professionals during my husband's many years of rehabilitation included the following comment, "Good family support". And while this was intended to suggest potentially better outcomes – a strength – it also meant fewer services, the assumption that there is a family who will do what needs to be done.

My own journey through the literature on dignity brought me via the world of the Stoics—those early Greeks who taught the development of self-control and fortitude. Today a stoic is described as "a person who can endure pain or hardship without showing their feelings or complaining" (Oxford Living Dictionaries)—someone who can be in harmony with a world over which they have no control. (Do you remember the Marxist idea of a false consciousness?) The stoic model brought back memories of the person who chastised me for sharing my frustrations with the caregiver role that was thrust upon me – clearly the expectation was that I would keep a "stiff upper lip".

So, had "dignity" become code for "accept things as they are"? Did I start believing the many people who told me (and still do), "Tessa, you are a saint". Which other practices designed to recognize agency, to dispel the notion that we are just puppets, have been coopted by a neoliberal ideology?

Feminists are the first ones to emphasize that individuals have agency, and that we need to recognize the knowledge and skills of non-experts – but our good intentions can easily be exploited by an ideology that emphasizes individual self-reliance over state care. Consider a strength-based approach in development which, some critics argue, focus more on the responsibility of the individual and less on challenging the system (Gray, 2011).

- And what about resiliency in human services? Joseph (2016) argues that the emphasis on individual preparedness, making informed decisions, understanding our roles and responsibilities, and showing adaptability to our situation and being able to 'bounce back' should things go wrong fit with neoliberal approaches that put emphasis on the responsibility of the individual to govern themselves in appropriate ways.
- Reveley (2016) calls mindfulness a kind of "neoliberal self-technology".
- And finally, positive psychology wants us to be happy.

This brings us to our next dimension of dignity:

Dignity as Meaning

Whereas dignity as autonomy focuses on the individual, Dignity as Meaning recognizes that dignity lies in how we are perceived by others and how we perceive ourselves, and that this is an active process created through interaction. This approach is in direct contrast to the neo liberal approach – as Shafi (2014) puts it, "the autonomous liberal subject versus humans as embodied and vulnerable" (p. 149).

Unlike the previous two approaches to dignity (and care) which focus on the individual caregiver or person cared for, we are reminded of the relational model of psychologist Gilligan which puts care at the center. The ideal is a society that recognizes the caring relationship as a fundamental human condition. This challenges the way in which caring has become socially devalued and regarded as a burden that needs to be dealt with in a stoic way. Instead, care is a humanizing activity because our humanity is rooted in our relationships with others. This view of caring sees it as a positive dimension in our lives that has been socially devalued by the capitalist and/or patriarchal order and it is deeply implicated in the sex/gender system.

In this vein Galvin and Todres (2015) use a phenomenological approach. For them dignity exists both 'out there' as relational situation and also 'in here' as experience. It is affirmation of something valuable in oneself or another – self-valuing and valuing others. They furthermore emphasize the fact that value and vulnerability are two sides of the same coin. They use the concept of honor-wound where wound is a metaphor for *frailty, unprotected, exposed, limited, susceptible,* and honor is a metaphor for *uprightness, worth, value, stature, recognition*.

Duffy et al., (2015) suggest the concept of a "human infrastructure"—as opposed to the physical infrastructure—that addresses a range of care needs of American families and that is important to support our economic, social and civil lives. They propose that this be seen as a collective responsibility and societal contribution. They argue we have to look at care of children and youth and that care of all dependent groups is not only an economic necessity but an ethical imperative.

Political scientist Joan Tronto has for years been building on Gilligan's work (e.g., Tronto, 1993) and I urge you to read her latest book *Caring Democracy* (2013) in which she argues that we need to rethink American democracy, as well as our fundamental values and commitments, from a caring perspective. What it means to be a citizen is to be someone who takes up the challenge: how should we best allocate care responsibilities in society? She makes a compelling argument for the need to make care, not economics, the central concern of democratic political life.

The idea of democracy of course brings us to the idea of equality. This brings us to the final way of seeing dignity, namely Dignity as Equality.

Dignity as Equality

In ancient times the Greeks saw dignity as tied to high status. Over time there was a shift so early Christianity, for example, argued that all human beings reflect the dignity of God and Kant's view of the inherent dignity of all was certainly a leveling of the playing field, which culminated in the International Declaration of Human Rights based on the idea of the inherent dignity of all (Rosen, 2012).

Yet the notion of dignity and social status are still intertwined in our thinking. Think about social expectations for interacting with those of higher social status: they demand to be treated with "dignity" which really means not stepping out of place, maintaining some level of formality in interaction, keeping the focus on the social position rather than the individual characteristics of the person.

In the tradition of Marx and Foucault we have to recognize that our society is one of systematic oppression, or structural violence. Individuals and groups of individuals are caught up in a hegemonic system. This reality leads me to an examination of inequality from a feminist point of view.

Let's start with informal care: Socialist feminists have long argued that women's unpaid domestic work, including caregiving work, directly benefits the state. Thus, both the receivers and givers of care are marginalized–none are recognized as productive members of society. The fact that much caregiving happens in the isolation of home leads to further marginalization. And because we have an inadequate welfare program in our country caregiving is driven into the informal economy.

As for paid caregiving, did you know that the home care industry is much larger than that of the iconic auto and steel industries? (Boris & Klein, 2012). Furthermore, as I suggested before, paid care reproduces inequalities among groups of women. First, those cared for are often marginalized and vulnerable, with limited funds – many rely on so-called entitlements like Medicare and Medicaid, which are currently under threat. Secondly, we talk about paid care work, it is no secret that wage inequalities affect different groups in different ways. In addition, we have to bear in mind that home care aids are predominantly Latin American, Chinese, Vietnamese, Hmong, Eastern European, African and Caribbean (Boris & Klein, 2012).

In fact inequalities based on gender, race, ethnicity, citizenship, disability, and class are most noticeable in this arena. In talking about care we should never lose sight of in Patricia Collins' words the *matrix of domination* (1990) where oppressions interact to reproduce structures of power, domination, and privilege. And I am not proposing the gentrified, sanitized version of intersectional feminism but rather intersectionality as Crenshaw (1991) intended it—something that is deeply political.

We also have to talk about inequality within the bureaucracy of paid care: Decisions are made by "experts" in a patriarchal bureaucratic system so that caregivers at the lower echelons of the system as well as those being cared for have little say in institutional priorities. Those with most power are the upwardly mobile professionals who claim a body of scientific knowledge (and supervisory roles)—those with more "expertise" take care of "medical decisions", whereas those on lower levels take care of the emotional and every day needs of people cared for. Demands of the marketplace triumph and those of you in the field will know that often it is not client needs but the political process or demands of funders that help shape an agencies purpose and need for self-perpetuation. Bureaucratic caring grows out of a political process that precludes control by care-receivers, so that bureaucratic caring is fragmented and inadequate.

Looking at caregiving from this perspective demands that we take the social historical context into account. We cannot simply talk about caregivers as if this is a single, monolithic category of people. In fact, we can only agree with Boris and Klein (2012) when they state, about home care workers, "their lives tell us much more about the shifting relations between home and market, state and family. Their fate links together some of our most challenging social issues: an aging society and an inadequate national long-term care policy, the rise of a medical-industrial complex, the neoliberal restructuring of public services, the need for disability rights, the crisis of domestic labor and the decline of family income, new immigration and systemic racial inequality, the expansion of the service economy and the precariousness of the American labor movement" (p. 6). So where does this leave us? How can we claim **Dignity as Care**?

I want to conclude by suggesting the following path, which incorporates lessons from all of the road maps I have outlined so far.

1. We cannot ignore the reality that we find ourselves in a neoliberal climate. I suggest we be subversive and work toward shaping this climate to be as supportive of the reality of care as a basic human endeavor as possible. Can we seize the "Me Too" moment, understanding that exploitation of women and the vulnerable reaches beyond sexual exploitation? Let's promote the idea that care is moral imperative. Let's loudly and publicly support people like Senator Tammy Duckworth who brought her infant to the senate floor, or the State Representative in Iowa who brings her infant to work with her daily. Let's bring about a shift from the idea that "maternity" leave is a privilege to a place where "Parental leave" is a given. Let's push to make sure care work is recognized as important "work" and find ways to monetize tasks in order to give it greater weight and social legitimacy. Can we somehow capitalize on the idea of care as a "public good", as economists frame it? *In other words, let's "play the system". But instead of "leaning in" let's occupy.*
2. At the same time, let's put our efforts toward developing a new "social contract" that truly values care and vulnerability, not only care of our own, but care for and care of our fellow human beings. And let's be sure to recognize the conceptual difference between working for a reward, where the focus is on the autonomous liberal subject, but instead shift prioritizing humans as embodied and vulnerable. Let's ensure that this is part of the public debate–also as we enter another election period.
3. Let's not lose sight of the social context and the intersection of oppressions–so finally let's learn from modern social movements which recognize that all social justice issues are interrelated. A social justice focus on caregivers should attend to racism, classism, religious oppression, sexism, heterosexism, transgender oppression, ableism, and ageism.
4. I want to re-introduce a proposal from a long time ago–during

the Detroit conference Connie Steele, Susan Wolfgram and I presented a motion that Groves, at the conclusion of our conferences, do a press release with a position statement–I can't remember whether Groves ever voted on this or not–but today I would like to again challenge Groves to prove itself at the cutting edge. Let's, as we discuss different aspects of caregiving over the next few days, consider concluding our meetings with a position statement about the importance of caregiving as a fundamental human endeavor that could at the very least be on our website. You are all experts–so at this point, rather than "take questions" I would like to open the floor for discussion, for the opportunity for you to share your experiences and maybe offer your thoughts on how we can advance the Caring Society.

References

Boris, E. & Klein, J. (2012). *Caring for America. Home health workers in the shadow of the welfare state.* Oxford University Press.

Centers for Disease Control and Prevention. (2011). *Key Findings: Trends in the prevalence of developmental disabilities in U.S. children, 1997–2008.* Retrieved from https://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html

Centers for Disease Control and Prevention. (2018). *CDC's autism and developmental disabilities monitoring (ADDM) network. (2018). Understanding autism spectrum disorder and other developmental disabilities.* Retrieved from https://www.cdc.gov/ncbddd/autism/documents/ADDM-Fact-Sheet-comp508.pdf

Centers for Disease Control and Prevention. (2018). *Stroke.* Retrieved from https://www.cdc.gov/stroke/

Collins, P. H. (1990). *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*. Unwin Hyman.

Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review 43*(6), 1241-1299.

Dodson, L. & Dickert, J. 2004. Girls' family labor in low-income households: A decade of qualitative research. *Journal of Marriage and Family, 66*(2), 318-332.

Duffy, M., Armenia, A., Stacey, C. L. (Eds.). (2015). *Caring on the clock. The complexities and contradictions of paid care work*. Rutgers University Press.

Folbre, N. & Nelson, J. A. (2000). For love or money—or both? *Journal of Economic Perspectives*, *14*(4), 123-140.

Galvin, K. & Todres, L. (2015). Dignity as honour-wound: An experiential and relational view. *Journal of Evaluation in Clinical Practice*, *21*, 410-418.

Gilligan, C. (2016). *In a different voice*. Harvard University Press.

Gray, M. (2011). Back to basics: A critique of the strengths perspective in social work. *Families in Society: The Journal of Contemporary Human Services, 92*(1), 5-11. Retrieved from https://www.researchgate.net/publication/274821656_Back_to_Basics_A_Critique_of_the_Strengths_Perspective_in_Social_Work

Hesse-Biber, S. N. (Ed.). (2014). *Feminist research practice. A Primer*. Sage.

Hill, T. J. (2015). *Family caregiving in aging populations*. Palgrave Macmillan.

Joseph, J. (2013). Resilience as embedded neoliberalism: A governmentality approach. *International Policies, Practices and Discourses, 1*, 38-52. Retrieved from https://www.tandfonline.com/doi/full/10.1080/21693293.2013.765741?src=recsys&mobileUi=0&

Olin, H. (2018). 5 years later, 'lean in' seems like a relic from another time. *The Nation,* March 21, 2018. Retrieved from https://www.thenation.com/article/five-years-later-lean-in-seems-like-a-relic-from-another-time/

Oxford Living Dictionaries. n.d. Retrieved from https://en.oxforddictionaries.com

Reich, R.. (2018). *Trump's Brand is Ayn Rand*. http://robertreich.org/post/171545493770

Reveley, J. (2016). Neoliberal meditations: How mindfulness training medicalizes education and responsibilizes young people. *Policy Futures in Education, 14*(4), 497-511. Retrieved from http://journals.sagepub.com/doi/10.1177/1478210316637972

Rosen, M. (2012). *Dignity. Its history and meaning*. Harvard University Press.

Sandberg, Sheryl. (2013). *Lean in: Women, work, and the will to lead.* Alfred A. Knopf.

Shafi, M. (2014). Caregiving, work, and the debate on "why women still can't have it all". *Women in German Yearbook, 30*, 149-163.

Stacey, C. L. (2015). It's time to look at how we value home care work. *The Conversation*. Retrieved from http://theconversation.com/its-time-to-look-at-how-we-value-home-care-work-36897

Stanley, L. (Ed.). (1990). *Feminist praxis. Research, theory and epistemology in feminist sociology*. Routledge.

Tronto, J. C. (1993). *Moral boundaries. A political argument for an ethic of care.* Routledge.

Tronto, J. C. (2013). *Caring democracy: Markets, equality, and justice*. New York University Press.

United Nations Census Bureau. (2014). 10 Percent of Grandparents Live With a Grandchild, *Census Bureau Reports*. October 22, 2014 Release Number CB14-194.

Whitehurst, G.J. (2017). Why the federal government should subsidize childcare and how to pay for it. *Brookings Institution. Evidence Speaks Reports*. 2(11). Retrieved from https://www.brookings.edu/research/why-the-federal-government-should-subsidize-childcare-and-how-to-pay-for-it/

Hayloft provided quiet retreat for adult and child, sharing books together

Volume Figure 2: Johnson, E. (circa 1877). *The Quiet Hour* [oil on canvas]. Portland Museum of Art, Portland, Maine.

Eastman Johnson (United States, 1824 - 1906)
The Quiet Hour, circa 1877
Oil on canvas, 19 x 21 1/2 inches
Portland Museum of Art, Maine. Museum purchase with support from the Freddy and Regina Homburger Endowment for Acquisitions, the Friends of the Collection, and the W.D. and the M.L. Hamill Fund for American Art, 2013.18.
Image courtesy of Luc Demers

Chapter 4

Groves Academy and Lifetime Members Weave Personal and Professional Stories of Family Caregiving Together for Meaning

Barbara H. Settles
University of Delaware

Pauline Boss
University of Minnesota

Christine A. Readdick
Florida State University

Eleanor D. Macklin
Syracuse University

Judith Fischer
Texas Tech University

The opening evening of the 2018 Groves Conference in Portland, Maine included a panel of long-time Groves members who shared "A Groves Perspective on Caring." This chapter emerged from that panel discussion and captures the collective wisdom of five long-time Groves members, four whom participated in the Portland panel. This compilation of essays provides a rich blend of personal, practical, and professional wisdom on family caregiving and is delivered in a conversational style that is uniquely Groves.

Intergenerational Caring and Sharing: A Personal and Professional Exploration

Barbara Settles

Intergenerational caring and sharing is one of the great experiences of family life. It is not usually simple or rewarding all the time. Much

Barbara H. Settles, Professor, University of Delaware; settlesb@udel.edu
Pauline Boss, Professor Emeritus, University of Minnesota; pboss@umn.edu
Christine A. Readdick, Professor Emerita, Florida State University; creaddick@fsu.edu
Eleanor D. Macklin, Professor Emeritus, Syracuse University; elliemacklin@gmail.com
Judith Fischer, Professor Emeritus, Texas Tech University; judith.fischer@ttu.edu

emotional and physical effort is needed for success. Because caregiving is both an intimate interaction and also a negotiation with formal care and treatment processes, a wide variety of skills and problem-solving approaches are required for quality and effectiveness in caring. In family caregiving, the parties involved have resources of shared experiences, emotional connection, and relationships. Formal care and treatment organizations are now more cognizant of the need to relate both to the person in need of care and those who may be able to provide care. However, it is a delicate interplay of different perspectives, various types of knowledge, and experience in complex decision-making situations, as well as ordinary support and task accomplishments. This short discussion will present my own perspectives on family caregiving and how they are illustrated in my professional and personal experiences.

I have been professionally involved in examining families as intergenerational systems of decision making, care, and continuity. I acknowledge my undergraduate Home Economics background as a source of my early thinking in terms of prevention and long-term planning as essential aspects of caring. That interdisciplinary study was also very practical about how care can be integrated into everyday life. Sanitation and clean water, good nutrition, accommodations in clothing, housing, and transportation for those with special needs and the aged, safety, family relationships, management and planning, educational and medical access, and early childhood education were and still are strong components in all levels of education and community action. My graduate studies focused on family studies with minors in sociology, higher education, and academic leadership. The roles of community, social structure, and changing norms have been important in understanding the challenges of an aging society and the response to medical and health systems that now depend upon more responsibility and participation of family and friends in implementing and coordinating care.

My own interests in caregiving have included policy and program possibilities and reform. My activism has included founding, with others, a faculty union on my campus. Supporting faculty governance and committees at my university came from a belief that it is not just individuals and families who must adjust to programs, resources and policies that are currently offered. Maternity leave, family leave, fair, nondiscriminatory compensation, insurance, and medical choice are among the issues for which I have been willing to seek institutional change. I also have continued to speak and work for equal opportunity, equal rights amendment, integration, women's equity, racial and ethnic justice, gender freedom, education, access to medical and health resources, support and accommodations for special needs and disabilities and the aged, children's rights and support, economic social justice, legal changes, and other institutional changes which are more equitable and just. Friendliness and inclusion can be a basis for sharing and caring.

Also, my own research looked at junctions where we have not succeeded in handling long-term family problems. My first important practical research was a set of foster care studies that produced a rubric for adjusting foster care payments based on available research and parents' perceptions of financial need. The bulletin was sent to every county in the USA by the federal Administration of Children Youth and Families and became the basis for many divorce settlements as well. A study on the families of Cystic Fibrosis, at the time when better treatment programs were increasing healthy life spans, showed that it was difficult for families to let go of earlier regimes and medicines for fear of losing something that had worked for their child. Decision making under stress runs through caregiving literature in a more generic way.

Another major practical funded project was Interactive Planning for Family Futures which explored how we might better get families and individuals to plan and take action for more secure retirement and handling family crises. (Two of the most long-lasting and useful concepts we explored and developed programs for was helping people disengage from previous decisions that were no longer useful and how to find more resources and reliable information.). Family life education is needed on many topics and for diverse audiences, and caregiving is one test that reveals many needs for knowledge and skills. This research stimulated other projects with different educational challenges and was the basis of work with teachers in Panama and translation into Spanish.

Family caregiving ranges over a wide spectrum of activities, communication strategies, situations, and requirements. Fundamentally, it is a rather informal set of mutual linkages among family members and fictive kin as defined by themselves and the relative recognition that is given by family networks, other close or local people who may be rallied and recruited, and professional or paraprofessionals who have been secured to help with the situation. The various bureaucracies and services also take positions on what is family, and what is family caregiving. In general, organizational policies often require a single point of contact with family networks when exchanging information and in decision-making. Patient confidentiality, also, promotes a single point of contact, often only the patient. These requirements do not fit the actual nature of sharing and caring processes. Families and fictive kin operate usually as a moving equilibrium with different people being able to help at various times and for different tasks.

The sharing and caregiving network includes not just the family/

fictive kin network but may include also paid help, friends, neighbors, volunteers, community services, and medical/ health professionals and carers. Coordination and communication are usually left up to the family sharing and caring network with "someone" being left to doing the leadership to follow up and keep everyone informed. Robust networks often have several members who can take the lead at different times.

There is another aspect of care of family members who are not living close together: figuring out if they each need help? *Communication has moved rapidly forward from the Sunday night calls to Ohio we did for our parents, after we moved to Delaware. If we called any other time, they worried about us.*

I actually was a negligent Mom recently. I did not notice that my answering machine had died and wasn't recording messages. I got a call late on Thursday evening, because I was gone to a university event that evening, from my eldest son who was worried about me and concerned that I had not sent contact information for my trip to the Portland Groves Conference. He had called 3 times during the week. It is my responsibility to be more alert if I want to be on my own some of the time.

Sharing and caring is not just responding to incidents and events. Attention to prevention is clearly better than fixing problems. Not having a "fall" is far better than caring for an injury and its complications. *Also, I don't climb ladders anymore!* Transportation, shopping, house maintenance, visiting and interaction are included in the many tasks of sharing and caring. One of the reasons families are available for mutual help is that there are many challenges across time and space to which families normally expect, experience, and respond. Sometimes there is a huge burden if multiple needs for many in the network outstrip resources, but generally, families accept that the care flow among members and social and material exchange have a long-term balance and welcome the fact that heavy duty care is not always needed. However, research suggests that some ways of handling short-term inequities or overloads work better than others to keep care flowing when and where it is needed. Heavy stress and poor coping can break up the network or estrange relationships.

The most intense situation my family experienced was when my husband Andy thought he had flu and our regular physician was away. The backup doctor saw him for the flu and wasn't satisfied and ordered an X-Ray. He was found to have "something" in his upper chest and neck. When we met with his regular doctor, he suggested we would need to look for other medical expertise. My doctoral students from nursing who were in my family theory and research course helped me with what were the key places and questions to ask about referrals, and Willa Choper, a longtime member of Groves, contacted me and *shared what was on the government internal health website (no internet at that time). We did cold calls, and he had telephone interviews and followed up with in-person interviews and decided on Johns Hopkins. After an operation, he was treated twice. The first chemo did not provide a cure. When he went back, they decided to prepare him and admit him to an autologous bone marrow transplant which was still experimental. It worked. There are many little incidents that we remembered and laughed about in the next quarter plus century, as he continued to be treated for the consequences of the successful treatment of non- Hodgkin's B cell lymphoma. I always remember to tell people how much my husband appreciated that I was tenured professor with such benefits as college tuition coverage for our sons.*

Some sharing and caregiving can be planned and strategized. That sort of interaction can develop a decision-making process that continues under stressful conditions to manage crisis and long-term needs well and be responsive to the need for change as events occur. The ability of families to absorb new demands and adapt the system is quite variable depending on the stressors. Certainly, when some events are resolved, and people are somewhat satisfied it is easier to build upon that adaptation. The term coping has always seemed to me to be a low expectation, more reactive than proactive.

My sister had a child born with a congenital hip defect. In Delaware, we have the leading children's hospital, Alfred I. DuPont Institute, for orthopedic diagnosis and treatment. I urged her to come to get a second opinion, and she raised the common response that it was too far away from Columbus, Ohio (We later found in our Family Futures research that this was often a problem in medical decisions). Later, when an operation in Columbus went wrong and my niece developed an infection, my mother called and asked me to pray for Mary Beth. I realized she meant me to do the role of finding help. I called friends in nursing who told me what to say and then I called A. I. DuPont Nemours and they said they could admit her the next day. So, I called my mom and told her what they had to do. They took her out of the hospital, hired an ambulance, and chartered an airplane and came to Delaware.

It is a long and complex story with many operations and visits and recuperations at our house lasting through to her adolescence. The outcome was that my niece's life was changed positively, and she became a doctor. Our mother was also back and forth taking care of grandchildren in both Delaware and Ohio over many years, and friends and relatives also were involved. Mary Beth's brothers were also stressed. When she was medically evacuated to Delaware, her younger brother was only a toddler himself and didn't get to say goodbye and it was many weeks until the family members were reunited.

What is lost in much of our research on sharing and caring is that the economics of its transactions are not conventionally even or likely ever to be seen as a simple exchange. Rather some of the effort is just a long-term equity or savings program for the future, mostly based on love and care over many years. Dyadic relationships especially are prone to be characterized by care as a loving act. The more complex and distant relationships often need to be structured to see that fairness norms are met. Sometimes small differences in approach or preferences can be breaking points for caregivers. Conflicts of interest may not be evident at first and may be difficult to manage or resolve without animus. Exploitation can occur, often because no planning was done to avoid such problems.

Why intergenerational? While there are fewer intergenerational households, family and health research have shown that there are many flows of help, support, rescue, and awareness back and forth in close relationships across households and distance. Sharing communication and resources happens through the life course. The spacing and demands for caring are interspersed with many more occasions for sharing and building the ties that create trust and responsibility. Sharing perspective, support, and memories creates prevention capability, skills, understanding, and affection that makes caring a further expression of love. Having a family advocate in dealing with institutional services is crucial and may even be required especially in educational and medical settings. Some of these exchanges are so common that we do not see them as caregiving.

My mother came to Delaware just before my first baby was born and helped me be able to continue teaching and covered my graduate course the evening I was in labor. She got to know my new babysitters and basically vetted them. She often came from Ohio when she could help out.

Lots of caregiving is provided by the same cohort of individuals: siblings, partners/married couples, cousins, fictive kin. Lots of sharing may be part of everyday life. Cross generational "carers" include parents, grandparents, aunts and uncles, nieces and nephews, and the "great" ones are expected to care, when needed. Less certain are the expectations of care for step relatives, foster care, divorced, and otherwise entangled or estranged relationships. Interaction and shared experiences provide the "normal" and give the context for care at specific points in the family's roles. Interaction and shared experience provide the norm understanding of a person so that behavioral and physical changes are seen against a baseline. Family networks may accumulate unsettled disputes, poorly addressed chronic stress, inequities, jealousies, secrets, and simply different values and goals. Proposing strategies, managing care, and providing support are played out against this panorama of pluses and minuses. Each person has their own preferences. Since cohort relationships share similar experiences and ideas, manners and language often meet clearly and, to some extent, values and priorities may at least be recognizable. Across generations, differences in experience and technologies may play out in perceptions and preferences. Still, families have many common activities and events that link perspectives and may be the basis for shared decision-making.

How do we help children and youth to grow up as "carers"? In our family, we let our sons care. All through growing up, the trip home to grandparents was important. *Another example was that my younger son Mark didn't get to be in a Robin Williams movie which was filming at a private school near us that he had been invited as an extra, because we needed him to help their grandfather move into assisted living in Ohio that Thanksgiving holiday. Our sons made many extra efforts to make things easier for us as parents as well. They chose to go to University of Delaware. When Alex graduated from college, they were happy to go on a huge sailing trip with us in the Greek Islands. Even on this glorious trip they were handling their Dad's emotional highs and lows. I guess we would say that bone marrow transplant leaves some stress related consequences: a sort of mini-PTSD.*

Families need to access many services, expert advice, and materials to support caregiving at home. Choosing when and how to use out of home services, living and caregiving arrangements, is an ongoing weighing and choice-making process. Knowing the systems and understanding the financial implications of different choices is a prime consideration. Elimination of pre-existing medical conditions limits has been a major reform across the life course.

My most recent major caregiving was Andy's decline with heart failure. We were able to buy some time with heart valve surgery, but eventually the long-term effects of many treatments, especially the whole-body radiation, could not be held in check. For me, the transition was at first manageable, and we came to Groves in Boston in 2013 where everything was made easy for us. Coming home from the airport following the meeting I was myself tired, and, when, he asked me to stop the car so he could get the mail, I stopped. Then I saw him walk over the drive and bend down to pick up a newspaper and saw him tumble down our steep drive. He recovered with just a cut on the forehead, but that was the transition. He was able to stay at home and even traveled a few more times.

In the winter of 2014, his condition went downhill and I got some help at home. We chose Hospice at home in May. My sons were living in New Jersey and Florida. They came often and that winter brought the Florida grandchildren at spring break. Then every weekend at least one would turn up in the weeks that followed. He died just before Groves Conference in Pennsylvania. In terms of caring, I was surprised the difficulty even a person with resources has to find appropriate help as my university life often had late day activities. We lived on the main floor of our home and I assembled and had installed the *equipment needed. Also, I became aware that having Blue Cross Blue Shield, not having Medicare, did not protect us from bureaucratic demands that the state line should be a boundary in care. His doctor from Hopkins came for a house call in May, by bringing his ethics students on a field trip to see how home hospice works. There are many ways to work around the rules of care, but you need professionals that care.*

What is the role of self-care as it relates to giving and receiving care within families over the lifespan? Many caregivers and recipients become a burden to others because they do not think of their own responsibility to themselves. In the medical trade, they often call this problem noncompliance, because they see so many people who don't understand, or don't like side effects, or just want to do as they like. Often, caregivers are so lost in their responsibilities that they don't take any leave or time to recover. Sometimes, there is no one else, but often it is not having practiced self-care consciously. It is true that a family caregiver may know so much more than any other person, friend, family or professional that is seems best to do it all by one's self. However, the consequence is that the caregiver may be in trouble while needing much more support than being willing to accept such support. Support groups and online friends can help with emotional support and some tips, but the actual rest and recreation everyone needs may not be easily accessible. Fictive kin are so important. You can make friends across the life course, but family is not always so renewable. For the isolated caregiver, we need outreach and home visiting and respite care, but most families have very limited access to services of this kind, today.

How do we develop an actionable ethic of care that addresses issues of social justice? First, we must understand how much of our health problems are created or made worse by environmental decisions.

Our county in Delaware is sometimes called cancer alley. A wide range of chemical and petroleum storage and plants mean spoiled land and releases in the air. I had discouraged my husband from working where he would wear a radiation badge, but we didn't see through a chemical company's safety program which turned out to be a shield against accountability. In addition to working in these facilities many families are located in dangerous places that may not be identified.

Second, access to quality medical services and care are far from being broadly available. American health care is great if you can get it. The relationships among: "Big pharma", "Big energy", "Big development", etc. and any regulation or oversight is fraught with secrecy, corruption, and lack of leadership. The family seems quite small in terms of managing both environmental and health issues.

One of the biggest caregiving inequities is the assumption that caregiving is mostly a female family task. Of course, happy families do want to run their own caregiving and provide as much care as they can. The gaps that come from our success at living much longer and young people needing to be more mobile in finding work and education are not going to be filled easily. It is distressing that as we have used and misused immigrants for some of this care, the society has become more hostile to them.

A colleague in England reported on some longtime immigrant citizens from Japan that founded a rest home for Japanese-English elderly. They worried that as they aged their English might fade faster than their Japanese. Similar feelings have been voiced by LBGQT* community in picking settings that will be friendly in old age.

Many elders do not have family ties to be used as a fallback resource. In terms of other inclusion issues, many special needs adults are themselves reaching old age living in their families as their parents grow old. The two relevant governmental programs--disabilities and aging--have never figured out they need to be coordinated. For African Americans, the care issues we associate with aging have occurred at much younger ages and they may have not had the opportunity to have the long lifetimes that others take for granted. Here self-care and early care are key issues.

We, as professionals, also have a huge concern in term of prison reform and care of the frail elderly there. Prisoners are taking care of each other to the extent that any care is being provided. Having facilities for appropriate care and access for treatment is not being addressed for many other special populations.

How can family science add its voice to the development of a coordinated national system of family caregiving? First, we need to address models that might work in local and state directed programs. As long as almost every medical and care support program is managed and directed at a state level, it is unlikely that any national program will evolve. One of the key reasons the current administration has not been able to move away from some of the Medicaid and Affordable Care expansion is that states got vested in them and put their own twist on how it works. Without a new theory of family caregiving and governmental support, we are stuck in “Who do you know who can tell you? What to ask to your local agencies?” Much of what is being done now works on waivers or subcontracting at the local level.

Second, much of what has gone right for families with disabled members came about from parents’ organization and lobbying. The outcome was a new model of educational rights administered at the school level, requiring and including parent involvement. It was part of deinstitutionalization movement in this country that has been quite broad and effective. Deinstitutionalization also happened for the mentally ill, but families were shuffled aside. Privacy of the afflicted adults was invoked which kept their caregivers from knowing what to do. Similarly, part of the punishment of incarceration is in attenuating family ties. Longtime and frequent prisoners have no financial or social support and most have not even a quarter of social security eligibility.

Another worry for those who have planned ahead and invested in a housing scheme that promises some kind of care and admission to care facilities is being concerned about the sturdiness and financial health of these organizations. Many families have not gotten the full pensions that they were expecting, and company reorganizations are proving treacherous for remaining pensions and benefits. The fact that many women forgo full employment to care for family members over a long term means that their own financial and care future is endangered. This situation is also intensified for women who withdraw from employment to care for their children and take long term wage and promotion penalties. Many persons who have been a "carer" have no one to care for them. Finally, the support for decision making and finding technical and care solutions is even more important than performing tasks. Coordinating the care is a prime task of assuring quality care.

What steps in the past have we taken, in this direction, and what steps might we choose to take in the future? We have often expressed our concern over specific programs and laws, but this idea of caring and sharing is much more complex. Buried in all the conflicts of inclusion and stereotyping of gender and aging roles is also mixed emotions about who is deserving of care and at what level of support. We should actually see if we can bring together scholars both from family and from politics and aging to get some overarching perspectives that we might start introducing at many levels and in other professional organizations.

Many family science and policy organizations have expressed concern over specific laws and programs, but caregiving over the life course is much more complex. For example, a father who did not have custody after a divorce or did not pay child support may not be as close to their adult children. The use of the term adult children hides our ambivalence toward care in today's situation. *One of my recent students wrote about how strange it was to read about "Adult Children" as caregivers and then see in the study that they were all over 65 in research articles.*

Organizations have many routes to support change and new theories and methodologies: regular conferences, newsletters, journals, focus groups, policy education, outreach and use of the media are common. For example, conferences that were held on other breakthrough topics such as child abuse with AHEA, NCFR, and ASA, fathering research at TCRM, HIV/AIDS at Groves. We have also often looked at big ideas like health and peace. We could follow Margaret Feldman's example and schedule workshops and working sessions at other conferences such as the family policy workshops at NCFR. There are many contacts in gerontology we could activate. We need to do more with our Groves books. Perhaps we need to reach opinion leaders and present them to those who are interested in policy and program change.

As academics in our classes and with our students, and through them, reaching the community and encouraging community involvement is another priority. Working to improve policy and secure inclusion is another important approach. Action is important too.

One of my students was head of a fund raiser for children's cancer on our campus two years ago. The event called Udance raised about $2,000,000 for children's cancer research and family support with broad participation of the students and university community. On a less grand scale, I remind my students that giving blood or platelets is something any young healthy person can do for ill babies and cancer patients that saves lives.

When there is a rich network of competent people, and the target of care is an active participant, outcomes may be positive for everyone. The challenge may be to coordinate and appreciate each other's contributions. Frequently, families have a small network of relatively poorly resourced people in fragile relationships who do not have a group strategy or respite options. Stress is not just in sharing and caring, but in managing the emotional and physical fallout. Rugged independence has been a common American value that is not helpful in intergenerational sharing and caring. Likewise, an over-commitment to privacy and secrecy can cause failure in the best of caregiving processes. Sharing ideas, resources, concerns, and worries is necessary as a foundation for caring demands to be met. One of the tasks may be to report one's perception of the person's intentions or preferences, which would be unknown without sharing. This sharing and caring approach recognizes that much of it goes on among and between dyads in the network in real time. Each incident separately has a directional flow.

If I have made it sound like good communication and relationships and technical support will make caring effective and positive, that is more of a hope than a promise. Over the years small and large crises and ongoing demands may leave many hurts and disagreements unresolved and perhaps unresolvable. Feeling and being unappreciated may contaminate every interaction. The actual taking advantage of vulnerable family members is more common than we like to think. Distance and lack of oversight add to the possibilities of sharp dealing by some family members. Managing assets and money is often not planned and arises without transparency. Violence is often found in family settings. Untrained "carers" may try to force patients to take medicines or restrain them in chairs or beds. Supervising those hired to help may not be adequate and it may not be easy to get replacements.

In conclusion, the following issues may be open to better research, policy analysis, and program development:

- Needs and possibilities for caregiver education.
- Access to specialized support and information for specific caregiving across the life course.
- Decision support for specific presenting problems.
- Funding and disseminating a full range of services, technologies, supports, experts, and interventions to improve quality of care and reduce caregiver stress.
- Provision for providing professionals with training for support of caregivers and family networks.
- Emergency response and securing second opinions, expert consultation, palliative care, overcoming distance and insecurity, and developing accommodations.
- Respite and backup care for caregivers.
- Medication and therapy for caregiver networks.
- Helping all to be more discerning consumers of facts and data and media content.
- Legal help and oversight options and alternatives.
- Developing a more accessible, articulated, and responsive health and medical system across the life course.

The challenges of the 21st century are found in more options for resources, the need for repeated evaluation, having responses to frequent possible emergencies and managing ongoing coordination and coverage. Caregiving is both a process and an interaction and quality is not just in services rendered.

Selected Supporting Vita Entries

Doneker Mancini, K. (2012*). Caregiving of Aging Adults and Adults with Disabilities: Theoretical Foundations and Policy Alternatives*. Doctoral Dissertation.

Flexman, R., Berke, D. L., & Settles, B. H. (1999). Negotiating family: The interface between family and support groups. In B. H. Settles, S. K. Steinmetz, G. W. Peterson, & M. B. Sussman (Eds.), *Concepts and definition of family for the 21st century* (pp.173-190). Haworth Press.

Hanks, R. S. & Settles, B. H. (1989). Theoretical and ethical issues in a family care-giving relationship. *The Journal of Applied Social Sciences,* *13*(1), 9-39.

Hanks, R. S. & Settles, B. H. (1990). Theoretical and ethical issues in a family caregiving relationship. In D. E. Bugal & A. Blum, (Eds.), *Aging and Caregiving* (pp. 98-120). Sage.

Salzbrenner, T. L. (2016, Summer). *Waiting for the New Normal: A Case Study of Military Family Support Processes in the State of Delaware.* Master's Thesis.

Settles, B.H. (1986 – 1990). *Interactive Planning for Family Futures.* Administration on Aging USDHHS.

Settles, B. H. (1993). Expanding choice in long term planning for family futures. In B. H. Settles, R. S. Hanks, & M. B. Sussman (Eds.), *American families and the future: Analyses of possible destinies* (pp. 1-36). The Haworth Press.

Settles, B. H. (2000). Language and multicultural issues in adapting family life education and evaluation: A model for collaborative development. In Settles, B. H., & Robles, I. V. (Eds.), Building support for the well being and future of the family (pp. 84-95). *Family Science Review, 13*(3&4).

Settles, B. H. (2001). Conflicts between family strategies and state policy in a global society. *Journal of Comparative Studies, 32*(2), 147-166.

Settles, B. H. (2001). Everyday life in family scholarship and family life: Sketches and interpretations. In S. K. Steinmetz & G. W. Peterson (Eds.), Independent Spirits. *Marriage and Family Review, 32*(1/2) 149-172.

Settles, B. H. (2013). Global grandparents: New roles and relationships. H. Selin (ed). *Parenting across cultures: Childbearing, motherhood and fatherhood in non-western cultures.* Dordrecht: Springer, pp. 393-419.

Settles, B. H., & Barboni, T. (1998). Developing on-going family life and prevention programs in Panama, Costa Rica and Delaware. In N. B. Leidenfrost (Ed.), *Proceedings of International Federation for Home Economics Americas Region Conference* (pp. 105-111). University of Puerto Rica-Mayaguez, PR Campus.

Settles, B. H., & Foulke, S. R. (Eds.), (1989). *Family futures: A manual for peer leadership.* (Available from B. H. Settles, Department Individual and Family Studies, Newark, DE: University of Delaware).

Settles, B. H., Davis, J. E., Grasse-Bachman, C., Janvier, K. A., & Rosas, S. R. (2000). Developing community and peer support for young parents: Process and outcome evaluation inputs in prevention programs. In Settles, B. H., & Robles, I. V. (Eds.), Building support for the well being and future of the family (pp. 182-196). *Family Science Review, 13*(3&4).

Settles, B. H., Davis, J. E., Hanks, III, D. E., & Grasse-Bachman, C. J. (1999). Family life education and prevention programs: A cross-cultural program development model. In R. Richter & S. Supper (Eds.), *New qualities in the life course: Intercultural aspects* (pp. 219-236). Ergon-Verlag.

Settles, B. H., Hanks, D. E., III, Grasse-Bachman, C. J., & Davis, J. E. (1998). Building bridges of inclusiveness in multiculturally diverse groups: The challenge for family life education and prevention. In S. C. Ziehl (Ed.), *Multicultural diversity and families* (pp. 397-454). Rhodes University.

Settles, B. H., & Lucca, J. (1981). Effects of children's disabilities on parental time use. *Physical Therapy, 61*(2), 196-201.

Settles, B. H., & Settles R. A. (2005, April). Being retired or just another transition? In E. D. Macklin (Ed.), *Tales of retirement: Views and experiences of senior faculty*. Paper presented Groves Conference on Marriage and Family, Washington, DC.

Settles, B. H., & Sheng, X. (2005). Social transformations and the future of intergenerational relationships in families and societies: Implications for theory, research and programs in family studies. *Special Publication in Celebration of 60th Birthday of Bernard Nauck*. Chemnitz, Germany.

Settles, B. H., Zhao, J., Mancini, K. D., Rich, A., Pierre, S. & Odour, A. (2009). Grandparents caring for their grandchildren: Emerging roles and exchanges in global perspectives. *Journal of Comparative Family Studies*, *40*(5), 827-852.

Sheng, X., & Settles, B. H. (2006). Intergenerational relationships and elder care in China: A global perspective. *Current Sociology, 54*(2) pp. 293-313.

Sherif-Trask, B., Hepp, B. W., Settles, B. H., & Shabo, L. (2009). Culturally diverse elders and their families: Examining the need for culturally competent services. *Journal of Comparative Family Studies, 40*(2), 293-304.

Van Name, J. B., & Settles, B. H. (Eds.). (1977). *Measuring the Cost of Foster Family Care.* DHEA NO. (OH DS) 77- ·0126; ERIC EJ164805. Distributed to every county in the United States.

Van Name, J. B., Culley, J. D., & Settles, B. H., (1977). Measuring the cost of caring for a foster child. *Child Welfare*, *56*(7), 431-439.

Zhao, J., Settles, B. H., Sheng, X. (2011, September- October). Family to work conflict: Gender, equity, and workplace policies. *Journal of Comparative Family Studies, 42*(5), 723-738.

Excerpts from *Loving Someone Who Has Dementia*

Pauline Boss

[From Boss, P. (2011). Loving Someone Who Had Dementia, Chapter nine: The good-enough relationship, pp. 155-157. Jossey-Bass. Reprinted with permission.]

Rarely is there absolute presence or absence in human relationships. Being 100 percent present—emotionally and physically—for someone is rarely possible in mobile societies where family members work outside the home or move away. But if your loved one has dementia, the incongruence between your loved one's absence and presence can be debilitating, if you let it be.

Until there's a cure or preventive measure for dementia, the only window for change lies within your own thinking. Your perception of a good relationship must shift to a new value: the less good. You can soften your standards of perfection so that you gradually see that a "good-enough" relationship also has a place.

Accepting the idea of a less then perfect relationship is not equivalent to giving up. This type of acceptance is an active decision to recognize the reality of a relationship compromised by dementia. You eventually come to an awareness of things as they really are, imperfect and less than ideal,[1] but the emphasis shifts to self-control and with that, you retain the dignity of free will. It's not about giving up. It's about staying strong and in charge. Valuing a less than perfect relationship is *your* choice.

To make this shift, stop fighting the ambiguity, and acknowledge what you still have. If you can still touch the person you love and talk with him, even if the conversation is one-sided; if you can smile with her, even if it's not returned; if you can just be there thoughtfully, it can be good enough. There's a new kind of hope for you in this. You are making this choice, and you're no longer spending precious energy trying to fix something that very likely won't get better. In the case of dementia or any condition that compromises presence, you discover new hope only when you embrace the imperfections of love and caring. Your relationship may not be perfect, but you can choose to accept what there still is as "good enough." This part is within your control.

As a therapist, I have been awed many times as I witness this *relational* shift. You can make it, too, but it's not automatic. Once you intentionally change how you see your relationship and, assuming there is no abuse, accept it as it is, you'll feel a peacefulness and strength you never knew you had before.

In learning to accept unanswered questions and temper your desire for closure, you find that stress and anxiety diminish, allowing you to cultivate the resiliency to positively endure a relationship with someone who now depends on you for care. If you allow dementia to act as a teacher, of sorts, it shows you that *you* have to change not only your perceptions but also the core of your being. There are lessons in adversity, and you can become stronger if you are willing to change.

Before you can decide to shift into the good-enough relationship, you must be willing to relinquish some of your desire for independence. In our culture, this is not a simple thing to suggest, but many have done it in an effort to preserve themselves as well as the loved one they care for. As we enter midlife, leaning on our partners, children, and friends for help is increasingly necessary—and when we do so, the ideals of self-sufficiency and independence begin to break down.

[1] P. Mishra, *An End to Suffering* (New York: Picador, 2004).

From p. 160

Independence becomes less attainable as you grow older. Out of necessity, interdependency becomes the norm. One partner depends on the other, or a parent depends on an adult child; first, for driving, paying bills, and managing medications, and later for more: dressing, feeding, drinking, toileting, and transferring from bed to chair and back again, day after day, year after year. Survival depends on a person's willingness to always be there to meet the needs of the other. But here's the rule for caregivers: That person cannot always be the *same* person. It cannot always be you, or you will burn out. Arrange for others to fill in so that you can take a breather and get some rest and recreation.

Reflections on Family Caregiving in the Sewing of an Apron

Christine (Coco) Readdick

I visualize the fabric of my life comprised of the vertical threads of my personal life as daughter, sister, wife, and mother, woven inextricably with the horizontal threads of my professional life as a Professor Emerita of Child Development and Lifetime Member of Groves. I, like you, have experienced the changing tempo of giving and receiving of care.

As I write this reflection on care in the context of family, I am stitching another "apron" for my 97-year-old mother (or bib, as some caregivers used to refer to this cover) to be placed over my mother's clothes while she eats. Early in my mother's "career" as care recipient, a caregiver brought in some hand-me-down "bibs" sewn from used terry cloth towels from a previous and now-deceased “caregivee”. The messages here were too painful— “mama is a baby”, “mama is unworthy of something new of her own in that she will soon pass, too”. Incensed on one hand, yet, on the other hand, alert to showing my appreciation to our caregiver for sharing, I immediately sewed three brightly colored and happily trimmed “aprons”, placing the hand-me-downs deep in Mama’s drawer.

Yes, my mother, despite her age and frailties, is a grown-up person worthy of all the respect we should afford another human being, anywhere along their life path. The apron I am sewing now is of soft cotton knit in turquoise with fanciful birds to be edged and tied with bright yellow binding. While she may not call my name any longer and needs help holding her glass to drink, we, as a collective of family and caregivers, are now united in our determination to celebrate my mother’s remaining competencies rather than focus on her waning skills of self-care and other-care.

To provide a backdrop—six years ago, in the blink of an eye, my completely independent, then 92-year-old, mother tumbled on her newly leveled brick sidewalk. In one month’s time—after hip surgery accompanied by profound anesthesia, a Medicaid-funded month in nursing home rehabilitation, and return home, she transitioned from her life-long role as caregiver into her new, unrehearsed role as care receiver, accompanied by rapidly diminishing physical, cognitive, and socio-emotional skills.

Honestly, as a family, none of us (my mother, sister, nor I) was prepared. Where will mother stay? Who will help her with her activities of daily living? How will we pay for her care? We had not imagined or confronted the “what if” or “when” or “how” of our mother’s aging together. In hindsight, we ignored or discounted her more frequent stumbles, her search for words, her rifling through objects in her dresser drawers late at night, her fretting about “strangers” in the marsh behind her house, her attempts to feed a spoonful of Jello to a baby bird she had “rescued” from its nest on the front porch.

Doctors gave a grim prognosis: most patients of similar age and disability are deceased within six months. This was harsh news, but we assumed we could take care of mother for this length of time. But, now, all these years later, we continue down our creative (by-the-seat-of-our-pants) path of family caregiving. How have things worked out? First, we accepted as a given that mother should be able to live in her own home. This decision was based on our observations of our mother’s own mother’s isolated decline in a nursing home and the absence of an up-to-date will for mother. In Georgia, because mother owns her home, she is ineligible for in-home or out-of-home support.

Next, my sister, already residing at home with mother and working as a small business owner, assumed oversight of daily living and supervision of our evolving team of independently contracted and certified nursing assistants who continue to provide companionship and to meet mother's needs for care around the clock. I, still 200 miles away and teaching at the time, cobbled together a barely sustainable funding stream, including my father's pension, mother's Social Security, a VA pension for surviving spouses, income from my sister's needlework shop, contributions from my retirement pension fund, and most recently support from Hospice.

Back to the sewing thing and why am I making a big deal about it. Because my mother used to sew lovingly for me, making the sweetest dresses and other outfits well into adulthood--from the identical blue pinafores printed with little raccoons that my sister and I wore proudly to Pittsburgh Pirate farm team baseball games to the gorgeous red boucle dress I wore to the rehearsal dinner for my marriage. Most warmly I remember the ritual—me standing still as a statue, rotating like one of those ballerinas on top of a music box, mother, sitting on the floor, pinning up the hem, making sure my finished garment was perfectly even all the way around. Surely this was caring.

Sewing stitched us together in a life-long relationship of care. I believe that this among other small acts of daily living helped establish an ethic of care, the basic foundation that has guided both my personal and professional relationships. As it should be, it is my turn, now, to sew for Mama--hemming up day gowns, stitching lap robes, with accessories like buttons and pompoms to be fingered as she watches Andy Griffith or the Atlanta Braves or studies the cardinals and chickadees at the feeder outside her window, as well as her pretty aprons. Once my mother's turn to introduce my sister and me to all the flora and fauna of our south Georgia environment, it is now mine to exclaim and rename, as we look together at tufted titmice and cardinals and the multitude of grey squirrels she last called "little soldiers".

Being pretty much a "free-range" child growing up, I have always been keyed into my surrounding, my hands-on environment, and paid attention to its rich affordances/opportunities (Gibson, 1977)—dirt roads on which to run barefoot, trees to climb, beans and corn and strawberries to plant and eat, cats (where did they all come from?) to name and pet and tend and love, creek to crab in and frolic along—that allowed me to exploit the limits of my curiosities and competencies. Where was I? Down the road. Who was I with? My sister, Bo, or Gail or Bernice or Little George or Little Robert or Earldean, one or all. What was I doing? Playing, growing, learning. My mother knew.

Fancy me an acrobat in the circus, a forester, a florist, a teacher—all of these presented as possibilities when I was young. But, with school followed by more school and even more school, certainly I knew a lot more about teaching than any other occupation, having had some 36 teachers before graduating from high school—most outstanding. Career development in a nutshell--elementary education at Emory, followed by emersion teaching and hands-on learning in Atlanta public schools during the long overdue era of integration; substitute teaching at an army school and work as a file clerk in a building savings and loan bank in Germany; with no job landed to teach in Utah public schools, directing a summer enrichment program for Hispanic children whose parents were migrant workers in the fruit and vegetable orchards of the Salt Lake valley; found a mentor in Jean Kunz at Weber State College in Ogden, followed by an invitation to serve as preschool teacher in the Weber State child development lab school.

I was hooked; I had found my grown-up professional environmental niche. In not so rapid succession, I earn a Master's at the University of Georgia in Child Development, doctorate in Child Development at the Pennsylvania State and Florida State universities--lots of theories, lots of research, lots of paying attention to and caring ever more successfully for children and families, by now my own included.

Being trained and having practiced in nursery lab school environments (not only at Weber State, but also at the University of Georgia, Hood College, Penn State, and Florida State) where "looking" was an essential experience, I continued to develop the ability to pay attention from the vantage points of near and far, and came to view this "seeing" as the foundation of providing appropriate care. Viewing my young charges at a physical and emotional distance from behind the black cambric screen in the observation booth at Hood College (Benson, my butterfly boy, flitting from spot to spot, who or what in this whirling environment invites him to stop and engage?) or up close and personal (holding three-year-old Barbara in my lap, as she struggled to "graduate" from the environment of a flop house closet--yes, literally--and I pioneered, calming her and reading a story to her peers simultaneously in our enriching--over-stimulating for Barbara--summer preschool program at Weber State. Both views, near and far, were essential for establishing caring relationships with Benson and Barbara and successfully designing activities and environments for their growth and development.

Beyond vivid personal experience, what theories did I embrace that guided my thinking? Yes, Piaget informs my understanding of care—the caring for and the caring about another person. Our level of cognition is surely central to both our ability to give and receive care. The

Whitings' nomenclature of lap baby, knee baby, yard child, and community child (Whiting & Whiting, 1979) provides me a cross-culturally derived, visual environmental tableaux for the unfolding of the development of sensori-motor, pre-operational, concrete, and formal operational thought (Piaget, 1936) along with practices of care, nurturance, socialization that prompt the linear achievement of childhood developmental tasks to develop a sense of trust (are the folk in my immediate environment dependable), autonomy (can I do it by myself), initiative (ooh, I have this great idea to pursue), identity (wow, I am a special me so alike and so different from others in these ways), and so on (Erikson, 1950).

Teaching the ethic of care in a dandelion—I'd often begin my first undergraduate child study class this way—please draw a picture of a dandelion and write down everything you know about it. Quizzical and furtive looks, a little laughter. Show me your renderings and share what you know. A few hesitant volunteers—dandelions portrayed as some vague collection of petals, on a stem (usually) with a leaf (of some semblance). What is it? In chorus, "a weed" the class most frequently responded. How do you know? Teacher, parent, T.V. ad told me. You should exterminate it. What else do you know about dandelions? When the blossom dies, you can blow on the fluff and make a wish. And that was pretty much the extent of my students' experience with and knowledge about dandelions.

Using this dandelion conversation as a foundation, I asked my students to do a little investigation about dandelions overnight. The next day we assembled to explore, among other things, what else they had learned about dandelions. Second-day renderings were far more precise than the previous day's. Conversation became animated. Maybe it's not a weed but a flower that someone doesn't want. The word dandelion comes from the French dent de lion, meaning teeth of the lion, in reference to the jagged edges of the dandelion leaf. Oh, its young leaves can be eaten in salads in the spring. What, you can make wine from its blossoms?!

For me this exercise became a vehicle for introducing the concept of environmental care, that applies to children or animals or plants, that in order to know someone, one first must pay attention to it, give it a name, determine its similarities to and differences from others, and, in turn, by caring for it come to respect and love it. If I relegate this child or this family to a category of "weed", am I as likely compelled to care for that "weed" in the way I might care for a "flower" (with its' assumed many redeeming characteristics that I and others have taken time to identify and nurture)? Consider this lesson against the backdrop of your imagined work as a teacher or nurse or parent or speech pathologist or social worker, I urged.

You are a second-grade teacher, studying records of the students newly enrolled in your September class. You learn that Annie is reading at the fourth-grade level and is socially gifted for a seven-year-old. You discover that Alex is developmentally challenged, cannot read, and has limited social relational skills. Will you have different expectations and treat them differently? Will you consider Annie to be better than Alex, a flower rather than a weed? Will you open different doors of opportunity for them, not because you have allowed yourself to discover their own uniqueness and humanness, but because you value one more than the other because you have accepted someone else's hand-me-down judgment and prediction? And off we launched into our formal learning and practice of methods of observation and recording as diverse as the running record or narrative, checklist, even haiku poem—the various means at our disposal for paying attention as a basis for right action and care of our own and others' children.

The writings of Bronfenbrenner (1979) have been most influential. While it may have been the little collection of Russian matryoshka dolls used as a visual representation of his theory that captured my attention, I rather believe it was his conceptualization of the child, centrally situated, and developing within the context of ever-widening, mutually influential environments or systems that resonated. For most of us, the family and school are our most intimate and influential microsystem environments. It is here in the microsystem that I could best apply my love of direct observation identification of relational and environmental qualities (actions, interactions) that contribute to the growing child's competence.

Oh, I once even wrote Urie Bronfenbrenner and invited myself to afternoon tea, to talk about his "caring curriculum" notions. In his seminal book, Bronfenbrenner (1979) asked how can it be, today, that a child can grow up to become a parent without ever having cared for anything that depended on him or her, for thriving—no plant watered, no baby sat, no pet fed—and advocated for the creation of caring curricula in our homes and schools and religious institutions. While my invitation to tea was not forthcoming, I nevertheless endeavored to integrate a caring curriculum into my teaching anyway. An ethic of care assumes that because of our living being-ness, our family-ness, there will be junctures in our lives when we will provide care for a dependent other or receive care from others—like breathing in and out. How do we learn to do this well? What environments, relationships, and activities are best for giving and receiving care over the lifespan?

A career spanning 50 years, a life now spanning 72, I am privileged to have been part of this organization, Groves Conference on Marriage and Families. For this affiliation I am grateful to Mary Ward Hicks, former colleague, good friend, and eternal good spirit, who invited me to my first Groves conference in St. Petersburg, topic: aging families, me a child developmentalist.

Groves became my perfect professional organizational niche—a place for big idea generation, meaningful conversation, long-time friendships, leadership, and writing (I wonder what Bronfenbrenner would have thought of my formulation of the geosystem as a missing element in his conceptualization of nested systems of development) (Readdick, 2014). After all, we all live somewhere specifically on this physical earth, and where that is makes a difference in the risks and opportunities afforded us throughout our lives. The Groves tradition of studying topics of pertinence to families in a specific place at a specific time makes our organization unique among others.

For me, Groves is opportunity to think broadly not narrowly, to explore topics like globalization and incarceration or climate change or family caregiving and to do something about what we learn—to be better or teach better or help graduate students think better or to push in some way for a greater good. It is a place or context affording me optimal experience or flow because of these organizational characteristics: clarity, centering, choice, commitment, and challenge (Czikszentmihalyi, 1990).

Accordingly, I believe a change of name for our organization to *Groves Colloquy on Social Justice for Families* may be a better description of our history, reflection of our valued organizational characteristics, and moral compass for the future. For this, I must thank Barbara Settles and Libby Blume for our conversation about "what Groves is" during our visit and stroll through the Frederick Law Olmstead-designed gardens at the former Buffalo State Asylum for the Insane during out 2015 conference focused on the theme of "Families at the Intersection of Mental Health and Disabilities". I have chosen *colloquy* as opposed to *conference* to better describe our rich, focused conversation about a topic of mutual concern and interest, our enduring topic being for *social justice for families*.

As for my own family-making and caring, I think it is "good enough" (Winnicott, 1973). Next year, 2019, I will have been married to my husband Steve for 50 years (like Konrad Lorenz's geese) (Lorenz, 1935). I became early attached to, imprinted on this man, I admit), and we continue to love and work together to be good friends and faithful allies (first date—watching sea turtles lay eggs on the beach on St. Simons—last date, a summer spent in our log cabin in Montana overlooking Flathead Lake—not counting yesterday's visit to Home Depot to buy a new wheel barrow). In retirement, we spend as much time as we can with our families and old friends in our shared hometown in coastal Georgia. We have one daughter, Hannah.

Hannah, admittedly, inspired/provoked much of my research and writing—yes, I established most children climb before they walk (a conveniently ignored fact in most child development texts) (Fairbrother, Readdick, & Shea, 2008); children engage rabidly in social comparisons as they construct a sense of self (Readdick, Santrock, & Pollard, 1980); we shortchange children when we say play is their work; no, play is play (self-directed) and work is work (other-directed) and children like adults need to do both (Readdick & Douglas, 2000); children with little hands need little tools to draw and write (imagine fitting our little children in big shoes because they are less capable than adults wearing them) not bigger than adult-size tools we often foist upon them (Readdick, 1994).

Today, my daughter is a talented and respected nurse in cardio-vascular intensive care at our local hospital, with aspirations of college teaching as well. (While still in college, she taught research ethics to my child study students who were captivated by her poise, knowledge, and joy). That day she talked about the Belmont Report, the Nazi atrocities committed in the name of science, the incarceration of the Dionne quintuplets in Canada, the Tuskegee experiments with male African American sharecroppers in Alabama. Married, she and her husband care for 7 chickens, one rooster, 3 rescue dachshunds, and one indoor cat, Hermine, blown onto her yard during Tropical Storm Hermine a couple of years back, one outdoor cat, and a front porch-full of exotic succulents. (Postscript. In July of 2019, Hannah gave birth to a daughter, Lily, joining their bustling household and our family. And, yes, I am thrilled to be part of a new family caring regime and already sewing items for my granddaughter.)

As my mother lingers, I have been given the gift of time to spend more time with her and my sister and to review our lives together as mother and daughter and sister, which has even helped to heal old perceived wounds—time to countenance the contradiction of a having a mother who cared deeply in so many ways but fell short in others. Being chased around the house with a hairbrush, she hoping to land and me hoping to avoid a blow, is an indelible memory. Yet, so, too, are the many more sweet times of picking wild strawberries in the mountains or practicing spelling words or sewing together or sitting on the stool in our kitchen after school, eating A&P cinnamon raisin bread with icing, toasted, and regaling her with every detail of my school day. Now, with each visit with my mother, expecting less, I love her more. Holding her hand in mine, I grow more grateful for a lifetime with her. It remains my turn to care for her. (Post-postscript. My mother died in November 2019. I will forever treasure the memories of my daughter helping her grandmother, my mother, cradle her new and only great-grandchild in her lap, holding one little foot, and resting her cheek softly against the top of my granddaughter's head.)

References

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.

Czikszentmihalyi, M. (1990). *Flow: The psychology of positive experience.* Harper & Row, Publishers, Inc.

Erikson, E.H. (1950). *Childhood and society*. W.W. Norton & Company.

Gibson, J.J. (1979). *The theory of affordances.* In R. Shaw & J. Bransford (eds) *Perceiving, acting, and knowing. Toward an ecological psychology* (pp. 67-82). Lawrence Erlbaum Associates

Lorenz. K. (1935). *Der kumpan in der unwelt des vogels. Der art genosse als auslosendes moment socialer verhaltenweisen. Journal fur ornithologie, 83,* 137-215, 289-413.

Piaget, J. (1936). *Origins of intelligence in the child*. Routledge & Kegan Paul.

Whiting, B. & Whiting, J.W.M. (1979). *Children of six cultures: A psychocultural analysis.* Harvard University Press.

Winnicott, D.W. (1973). *The child, the family, and the outside world*. Penguin.

Selected Personal Publications

Fairbrother, J.T., Readdick, C.A., & Shea, J.B. (2008). A human factors approach to the forensic investigation of a portable crib collapse. *Ergonomics in Design, 16*(1), 14-18

Readdick, C.A. & Park, J. (1998). Achieving great heights: The climbing child. *Young Children, 53*(6), 14-19.

Readdick, C.A., Santrock, J.W., & Pollard, L. (1980). Social comparison in sibling and peer relations. *The Journal of Genetic Psychology, 137,* 91-107.

Readdick, C.A. & Douglas, K. (2000). More than line leader and door holder: Engaging young children in real work in the early childhood setting. *Young Children, 55*(6), 63-70.

Readdick, C.A. (2014). The Irish geosystem and family well-being. In C.A. Readdick (Ed.) *Irish families and globalization: Conversations about belonging and identity across space and time*. University of Michigan Library.

Family Caregiving: An Important Commitment

Eleanor D. Macklin

For the purposes of this paper, I define caregiving as "a commitment to providing care to the extent needed and for as long as needed."

Family caregiving is when such caregiving is extended to family members, whether related or adopted family. It refers to a serious commitment of intent, effort, and resources on behalf of kin and loved ones, as needed.

Caregiving does **not** mean simply lending a hand when asked to do so. It means a commitment to working for the physical security and emotional comfort of a loved one over the long haul. It means a commitment to ensuring that a vulnerable loved one will not be abandoned to cope on his/her own. It means that "I will be there for you, you can count on me"; that "you are not alone, I have your back"; that "I will do whatever I can to facilitate your well-being."

The word I wish to emphasize is *commitment*. All creatures need to feel safe in their surroundings, and humans have a particular proclivity to attach to persons who provide that sense of safety and comfort. Knowing that I can "count on you to be with me, that you will act on my behalf" can provide immense comfort, particularly when one is in a vulnerable state. That kind of comfort can only come from behavior that indicates you are to be trusted, from behavior that proves I can rely on you. Such behavior is the outward and visible sign of commitment.

Family caregiving is usually interpreted as a commitment to caring for a handicapped or disabled family member or for senior parents who can no longer care for themselves. However, it can also refer to adults in their roles as parents, in that parents are expected to care for the well-being of their children until maturity. Likewise, it is relevant to married partners, as in the promise to "have and to hold, from this day forward, for better, for worse, for richer, for poorer, in sickness and in health, to love and to cherish, 'til death do us part." Commitment to care for family, no matter the personal sacrifice involved, has been a moral expectation in our society for centuries. With the shift from familism to individualism, it is less generally acted upon, although still needed.

The obligations of caregiving can seem fairly innocuous at first. Initially, there is little way to predict the care that will be needed down the road or the potential demand on the caregiver. The first offers of help may not even be seen as caregiving--just a few hours a week to take dad to a medical appointment or a few dollars to hire someone to check in on him. It can all seem quite manageable—until suddenly it is not.

The change in need is usually triggered by a medical emergency, with an accompanying urgency to re-evaluate old routines. Suddenly big decisions need to be made: Is it time for assisted living, maybe a nursing home? Time to sell the family home and downsize? Should we go for a second round of chemo or are we ready to call it quits? Family members may disagree on the best route to take, with sister insisting that "we do everything possible to keep dad in his house" and brother arguing "that would be a stupid move", with the potential caregiver caught in the cross-fire. Ensuing resentments are common, especially if the caregiver feels unsupported or unfairly burdened.

The facts in 2017 were that more than one-half of today's 65-year-olds will require long-term care at some point (most for less than two years); one in seven will face more than seven years of disability. Institutional care is expensive. The median cost in 2017 for a one-bedroom assisted-living apartment was $45,000-$60,000 a year, or about $4,000 a month. Nursing home care was estimated at $82,000 a year for a semi-private room, and $20 an hour for health aides. Moreover, Medicare does not pay for long-term care, and Medicaid only covers the costs of long-term care after the resident has paid down all his/her assets. The caregiver will likely be responsible for finding such care and for ensuring there is money to pay for it, and many will find the option unaffordable.

Caregiving can exact immense sacrifice of time, money, and freedom. It is often emotionally and physically stressful, can interfere with one's personal and professional life, may use up savings, and leave one exhausted and overwhelmed. "Compassion fatigue" and "stress pile-up" are common complaints. So why would anyone choose to be a family caregiver? It is easy to predict the answers: "I felt it was the only right thing to do"; "I didn't see any other option"; "You do not abandon someone you love"; "I wanted to give back what I have been given"; "I couldn't live with myself if I hadn't done all I could."

The experience of caregiving is heavily influenced by the quality of the relationship with the care-receiver. In turn, the relationship will be heavily dependent upon the relationship skills of the persons involved. Persons in need of care struggle with loss of skill and status, with becoming a burden on others, with diminishing health and autonomy, with increasing dependence and lack of control. They will likely exhibit periods of anger and depression, fear and shame. I can remember my father saying, as I gave him a bath, "It's really sad when a daughter has to bathe her poor old dad."

The caregiver/care-receiver relationship will depend largely on the ability of the two persons to empathize with one another and to talk easily about their realities. Both will benefit from having others in whom they can confide, to whom they can vent their distress, and with whom they can reaffirm their hopes. Having an outside source of comfort can go a long way toward ensuring that the caregiving is done with respect and understanding and gentle kindness. Moreover, having an external network to supplement caregiving will do much to alleviate stress and burn-out.

All the above issues are likely to be magnified in the coming decade, as the "Baby Boomer" generation reaches seniority. Born between the years of 1946 and 1964 and representing one of the largest population spurts in American history, these adults now represent as much as 28% of the American population. It is estimated that 10,000 Baby Boomers will hit retirement age every day between now and 2030. These are persons who grew up during a relatively prosperous time in our country, with the result that they tend to value hard work, home ownership, and freedom of choice, and expect financial and physical comfort in return for their efforts.

As they age, these seniors will want to live at home as long as possible, will anticipate independent and assisted care when needed, and will resist being shunted to a nursing home. Critics have accused them of being in denial about the challenges of aging and unrealistic about the costs associated with their later years. Many observers are concerned that the funds paid into social security, Medicare, and long-term insurance will be insufficient to meet the demand. How easy will it be for the next generation--who struggle to find secure work, are hesitant to marry and own property, have less disposable income, and are burdened with extensive debt--to pick up the pieces for their aging parents? What kind of commitment will they find they can realistically make for their care? And what are the alternatives? Such are the issues we will discuss in the days to come.

Theoretical Considerations and Personal Reflections on Reciprocity in Care Giving/Care Receiving

Judith Fischer

"I love you."
"I love you, too, Mom."

The opening quotes reflect a frequent exchange between my mother and me in her later years. They also illustrate a central point of this paper: that care giving and care receiving are reciprocal transactions in which actors simultaneously enact both roles. To begin, I'll briefly review the placement of care giving and care receiving within a stress and coping model. I consider reciprocal transactions as a component of social support resources. Then, I illustrate these points drawing on my own experiences as an adult caregiver of an aging parent but also as a recipient of her caregiving to me. Finally, I offer some concluding thoughts about implications for definitions of family caregiving and suggestions for extending research, theory, and practice.

Care giving and care receiving fit within a stress and coping model, such as variations on the ABC-X model (Anderson et al., 1993; Mc-

Cubbin & McCubbin, 1989). Applying the Anderson et al. variation (see their Figure 1 in Anderson et al., 1993), stress and coping in care giving/receiving situations take place in particular families (T for family typology). As one example of a family typology dimension, there can be greater or lesser family cohesion from too little (characterized by disengagement) to too much (characterized by enmeshment) with balanced cohesion in between. A stressor and the pile-up of stressors (A*: A, AA; use of an asterisk denotes a class of elements) contribute to family histories of interactions that inform a family typology. Additionally, there are appraisals of: the stress, the situation, and one's world view (C*: C, CC, CCC) that are brought to bear on the stressor(s). As well, individuals and families have greater or fewer resources to meet the stress and crisis situation and they have degrees of social support available or capable of being activated (B*: B, BB, BBB). Problem solving and coping (PSC) come into play. Each of these elements (T, C*, B*, PSC) interact with each other. Individually and together, when these elements are successful, there is individual adjustment and family adaptation (X*: X, XX). However, when these elements fail or lose their effectiveness, then such difficulties feed back and contribute to a build-up of stressors.

A definition of family caregiving involves a person who needs help (the "receiver") and a person, often a family member, who attempts to provide it (the "carer") (Talley & Montgomery, 2013). There are implications that follow when the stress and coping model focuses on these two people. The assumptions are that when the carer has more positive perceptions, more resources, and greater coping skills, then the carer can provide more help to the receiver. Thus, research and policy consider the carer's needs, perceptions, and emotions around the stresses of caregiving, and professionals attempt to find ways to help the carer become a more effective, less stressed caregiver (Talley & Montgomery, 2013). However, there is another lens within this stress and coping model that draws attention to the transactional nature of the care giver/care receiver relationship. Although there may be a number of locations for this transactional process, because social support is often conceptualized as gives and receives across several domains (Foa & Foa, 1974), I place the process within the BBB social support element in the resources category. First, I'll describe what the transactional process is not and what it is. Then I will come back to what I believe are the benefits of using this approach.

My central thesis is that care giving/care receiving are a form of communication that are simultaneous and transactional. Earlier descriptions of communication processes posited a linear model (communicator → receiver →) (Adler et al., 2005), where the communicator was seen as a sender or encoder of communication who sent that message over a channel to a receiver of that communication. The receiver, in turn, decoded the message and then sent a message back over a communication channel. Each message experienced noise in the channels of communication and existed within a particular cultural context. The transactional model of communication posits that both parties are communicators who *simultaneously* send and receive messages over channels of communication (within a cultural context that also contains noise) (Adler et al., 2005). Applying this transactional communication model to care giving/care receiving means moving from the linear model (care giver → care receiver →) implied in Talley and Montgomery (2013) to one where giving and receiving are simultaneously occurring both in the designated "carer"/"helper" and the designated "receiver"/"helped". *Both* people reciprocate care subject to their abilities in the situation.

Earlier researchers (Fischer et al., 1989; Foa & Foa, 1974; Leslie & Grady, 1985) described social support as including resources that are exchanged in interpersonal relationships, primarily in affectional/emotional and instrumental domains. Reciprocity and exchange of resources are considered important components of social support relationships and, by extension, helping relationships (Caplan & Killilea, 1976). Instead of focusing more attention on the carer, within the lens of reciprocity it is also important to ask: in what ways may the receiver of care reciprocate and enact the role of carer as well? Consideration of a transactional process highlights this important aspect of care giving/receiving that may otherwise be overlooked.

I turn now to illustrating how I see a transactional care giving/care receiving stress and coping model through descriptions of some personal experiences. I could comment on the transactional care giving/receiving that goes on as a parent of a child, or as a partner, or as a friend. Indeed, such relationships can occur and reoccur at any point along the life course (Talley & Montgomery, 2013). Perhaps because the experience is so recent and, for me, so clearly illustrates the concepts I have addressed so far, I have chosen to use as an example the experience of being an adult child of an aging and ultimately a dying parent. As Haley (2013) noted, end of life caregiving is a relatively unstudied situation. In keeping with the stress and coping model, a little of my background and that of my family may be helpful to provide a context for my situation.

On the surface I grew up in a "typical" suburban post-World War II family of mom, dad, three kids (I was the eldest). But the family was dysfunctional with an alcoholic father who raged within the family home, a home that my mother tried to keep together as best she could. Finally, when I was 13 he sought help and the fellowship of AA. Happily ever after? Not really. He was sober but he never seemed to me to have dealt with his anger and rage and his need for reassurance with respect to what he saw as his rightful place as the male head of *his* family. Sober, his bullying diminished but did not go away. Regardless of drinking, I believe he was challenged by my mother's career, a career undertaken first out of necessity and then out of self-fulfillment. In my view, drinking exacerbated his insecurities but refraining from drinking did not make them go away. I left home at 18 for college 2000 miles away and returned for only brief visits.

After my father's retirement, short version, my parents moved to where I lived (eldest daughter here). Within eight years my father had passed away and my mother at age 76 seemed to come into her own, involved in the community, art work, and church. By 87, she was experiencing difficulty keeping a large house and at 88 moved into an independent living retirement community. After a driving scare in which she became lost, at 89 she gave up driving and even helped to sell her car. She appeared to do well in tasks of daily living despite a diminishing ability to remember and to hear. When she was 92, I retired to work on my scholarly research, but my retirement also coincided with my mother's increasing needs for help. By 94, she moved to assisted living, had a grand 95th birthday celebration with extended family but continued to decline in health. Two months after her 95th birthday, after two hospitalizations, she moved to a long-term care facility. Eight months after her 95th birthday, she passed away under hospice care. It was probably not an unusual life experience for someone of this age. I was her primary care overseer as siblings lived far away. Nonetheless, my sister and brother consulted, supported, and came out for brief periods.

If the theoretical lens zeroed in on me as primary care giver, then I would analyze the stressors (A*) that I faced, my family history (T), the perceptions I had (C*), the resources I had or invoked (B*), the ways I tried to cope (PSC), and the ways I adjusted to the situation (X*). I might even consider the benefits to me (Haley, 2013) of this role: increased understanding, greater patience (a characteristic of mine greatly in need of improvement), greater appreciation for how she met the challenges of aging. And, I would ask, how did my adjustment or lack of it, affect my mother and her care? But if I look more deeply at the BBB level, social support as part of a reciprocal and transactional process between us, then the focus shifts to viewing how we, my mother and I, mutually negotiated this stressful time.

I consider myself very fortunate in that my mother did not have years of severe dementia nor years of immobility. Moreover, she did her best to present a cheerful face to me in our interactions. Positivity on her part reflected a change in the emotional tone of our relationship. During most of my adult life we seemed to enact a low-level conflict that sometimes manifested in negative communications from her over how I lived my life. She didn't quite understand how I could be seriously involved with someone and not want to live with him. We clashed over how I appeared, such as my hair, my lack of more than minimal makeup, the clothes I chose. But gradually those conflicts diminished to be replaced with increased expressions of love and gratitude from her. She was offering me the kind of care giving that I not only appreciated, but needed. Although I wasn't necessarily thinking of our relationship as a transactional process, over time, I became aware that when I offered care to my mother she offered care back to me! As might be expected, my support to her contained more instrumental components and hers to me was more expressive and affective. What is important to recognize is that I was as much of a receiver as she was: I didn't just give care, I received care from her that was helpful to me.

Using the transactional view of social support and applying it to our experiences, how did this transactional engagement occur? What did it look like? I'll focus on those last months of my mother's life. I would visit several times a week and I would ensure that staff people were doing the things that needed doing: putting moisturizer on her skin, seeing that she got her hair done, doing her laundry and putting it away, etc. I would also bring my cell phone or iPad and share Facebook posts of her children, grandchildren, and great grandchildren and photos of my travels. I would talk about music we were doing in choir, the little things that connected us and that I thought she would like hearing about. At virtually every visit she told me how much she appreciated me and what I did for her and she told me she loved me. I believe these expressions of appreciation and love were her way of giving me care, her way of fulfilling the potential for reciprocity in our relationship. And I found that I welcomed these heartfelt expressions. I could move out of my more instrumental role, mostly put to rest our past conflicts, and reciprocate her affection by telling her I loved her. Even though I believe we both felt love for the other, such exchanges of positive emotions had been a small part of our relating to each other prior to her health declines.

Until I began to think about the presentation I was asked to give at the Groves Conference that preceded this paper, I hadn't verbalized to myself how she, the supposed recipient of my care, was also care giving to me. I just thought it was nice of her to be so positive. But one of my mom's central characteristics as an adult was giving care to others. She would tell me that after taking care of my two grandmothers and my father that she understood what it was like to care for others. She wanted to be sure I knew how much she appreciated what it took to care for another. When she could still go out with me in the car, she would apologize for being so slow or for not being able to hear well. She wanted to make things easier for me. I have come to realize what a great gift to me were her attitude and communications. When she was dying, hospice helped my sister and brother and me to recognize what my mother needed emotionally from us. She needed to hear words that went beyond telling her we loved her and that she was a good mother to words that let her know that each of us would be okay. In this way, her own care giving role with her children was given closure. Her last words were to tell each of us she loved us.

Not everyone has a parent or someone they are caring for/receiving from who expresses gratitude and love. The valence of transactions can be important to both carers/receivers and deserves its own study and attention. Not everyone has a parent who can still remember them in their later years. Nonetheless, if norms of reciprocity are important aspects in the lives of many and awareness of these norms remains throughout much of aging, how might "receivers" express "caring" or how might "carers" interpret the communications of the other person in the transactional relationship as care giving from the "receiver"? Returning to the experience with my mother, I believe her finding a way to reciprocate my care provided her with some dignity in the situation, that she was doing what she could to maintain her end of the reciprocal relationship. I offer this extension of Talley and Montgomery's (2013) definitions of family caregivers as ones who care for relatives and loved ones to add that caregivers are also care receivers and care receivers are also care givers.

Future research could investigate this end of life stage through the lens of a transactional model and could identify aspects that promote reciprocal positivity beneficial to both actors in the situation. Among other aspects, such work could explore gender dynamics, boundary issues, financial well-being, housing issues, and how positive reciprocity can be enhanced in caregiving/care receiving. Research and practice in the family therapy field, such as the work of Gottman (2011) on couples and marriages, has highlighted the value of trust in relationships and the importance of a preponderance of positive messages over negative ones for couple well-being. I saw firsthand that positive reciprocity of care giving/receiving can be an invaluable social support, even a gift to those helping each other when one is facing an end of life.

I say, "Love ya', Mom."
And I hear her say, "I love you, too."

References

Adler, R. B., Proctor, R. F., & Towne, N. (2005). *Looking out/looking in (11th ed.)*. Wadsworth.

Anderson, E., Bell, N. J., Fischer, J., Munsch, J., Peek, C. W., & Sorell, G. (1993). Perspectives on risk taking. In N. Bell & R. Bell (Eds.) *Adolescent risk taking* (pp. 165-185). Sage.

Caplan, G., & Killilea, M. (1976). *Support systems and mutual help*. Grune & Stratton.

Fischer, J. L., Sollie, D. L., Sorell, G. T., & Green, S. K. (1989). Marital status and career stage influences on social networks of young adults. *Journal of Marriage and the Family, 51,* 521-534.

Foa, U. G., & Foa, E. B. (1974). *Societal structures of the mind*. C C Thomas.

Gottman, J. M. (2011). *The science of trust: Emotional attunement for couples*. W W Norton & Co.

Haley, W. E. (2013). Family caregiving at the end-of-life: Current status and future directions. In R. C. Talley & R. J. V. Montgomery (Eds.) *Caregiving across the lifespan: Research, practice, policy* (pp. 157 – 175). Springer.

Leslie, L., & Grady, K. (1985). Changes in mothers' social networks and social support following divorce. *Journal of Marriage and the Family, 47,* 663-673.

McCubbin, M., & McCubbin, H. I. (1989). Theoretical orientations to family stress and coping. In C. R. Figley (Ed.), *Treating stress in families* (pp. 3 – 43). Brunner/Mazel.

Talley, R. C. & Montgomery, R. J. V. (2013). Caregiving: A developmental, life-long perspective. In R. C. Talley & R. J. V. Montgomery (Eds.) *Caregiving across the lifespan: Research, practice, policy* (pp. 3 – 10). Springer.

Eastern light illuminated the beginning of a new day for family caregiving and love

Volume Figure 3: Käsebier G. (1913). *The Ruyl Family* [platinum print]. Portland Museum of Art, Portland, Maine.

Gertrude Käsebier (United States, 1852 - 1934)
The Ruyl Family, 1913
Platinum print, 9 x 7 3/8 inches
Portland Museum of Art, Maine. Museum purchase with support from the Photography Fund, 2006.14.3.
Image courtesy of Luc Demers. Reproduced with permission.

Chapter 5

Rural Grandparents Raising Grandchildren: Family Caregiving through Crisis, Adaptation, and Advocacy

Sandra J. Bailey and Bethany L. Letiecq*
Montana State University

Caregiving is a principal family function encompassing the provision of both physical and socioemotional care across the family life-course (Aldous, 1999). In general, family members—and especially women—are expected to give primary care to their children, to aging relatives, and to those with physical and mental health care needs. Family caregiving expectations, norms, and mores can differ across cultures, by race, class, and gender, and by one's opportunity structure (e.g., with access to more or fewer caregiving resources). Family caregiving can also be supported or constrained by a family's situatedness in society, by social policies and laws, and by one's family configuration. Beginning in the 1990s, family scholars began to document a new form of family caregiving, involving grandparents caring for their grandchildren without a parent present, often as a result of a family crisis (Bryson, 2001; Jendrek, 1994; Roe et al., 1994).

To be sure, across many cultures, grandparent involvement in the caregiving of children has a rich and complex history and has been a meaningful intergenerational caregiving mechanism essential to many families, where grandparents have transferred knowledge, culture, and care to their grandchildren. In certain cultures (e.g., Native American, African American), significant grandparent involvement in family caregiving is normative (Stack, 1974; Cross et al., 2010; Yancura, 2013). How-

*Correspondence to: Sandra J. Bailey, Professor & Extension Specialist, Montana State University; baileys@montana.edu

ever, grandparents solely caring for their grandchildren because parents are either unwilling or unable to parent is a more recent non-normative familial phenomenon occurring across racial/ethnic groups and across diverse geographic locations, including families residing in rural areas (Van Dam, 2019). This type of caregiving is considered off-time, and often is unexpected, following a crisis in the family system and the need for kin intervention (Bailey et al., 2009).

Grandparent caregivers in these family configurations often face a multitude of challenges, including family trauma, abuse and neglect, lack of institutional supports and resources, caregiver burden, social and emotional stress, financial insecurities, legal constraints, intrafamilial conflict, a loss of community, and concerns about their abilities (both physical and emotional) to meet the needs of their grandchildren (Hayslip & Kaminski, 2005). The adaptation to this new family structure takes time, new resources, navigating new systems, and often demands that grandparents adjust their familial roles from that of grandparent to that of parent and primary caregiver of their grandchildren (Letiecq et al, 2008a). Grandparents residing in rural locales may face additional challenges due to their geographic isolation, with limited economic opportunities and limited access to services (e.g., counseling services, specialized health care) and resources (Grutzmacher & Braun, 2005).

Although research on grandparents rearing their grandchildren has increased substantially in the past several decades (see Hayslip & Kaminski, 2005), to include rural grandparent caregiving (Letiecq et al., 2008a), the topic is often left out of the general family caregiving literature. The purpose of this paper is twofold. First, we highlight grandparent caregiving as an oft neglected form of family caregiving (Yancura, 2013). Second, we draw upon our work with rural grandparent caregivers and the work of other scholars studying grandparent caregiving to document the processes that grandparents rearing their grandchildren experience as they move through and past crises that precipitate this new family configuration. We illustrate how these families learn to adapt to their new family structure and advocate for grandfamily recognition and value in society.

Background

The Montana Grandparents Raising Grandchildren Project was created by the authors within Montana State University Extension in 2002 to address the needs of the growing numbers of grandparents in the state being called upon to raise their grandchildren when the parents were unable or unwilling to fulfill their parenting responsibilities. Montana is a rural state—the 4th largest state in the US with just over one million residents (U. S. Census, 2018). Montana is also home to seven Native American reservations, often located in the most remote regions of the state, with limited access to basic services, such as healthcare, grocery stores, clothing stores, and banks.

The first wave of grandparent caregiving as family intervention in many rural states was fueled by the methamphetamine epidemic of the 1990s (National Association of Counties, 2005). While methamphetamine continues to be an issue in this western state, nationally and within Montana, the opioid epidemic has greatly expanded the number of families in this new family structure (Generations United, 2018). For over 17 years the project has documented the lived experiences of grandparent caregivers, conducted applied research studies, developed fact sheets, and educated professionals in organizations, agencies, and policymaking about the needs and development of these families as they adapt to this new way of being a family. We have also supported the creation and passage of new laws in Montana giving grandparents rights, under certain circumstances, to make educational and medical decisions on behalf of their grandchildren (Caretaker Relative Educational Authorization Affidavit, 2017; Caretaker Relative Medical Authorization Affidavit, 2017; Caretaker Relative Rights Upon Return of Parent, 2017).

In our work, we have documented how grandparent caregivers progress from crisis when first taking in their grandchildren, to adjustment and adaptation, and to advocacy on behalf of their own and other similarly configured grandfamilies. Using the Double ABCX Model (McCubbin & Patterson, 1983) and drawing upon our extant research (Bailey, Haynes, et al., 2013; Bailey, Letiecq, et al., 2013; Bailey et al., 2009; Bailey et al., 2019; Letiecq et al., 2008a; Letiecq et al, 2008b; Letiecq et al., 2008c), we will discuss in greater detail the situatedness of this family structure, the journey grandparents take as they assume new roles within their families, and the adaptations that occur. But first we delve into some theoretical perspectives related to grandparent caregiving.

Theoretical Perspective

Grandparents rearing grandchildren experience an array of normative and nonnormative stressors as they navigate changes in their family system (Boss, 2002). To better understand grandfamilies' adaptation to stress and crises and their responses to family transitions over time, the Double ABCX Model of Family Adjustment and Adaptation is useful (McCubbin & Patterson, 1983). According to the model, families often confront and cope with both normative and non-normative stressors or life events impacting the family unit. To cope, families can take up resources available to them. There are three common resources that can mitigate stress and support positive family adaptation, including a family member's own personal resources (e.g., experience, knowledge, flexibility), the family system's internal resources (including family myths, traditions, and solidarity in the face of challenge), and social support (including informal supports, governmental resources, and social welfare programs). Finally, the family's perception of the crisis provides situational definition and meaning.

The Double ABCX Model recognizes that over time, families can experience multiple stressors, shifts in resources, and changing perceptions of the situation which can result in varied outcomes. For some families, their situatedness and access to resources (including governmental supports) may support resilience building post crises, where family systems bounce back from crises and experience greater cohesiveness and strength. For other families that have fewer resources or complex histories of trauma and stress, enduring crises can deplete their resources and render them vulnerable to poor outcomes. Central to the theorizing here is the recognition that families are dynamic, can withstand some stressors and crises, but may not be able to manage and cope with the layeredness of trauma and stress that can persist over time and confront grandfamily systems in complex ways.

When a crisis demands change in a family, effective coping often requires reframing and redefining the situation—clarifying issues, hardships, and tasks—so that the crisis becomes more manageable and controllable. Reframing the situation also can help decrease the intensity of emotional burdens associated with the crisis and encourages families to shift in ways that facilitate its fundamental tasks of promoting members' social and emotional development. Taylor et al., (2016) found this when studying grandparents who were raising grandchildren as a result of adult daughters' drug additions. The ability of families to form positive appraisals of the situation as an "opportunity for growth" as opposed to a "devastating crisis" can facilitate family adaptation for some families. Families who are unable to adjust and form positive appraisals can become stuck and may be limited in their adaptation and abilities to create a new state of equilibrium. Importantly, some families may be hindered in their adaptation by larger systemic forces that are beyond the families' control, yet, can exert pressure on the family and interfere with healthy adjustment and adaptation. For example, "informal" grandparent caregivers who do not have legal authorization to make educational decisions on behalf of their grandchildren or are not eligible for financial assistance or governmental services may be disadvantaged by "the system" and hindered in their ability to function, overcome myriad stressors, and meet their familial needs. Other families may be privileged by their positionality or residence in a more populous locality and their coping may be facilitated by, for example, their access to resources and services essential to their thriving (Letiecq et al., 2008a).

Transitions Necessitated by Off-time Parenting

Family caregiving can occur anytime over the lifespan and some is expected, such as caring for young children or aging parents. However, the unexpected caregiving situations such as taking on the parenting role for grandchildren can render grandparents in a state of stress and crisis. There are many reasons grandparents are called upon to care for their grandchildren including parents' being unable or unwilling to take on the parenting role because of mental or physical health problems, disability, substance abuse, teen pregnancy, incarceration, military deployment, or parental death (Bullock, 2004; Cox, 2003; Emick & Hayslip, 1999; Letiecq et al., 2008a; Taylor, et al., 2016; Weber & Waldrop, 2000). Such circumstances can be born out of familial crises and can thrust families into a state of imbalance and disequilibrium. For example, one grandparent couple we worked with received an unexpected call from family services that their grandchildren were panhandling outside of a grocery store. The grandparents were asked to take in their grandchildren immediately or else they would be placed in foster care. The immediate, unexpected, and non-normative stress caused by such a situation resulted in familial crisis and necessitated significant non-normative changes or shifts within the family system. Living in a rural town, these grandparents struggled to find the resources their grandchildren needed (especially clinical and mental health services) and they had to make do without resources and sources of formal supports that are common in more populated areas.

When a major stressful event occurs, families likely seek to use existing resources such as savings, support from other family members, and adaptations to routines to get through the event. The ability of family members, in this case grandparents, to cope with the stress has an impact on how readily a family can address the crisis. One grandmother told us that she, her husband, and the grandchildren stayed in the house, isolating themselves, and did not see others or go anywhere for the first couple of weeks after the grandchildren came to live with them. The grandparents simply did not know what to do, and their grandchildren had high needs due to parental abuse and neglect. For a period of time, this grandfamily was immobilized by the crisis. Once the immediate crisis – having the grandchildren move in – passed, the grandparents sought new resources, began to understand the extent to which their family had fundamentally changed, and started transitioning to their new family configuration. The transitions grandparent caregivers face and their ability to cope and adapt to the changes in their families may vary. Next, we discuss some of the more salient shifts or adaptations that many grandfamilies may experience, with an emphasis on rural family experiences.

Navigating Changing Roles

Grandparents who are called upon to raise their grandchildren experience many role shifts – including shifting from grandparent to becoming a parent of children again. Many grandparents may be reticent to make this shift because they remain hopeful that their children/parents of their grandchildren will "get their act together" and return to the primary parental role. This transition from grandparent to parent can be compounded by the "off time" nature of these events in one's life course. Often grandparents are parenting in the years when they had planned to be retired or experiencing an empty nest. Often, they ask themselves, "Am I a parent or a grandparent to my grandchildren?" Many exist in an ambivalent state, as they continue to dream and hope that their adult children will come back and take on their parenting responsibilities. However, to remain ambivalent can render the family system rudderless, as the grandchildren and grandparents are unsure of their respective roles within the new family constellation. How does one handle this intergenerational ambivalence?

There is no one way to resolve role confusion and ambivalence in grandfamilies. However, in our research, we found that resilience or a family's ability to bounce back from adversity was facilitated in systems where the grandparents made clear shifts within their families, taking on the role and identity of parent (Letiecq et al., 2008a). Adopting this new role in the lives of their grandchildren provided structure, discipline, and routines that appeared to promote grandfamily bonadaptation and well-being. However, doing this family work in rural communities can add a layer of complexity because of the limits of anonymity in a small town. In our research, grandparents often shared that they did not want their communities to know "their business" and worried about being the focus of town gossip. While some grandparents felt supported by their communities, others felt stigmatized and embarrassed by their circumstances as grandparent caregiving signaled the failings of their adult children as parents (Letiecq et al., 2008b).

As grandparents adjust their identity and roles and perform the day-to-day parenting functions within their family system, the grandchildren also shift and influence how the new roles manifest. Some grandchildren prefer to call their grandparents "mom" and "dad", while others like to continue to use "grandma" and "grandpa" or other grandparent titles. For the grandchildren, the terms can change depending upon the setting. For example, at school or in public places, the grandchildren may prefer "grandmother" and "grandfather" to dispel the stigma of not being raised by their parents, while using "mom" and "dad" at home. The terminology may be different for each child in the family. For example, within one grandfamily system, the younger child moved in with the grandparents at an early age and used the terms "mom" and "dad" when referring to the grandparents. An older sibling came to live with the grandparents at a later time, and preferred "grandmother" and "grandfather." The older sibling experienced more time with the grandparents in their traditional family roles and did not want to change those dynamics. Some grandchildren may also try to avoid the perception of disloyalty or betrayal of their parents by accepting their grandparents as their parents. The sibling mentioned above might also have tried to avoid the stigma among peers for being raised by grandparents.

Many grandparent caregivers are near or in retirement (Bailey et al., 2013). As they are adjusting to the role of parenting again, they also must adjust their finances and their relationships to the state, seeking financial assistance, health care assistance, and social welfare aid that they may have never sought before. In rural communities, the agency workers charged with delivering services may be known to the grandparents, and some grandparents may feel ashamed of having to take up assistance, particularly in rural locales where "pulling oneself up from the bootstraps" is expected and revered (Swader, 2013).

Grandparent caregivers must also grapple with their new social network realities. Many grandparent caregivers are aware that their peer group may no longer have similar interests or share similar concerns. Others their age may be planning trips or enjoying the freedom of the empty nest, leaving some grandparent caregivers with a sense of loss and feelings of isolation. When grandparents take on the role of parent, shifts occur within the self, within the grandparent-grandchild and other familial relationships, with their finances and retirement planning, and within their social networks and broader communities. Support, whether formal or informal can buffer negative impacts of caregiving grandchildren (Gerard et al., 2006).

Acknowledging and Coping with Mental Health Issues

Over the years that we have worked with grandparent caregivers, we have noticed how many grandparent caregivers shift or transition from crisis to adaptation and resilience. In our early work, like many researchers, we assessed depressive symptoms in grandparent caregivers and found similar results, that they tend to have higher levels of depressive symptoms and high parenting stress than other caregivers (Bowers & Myers, 1999; Burton, 1992; Caputo, 2001; Grinstead et al., 2003; Hayslip et al., 2002; Kelley, Whitley, Sipe, & Yorker, 2000; Letiecq et al., 2008b; Minkler et al., 2000). As grandparents adjust and adapt to the changing dynamics within their families and work to meet the needs of their grandchildren, social supports are important resources and can mitigate mental health burdens (Bailey et al., 2009; Landry-Meyer et al., 2005; Landry-Meyer, 2000). More recently, researchers have examined how grandparent caregivers help their families build resilience as they look for and utilize new resources and work to change their perceptions about the situation (Bailey et al., 2019; Bailey et al., 2009; Taylor et al., 2016). Importantly, complex and layered familial stressors, intergenerational traumas, and limited governmental resources for grandfamilies can exacerbate grandparent poor mental and physical health outcomes, especially in rural communities where access to health care can be limited.

Developing and Maintaining New Boundaries

Perhaps not surprisingly, many grandparents we have met have had to change or renegotiate physical and/or psychological boundaries within their family systems and (re)determine who is in or out of the family based on the adult child's behaviors. Often mental health challenges or substance abuse has forced grandparents to make tough decisions and cut their adult child out of their lives in order to protect their grandchildren and themselves (Bailey et al., 2009; Taylor et al., 2016). In such cases, as Boss (1999) suggested, the parent may be physically absent but psychologically present, leaving the child with an ambiguous loss. Maintaining boundaries and/or cut-offs can be difficult to achieve in rural communities where communities are close-knit and the chance of running into the cut-off family member is high. The family may experience struggles as the adult child comes and goes unpredictably, causing disruption to family routines and confusion within the system.

Other adult children with their own children may influence family boundaries too. Some adult children may feel that the grandchildren residing with the grandparents are given preferential treatment or receive more attention or familial resources than the other grandchildren who live with their parents. Negotiating these reconfigured relationships within grandfamily systems can be challenging, especially when grandparents may be feeling overwhelmed with their new parental responsibilities and the often high degree of care needs of their resident grandchildren. Tensions that arise across familial relationships can further exacerbate grandparent mental and physical health, deplete psychic resources, and render them vulnerable to poor outcomes, including depression and fatigue. Grandfamilies that can find a healthy “new normal” across kinship systems and cultivate supportive relationships rather than contentious ones likely will be more facile at building resilience and overcoming adversities.

Navigating Policies and Laws

When parents are unable or unwilling to parent, challenges to those who take over this role (e.g. grandparents) can arise, especially if the roles are informally established outside of the child welfare system (Letiecq et al., 2008c). In our work, we have found that grandparents often felt they had no rights or supports as they took over the parenting role. The lack of formal (and legal) custodial relationships with their grandchildren can leave both the grandparent and grandchildren in a state of legal limbo. Three areas that have caused legal challenges for the grandparents in our state were: 1) the ability to make medical decisions for grandchildren; 2) the ability to enroll their grandchildren in school; and 3) the lack of legal controls or authority over their adult children in informal kin caregiving systems, where adult children can threaten to or actually take their children back at a moment's notice with or without grandparent consent. One grandmother was unable to obtain immunizations for her grandson or enroll him in Head Start, even though the child's parents were unavailable. Such circumstances made it very difficult for the grandparent to function and meet the needs of her grandchild. Other grandparents and grandchildren were left in constant fear or worry of the parent returning after being gone for months or years. If a parent does return, law enforcement or social welfare agency workers often have no choice but to immediately return the children to the parents upon their return.

Financial Vulnerability and Well-Being

Financial well-being is another aspect that can be disrupted when grandparents take on the task of parenting a second time around. Our work with grandparent caregivers spans from young grandparents, age 36 to great-grandparents age 87, although the average age among grandparent participants was 59-60 years of age. Young grandparents may have the opportunity to continue a projection of building financial security and planning for retirement, depending upon the needs of the grandchildren. For older grandparents who are nearing or in retirement, the situation may be very different (Bailey et al., 2013). Grandparents planning on retirement often reported delaying their plans as they needed income to support the grandchildren. One grandmother, angry that her adult child was not being a responsible parent, pointed to her grandson, and said "that is my motorhome." She had dreamed of travelling in retirement and now the dreams were gone.

Some grandparents and especially grandmothers reported leaving the workforce as the grandchildren had emotional and/or physical needs that required constant care. Both grandfathers and grandmothers (especially single grandmothers) who were retired also reported going back into the workforce to support the new family constellation. Grandparents in our studies often reported having to reassess their resources and financial plans as their families morphed into grandfamilies. In rural communities, making this transition can be further challenged by the lack of opportunities to rebuild careers or restart employment that is in short supply. Grandparents rearing grandchildren are likely eligible for some financial assistance from the government to include Medicaid and food stamps. However, rural grandparents may be reticent to accept such assistance due to stigma and shame and insensitive service providers (King, et al., 2009).

Assessing Housing Needs and other Unforeseen Expenses

Housing can be a challenge for grandparent caregivers that can add stress to their situation. Some grandparents have downsized and do not have extra rooms for grandchildren when they are called upon to parent again. Others may have moved into senior-only housing that may require them to move. Many need to replace or acquire bedroom furniture, toys, and/or baby items to take in the grandchildren. Those taking in adolescents may need to purchase an additional car to transport grandchildren to school events and social activities. Others are challenged to find money in the household budget to support extracurricular activities in which the grandchildren may want to participate. One grandparent couple attended a single support group meeting. They were doing fine raising their teenage grandson but he wanted to play football. That was not in the budget, and the grandfather simply needed to know how he might find services to help with equipment costs. Another grandmother had a grandson who wanted to take a date to the high school prom. She too was making ends meet, but the cost of prom was more than she could afford. The grandparents may be willing to take on the role of parenting a second time around, however, the logistics can be daunting. In some cases, seemingly simple requests, such as money so a grandchild can participate in sports or school events, can add to stress levels and caregiver burden, especially when finances are tight and opportunities to generate additional income are limited.

Adapting to a New Reality: Moving through Crisis to Advocacy

Our research informed the work of the Montana Grandparents Raising Grandchildren Project. From the crises and transitions we observed in grandfamily systems, we searched for available resources and, in some cases, worked to create systems to address the needs of grandfamilies, support their systems navigation, provide educational information, and facilitate their advocacy for themselves or for other grandparent caregivers. Providing support and advancing policies that support this family configuration are necessary and needed (Taylor et al., 2016). For example, in Montana, we developed a system of psychoeducational support groups around the state to provide local support to grandparents rearing their grandchildren. Support groups have been found to assist with emotional well-being and positive adaptation (Leder et al., 2007; Strom & Strom, 2000). Often the group members move from needing emotional support, to seeking educational programming, to assist in creating a healthy family environment. Many reach a point of advocacy including helping fellow members navigate schools, agencies, and organizations with which the family interacts and working to create policy change.

To develop the system of support groups we first, as an Extension program, reached out to County Extension Agents to assess their interest in providing local support to grandparent caregivers. Next, we partnered with AARP Montana, the Montana Department of Public Health and Human Services, our state Office of Public Instruction and others to determine what resources and support were available for grandparent caregivers in the state. Then we developed a two-day training for Extension Agents and other interested community members to learn about grandparents raising grandchildren and how to start a support group. We utilized the *Parenting a Second Time Around* (Birkmayer et al., 2015) curriculum out of Cornell Cooperative Extension as a guide for the training. During the two days, we discussed the issues confronting grandparent caregivers, how to start and facilitate a support group, statewide resources, and how to search for local support.

The support groups have served as the backbone of our work to facilitate grandparent caregivers' journeys as they transitioned from grandparenting to parenting a second time around. The groups offer the opportunity for grandparents to share losses of what was, challenges in parenting their grandchildren, and successes as a new family model. Typically, after going through the loss and crisis of their family situation, the grandparents reach for new resources such as the support groups and engage in a process of "re-educating themselves" on successful parenting a second time around. Many grandparents have also engaged in advocating for their grandchildren and participating in larger, state-wide advocacy campaigns. For example, caregivers in one Grandparents Raising Grandchildren (GRG) support group were so frustrated by the legal challenges interfering with their parental functioning that they worked with state legislators to advance three bills that all passed the 2007 Montana Legislature. Two bills provided grandparents with pathways to make educational and medical decisions on behalf of their grandchildren if the biological parent was unavailable to obtain medical care and enroll the grandchild in school for 6 months or more. The third bill—a de facto custodian bill that has yet to be tested in court—blocks biological parents from returning after a 6-month absence and taking the children from the grandparents upon return without legal consent. Beyond the legislative efforts, grandparent caregivers have also participated on a national grandfamilies advisory council established by the Generations United non-profit organization based in Washington, DC. The council gives feedback to the organization which advocates for grandfamilies at the national level. Clearly, these grandparents have gone from crises to adaptation and advocacy.

Within the Montana GRG Project, we also have developed programming to address stress, such as workshops on managing stress and updating grandparent caregivers on current parenting practices. During workshops, grandparents were encouraged to share experiences, challenges and successes in off-time parenting, to consider stress management strategies, as well as learn strategies for financial, nutritional, relational, parental, school, and workplace health. We also utilized an evidence-based program called *Powerful Tools for Caregivers* (www.powerfultoolsforcaregivers.org) in partnership with grandparents to support their understanding of and nurture their self-care. Caregivers often ignore their own needs when taking care of others. For example, a grandmother caregiver may cut back on her prescribed medication to make sure there is money to pay for groceries for the family. This can result in deterioration of one's own physical and mental health (Baker & Silverstein, 2008; Hayslip et al., 2015; Letiecq et al., 2008b). The *Powerful Tools* curriculum has been helpful in creating a dialogue about self-care, caregiver burnout, and strategies for building resilience and overcoming adversities when parenting a second time around. Grandparents who participate in the class create action plans each week of how they will practice self-care. For example, one grandmother developed an action plan where she dedicated time to start knitting again – an activity she enjoyed but had given up when the children first came into her care.

Conclusion

Grandparent caregiving—where grandparents are the sole providers and caregivers of their grandchildren--is an increasingly common form of family caregiving that is often overlooked in the caregiving literature. Rural grandparent caregiving is likewise an area in need of more scholarly attention. This emergent family structure continues to grow as grandfamilies seek to "take care of their own" when a family crisis occurs and as child protective services seek kin as preferred caregivers when a child is removed from the custody of their parents (Letiecq et al., 2008c). Grandfamily caregiving is off-time, non-normative, and often sudden in nature resulting in grandparents experiencing familial stressors that can lead to crises. Grandparents rearing grandchildren in rural communities may experience additional stressors given the limited employment opportunities, limited resources, and limited services that may be available to support grandparent and grandchild functioning and well-being.

As we have learned over the course of our work with grandfamilies in Montana, assisting grandparent caregivers in unpacking the complex and layered experiences of this significant life event, helping them assess their current resources, assets and perceptions of the situation, encouraging them to access existing and new resources (if eligible), and supporting them as they go through the journey from being a grandparent to once again parenting children, appears meaningful for their adaptation. Given the diversity of grandfamily characteristics, circumstances, and contexts—including geographic challenges linked to rurality—it is critical that researchers, practitioners, and policymakers continue to work to understand the needs of diverse grandfamilies and align services, resources, and policies to better meet their needs in culturally responsive and appropriate ways. Grandparent caregiving has become a fundamental resource in our society that merits greater attention and support.

References

Aldous, J. (1999). Defining families through caregiving patterns. *Marriage & Family Review*, *28*(3-4), 145-159, DOI: 10.1300/J002v28n03_12

Bailey, S., Haynes, D., & Letiecq, B. (2013). "*How can you retire when you still got a kid in school?*": The economics of raising grandchildren in Montana. *Marriage and Family Review, 49*(8), 671-693, DOI: 10.1080/01494929.2013.803009

Bailey, S. J., Letiecq, B. L., Erickson, M., & Koltz, R. (2013). Resilient grandparent caregivers: Pathways to positive adaptation. In B. Hayslip, Jr. & G. C. Smith (Eds.) *Resilient Grandparent Caregivers: A Strengths-Based Perspective.* Routledge Taylor & Francis.

Bailey, S. J., Letiecq, B. L., & Porterfield, F. (2009). Family adaptation and coping among grandparents raising grandchildren. *Journal of Intergenerational Relationships, 7,* 144-159, DOI: 10.1080/15350770902851072.

Bailey, S. J., Letiecq, B. L., Visconti, K, & Tucker, N. (2019). Rural Native and European American custodial grandparents: Stressors, resources, and resilience. *Journal of Cross-Cultural Gerontology, 34*(2), 131-148, DOI: 10.1007/s10823-019-09372-w

Baker, L. A. & Silverstein, M. (2008). Preventative health behaviors among grandparents raising grandchildren, *Journal of Gerontology, 63B*(5), S304–S311, DOI: 3443/10.1093/geronb/63.5.S304

Birkmayer, J., Jensen, I., Variano, D., & Wallace, G. (2015). *Parenting the second time around* (4th Ed.), Ithaca, NY: Cornell Cooperative Extension.

Boss, P. (2002). *Family stress management: A contextual approach*. Sage Publications.

Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief.* Harvard University Press.

Bowers, B. F., & Myers, B. J. (1999). Grandmothers providing care for grandchildren: Consequences of various levels of care giving. *Family Relations, 48*(3), 303-311, DOI: 10.2307/585641

Bryson, K. (2001, November). *New Census Bureau data on grandparents raising grandchildren.* Paper presented at the 54th annual scientific meeting of the Gerontological Society of America, Chicago.

Bullock, K. (2004). The changing role of grandparents in rural families: The results of an exploratory study in southeastern North Carolina. *Families in Society: The Journal of Contemporary Social Services, 85*(1), 45-54, DOI: 230178335/F4547F511AE246A9PQ/8

Burton, L. M. (1992). Black grandparents rearing children of drug-addicted parents: Stressors, outcomes, and social service needs. *The Gerontologist, 32*(6), 744-751, DOI: 3443/10.1093/geront/32.6.744

Caputo, R. K. (2001). Depression and health among grandmothers co-residing with grandchildren in two cohorts of women. *Families in Society: The Journal of Contemporary Human Services, 82,* 473-483, DOI: 10.1606/1044-3894.166

Caretaker Relative Educational Authorization (2017). Montana Title 20. Education § 20-5-503. Caretaker relative educational authorization affidavit.

Caretaker Relative Medical Authorization (2017). Montana Title 40. Family Law § 40-6-502. Caretaker relative medical authorization affidavit.

Caretaker Relative Rights Upon Return of Parent (2017). Montana Title 40. Family Law § 40-6-602. Caretaker relative rights upon return of parent--continuing custody affidavit--review, finding, and order by district court--limited reconsideration—immunity.

Cox, C. B. (2003). Designing interventions for grandparent caregivers: The need for an ecological perspective for practice. *Families in Society: The Journal of Contemporary Human Services, 84*(1), 127-134, DOI:10.1606/1044-3894.76

Cross, S., Day, A., & Byers, L. (2010). American Indian grand families: A qualitative study conducted with grandmothers and grandfathers who provide sole care for their grandchildren. *Journal of Cross-Cultural Gerontology*, 25, 371–383, DOI:10.1007/s10823-010-9127-5

Emick, M. A., & Hayslip, B. (1999). Custodial grandparenting: Stresses, coping skills, and relationships with grandchildren. *International Journal of Aging and Human Development, 48*(1), 35-61, DOI:10.2190/1FH2-AHWT-1Q3J-PC1K

Generations United (2018). *Raising the children of the opioid epidemic: Solutions and support for grandfamilies.* Washington DC: Generations United. Retrieved from: https://www.gu.org/app/uploads/2018/09/Grandfamilies-Report-SOGF-Updated.pdf

Gerard, J. M., Landry-Meyer, L., & Guzell-Roe, J. (2006). Grandparents raising grandchildren: The role of social support in coping with caregivers challenges. *International Journal of Aging and Human Development*, *62*(4), 359–383, DOI:3443/10.2190%2F3796-DMB2-546Q-Y4AQ

Grinstead, L. N., Leder, S., Jensen, S., & Bond, L. (2003). Review of research on the health of caregiving grandparents. *Journal of Advanced Nursing, 44*(3), 318-326, DOI: epdf/10.1046/j.1365-2648.2003.02807.x

Grutzmacher, S., & Braun, B. (2005). Food security, food resource management, and health among rural, low-income families: Implications for nutrition education with limited resources. Society for Nutrition Education Annual Conference, Orlando, Florida.

Hayslip, B., Blumenthal, H, & Garner, A. (2015). Social support and grandparent health: One year longitudinal findings for grandparents raising their grandchildren. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 70* (5), 804-812.

Hayslip, B., Emick, M. A., Henderson, C. E., & Elias, K. (2002). Temporal variations in the experience of custodial grandparenting: A short-term longitudinal study. *Journal of Applied Gerontology, 21*(2), 139-156, DOI: 3443/10.1177/07364802021002001

Hayslip, B., & Kaminski, P. L. (2005). Grandparents raising their grandchildren. *Marriage & Family Review, 37*, 147–161, DOI:10.1300/J002v37n01_10

Jendrek, M. P. (1994). Grandparents who parent their grandchildren: Circumstances and decisions. *The Gerontologist, 34,* 206-216, DOI: 3443/10.1093/geront/34.2.206

Kelley, S. J., Whitley, D., Sipe, T. A., & Yorker, B. C. (2000). Psychological distress in grandmother kinship care providers: The role of resources, social support, and physical health. *Child Abuse & Neglect, 24,* 311-321, DOI: 10.1016/S0145-2134(99)00146-5

King, S., Kropf, N. P., Perkins, M., Sessley, L., Burt, C., & Lepore, M. (2009). Kinship care in rural Georgia communities: Responding to needs and challenges of grandparent caregivers. *Journal of Intergenerational Relationships, 7*, 225-242, DOI: 10.1080/15350770902852369

Landry-Meyer, L. (2000, June). Grandparents as parents: What they need to be successful. *NCFR Report: Family Focus, 45*, Minneapolis, MN: National Council on Family Relations, F9-F10.

Landry-Meyer, L., Gerard, J., & Guzell, J. (2005). Caregiver stress among grandparents raising grandchildren: The functional role of social support. *Marriage and Family Review*, *37*(1), 171–190, DOI:10.1300/J002v37n01_11

Leder, S., Grinstead, L. N, & Torres, E. (2007). Grandparents raising grandchildren: Stressors, social support and health outcomes. *Journal of Family Nursing, 13*(3), 333-352, DOI: 10.1177/1074840707303841

Letiecq, B. L., Bailey, S. J., & Dahlen, P. (2008a). Intergenerational ambivalence and caregiver coping among grandparents raising grandchildren: Implications for clinical intervention. (pp. 3-16). In B. Hayslip & P. L. Kaminski (Eds.) *Parenting the Custodial Grandchild.* Springer Publishing.

Letiecq, B. L., & Bailey, S. J., Kurtz, M.A. (2008b). Depression among rural Native American and European American grandparents raising grandchildren. *Journal of Family Issues, 29*(3), 334-356, DOI: 10.1177/0192513X07308393

Letiecq, B. L., Bailey, S. J., & Porterfield, F. (2008c). "We have no rights, we get no help:" The legal and public policy dilemmas faced by grandparents rearing their grandchildren in informal arrangements. *Journal of Family Issues, 29,*(8), 995-1012, DOI: 10.1177/0192513X08316545

McCubbin, H. I. & Patterson, J. M., (1983). The family stress process: The Double ABCX model of adjustment and adaptation, In H. I. McCubbin, M. Sussman, & J.M. Patterson (Eds.), *Social stress and the family: Advances in family stress theory and research.* (pp. 7-38). Haworth Press.

Minkler, M., Fuller-Thomson, E., Miller, D., & Driver, D. (2000). Grandparent caregiving and depression. In B. Hayslip Jr. & R. Goldberg-Glen (Eds.), *Grandparents raising grandchildren: Theoretical, empirical, and clinical perspectives* (pp. 207-219). Springer Press.

National Association of Counties. (2005). *The National Association of Counties holds a news conference on the problem of methamphetamines at the National Press Club.* Washington, DC: Congressional Quarterly.

Powerful Tools for Caregivers. Portland, OR Retrieved 10/20/19 from: www.powerfultoolsforcaregivers.org

Roe, K. M., Minkler, M., & Barnwell, R. (1994). The assumption of caregiving: Grandmother raising grandchildren of the crack cocaine epidemic. *Qualitative Health Research, 4*(3), 281-303, DOI: 10.1177/104973239400400303

Stack, C. (1974). *All our kin: Strategies for survival in a Black community*. Harper & Row.

Strom R. D. & Strom S. K. (2000). Meeting the challenge of raising grandchildren. *International Journal of Aging and Human Development, 51*(3) 183-198, DOI: 10.2190/FR92-EGW2-VEVU-P8CR

Swader, C. (2013). *The capitalist personality: Face-to-face sociality and economic change in the post-communist world.* (p. 97). Routledge.

Taylor, M. F., Coall, D., Marquis, R., & Batten, R. (2016). Drug addiction is a scourge on the earth and my grandchildren are its victims: The tough love and resilient growth exhibited by grandparents raising the children of drug-dependent mothers. *International Journal of Mental Health Addiction, 14,* 937–951, DOI: 3443/10.1007/s11469-016-9645-7

U. S. Census (2018). QuickFacts Montana. Retrieved from: https://www.census.gov/quickfacts/mt

Van Dam, A. (March 23, 2019). How these grandparents became America's unofficial safety net. https://www.washingtonpost.com/us-policy/2019/03/23/how-these-grandparents-became-americas-unofficial-social-safety-net/?utm_term=.aff87f301dc3

Weber, J. A., & Waldrop, D. P. (2000). Grandparents raising grandchildren: Families in transition. *Journal of Gerontological Social Work, 33*(2), 27-45, DOI: 3443/10.1300/J083v33n02_03

Yancura, L.A., (2013). Justifications for caregiving in White, Asian American, and native Hawaiian grandparents raising grandchildren. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 68*(1), 139–144, DOI: 3443/10.1093/geronb/gbs098

Many little hands wrote in threads to demonstrate their stitchery skills and love of earth.

Volume Figure 4: Stone, N. (1810). *Sampler* [silk on linen]. Portland Museum of Art, Portland, Maine.

Narcissa Stone (United States, 1801 - 1877)
Sampler, 1810
Silk on linen, 16 3/8 x 18 7/8 inches
Portland Museum of Art, Maine. Museum purchase, 1973.9
Reproduced with permission.

Chapter 6

Cultivating a Culture of Care Through Intergenerational Programming

Sharon M. Ballard, Annelyse Iglesias, Meghan Pomelow, Nicholas Viti*
East Carolina University

Intergenerational programs foster human connection between individuals from two different age groups, often older adults and children or youth (Gallagher & Fitzpatrick, 2018). Approximately 49 million people in the United States are aged 65 or older, and this number is projected to reach 79 million by 2060 (U.S. Bureau of the Census, 2018). These numbers highlight the need to nurture connections between generations and extend care and support for our aging citizens. Intergenerational programs bridge generational gaps by supporting older adults, building healthy relationships skills, and socializing our next generation of caregivers (McAlister et al., 2019).

Bronfenbrenner (1981) advocated for a "curriculum of caring" in which young people not just learn about caring for others but engage in caring activities. He claimed that "No society can long sustain itself unless its members have learned the sensitivities, motivation, and skills involved in assisting and caring for other human beings" (Bronfenbrenner, 1981, p. 53). Although his curriculum of caring was never widely implemented, over the past 30 years, there has been an increase in intergenerational programs involving young children and older adults (McAlister et al., 2019) and in intergenerational service-learning programs involving college students and older adults (Roodin, Brown, & Shedlock, 2013). This paper provides an overview of intergenerational programs, including benefits for both younger and older generations. It concludes

---

**Correspondence to: Sharon M. Ballard, Professor & Chair, East Carolina University; ballards@ecu.edu*

with a description of two intergenerational programs located in Portland, Maine, that exemplify how bringing generations together can promote a culture of caregiving in our society.

Benefits of Intergenerational Programs

Intergenerational programs allow for support and resource exchange between different generations in one shared setting, benefitting all involved (Au et al., 2015). They present opportunities that allow social interactions and learning of knowledge and skills to occur simultaneously for all participants (Babcock et al., 2016; Corrigan et al., 2013; Isaki & Harmon, 2015; Spiteri, 2016). The essence of intergenerational programming is captured by Margaret Mead: "The quality of a nation is reflected in the way it recognizes that its strength lies in its ability to integrate the wisdom of its elders with the spirit and vitality of its children and youth" (Mead, 1971, p. 2). This integration of wisdom and vitality results in many benefits to both older and younger participants, including promoting a) positive attitudes toward aging, b) psychosocial well-being, and c) a culture of care.

Promoting Positive Attitudes Toward Aging

Compared to other age groups, preschool children have fewer inhibitions about interacting with older people (Gallagher & Fitzpatrick, 2018) and have more positive perceptions of aging populations as compared to older children (Lineweaver et al., 2017). However, biases may be so embedded by late elementary school, that modifying these biases is not as easy as it would be for younger children (Babcock et al., 2016). Intergenerational programs can offset ageism as they increase the availability of unbiased age-related information (Flamion et al., 2019; Spiteri, 2016). Increased connections across generations develop the potential to challenge existing stereotypes held by individuals of both age groups and to change attitudes toward one another (Drury et al., 2016; Fair & Delaplane, 2015; Isaki & Harmon, 2015). The personal relationships that children form with older adults help them to develop a more realistic understanding of aging and a reversal of negative attitudes toward the elderly (Babcock et al., 2016; Drury et al., 2016; Heyman et al., 2011; Spiteri, 2016).

Similar to other discriminatory barriers, ageism restricts older and younger generations from establishing active communities (Spiteri, 2016). High-quality intergenerational contacts diffuse younger generations' stereotypes of older adults' physical and behavioral characteristics (Drury et al., 2016; Fair & Delaplane, 2015; Gaggioli et al., 2014). The quality of intergenerational interactions may be more powerful than the frequency (Spiteri, 2016); however, Flamion et al. (2019) found that both positive and frequent interactions with grandparents correlated with lower levels of ageism in children.

Promoting Psychosocial Well-Being

Intergenerational contact and connectedness reestablish a sense of worth and well-being within older adults (Gallagher & Fitzpatrick, 2018); whereas, the same feelings are being introduced and shaped in the younger generation (Gaggioli et al., 2014). Older adults are at heightened risk of isolation in their homes or long-term care residences (Gaggioli et al., 2014). The importance of creating opportunities for older adults to engage in society is often underscored (Au et al., 2015). Through interactions with the younger generation, intergenerational programs allow aging individuals to reconnect with fundamental ideas and life experiences, providing an opportunity for older adults to attribute positive meaning to life experiences (Spiteri, 2016).

Overall, intergenerational interactions improve well-being, comprehensive quality of life, feelings of self-worth, and social connectedness for older adults (Au et al., 2015; Gallagher & Fitzpatrick, 2018; Isaki & Harmon, 2015; Murayama et al., 2015; Spiteri, 2016). Young children establish roots and a sense of security for the future (Fair & Delaplane, 2015) and develop a more robust understanding regarding differences, empathy, and tolerance (Burgman & Mulvaney, 2016; Gallagher & Fitzpatrick, 2018).

Intergenerational programs create opportunities for lifelong learning at different stages of development (Babcock et al., 2016). Children learn through active involvement with people (Fair & Delaplane, 2015). Also, younger children learn primarily through observations of others and modeling adults (Corrigan et al., 2013). Although observational learning is predominantly viewed as being specific to younger generations, benefits for the aging population exist, furthering the idea of uniting these populations to exchange knowledge among one another. Joining both younger and older generations in intergenerational learning programs increases intercultural understandings and creates a sense of unity between the generations.

Intergenerational programs can provide different generations, who may otherwise be isolated from one another, with opportunities to share experiences and exchange knowledge (Canning et al., 2018). Continued learning among older adults creates a "transformational education" opportunity cultivating new or strengthened purpose in their lives (Corrigan, McNamara, & O'Hara, 2013; Gaggioli et al., 2014). As older adults renew or rediscover appreciation of life experiences, their ability to teach and nurture curiosity in youth is strengthened.

Promoting a Culture of Care

Intergenerational programs nurture a culture of care and a sense of community caregiving, benefiting individuals and communities with a shared ethic of care and companionship. Intergenerational programs provide opportunities to acquire more knowledge, gain personal life or professional development skills, and learn about diverse others (Corrigan et al., 2013).

Interactions with youth can encourage a culture of care among the aging generations as well as within the younger generation. Not all older individuals have grandchildren to take care of in their life. Intergenerational programs provide an outlet for aging populations to share their knowledge and skills through caring for youth. Also, children gain a better understanding of the reality of aging and develop more empathy and tolerance (Burgman & Mulvaney, 2016; Gallagher & Fitzpatrick, 2018). As youth gain a better understanding regarding age and the challenges older generations face, the development of empathy encourages a culture of care that can be transmitted throughout generations.

Types of Intergenerational Programs

There are many different types of intergenerational programs, but all share the goal of bridging the gaps between generations. One common type is integrating a preschool or early learning center within an assisted living facility in which the young and old can interact daily. Other programs incorporate interactions once a week through specialized activities such as dance, music, or reading (e.g., Belgrave, 2011; Canning et al., 2018). Other programs involve older adults visiting local schools to assist, interact, and converse with children for intergenerational programs within schools (e.g., Cohen-Mansfield & Jensen, 2017).

Intergenerational service-learning is an experiential learning activity in which members of two different generations work together to achieve mutual goals. Such programs, often conducted as a pedagogical strategy in university gerontology courses, have been shown to have similar benefits as other intergenerational programs such as increased positive attitudes toward aging (Kalisch et al., 2013; Roodin et al., 2013). Intergenerational interaction within service-learning programs varies greatly. Common examples include regular interactions throughout the semester in the form of visits with an individual older adult in their home or an assisted living facility, interaction with groups of older adults in senior centers or nursing homes, engaging in music or art activities, or helping with events like Senior Games. Intergenerational service-learning provides college students with opportunities to learn about gerontology, to re-examine their personal views on aging, to connect with their own aging family members, and to possibly choose a career in working with older adults (Kalisch, et al., 2013; Roodin et al., 2013).

Highlighted below are two intergenerational programs located in Portland, Maine, including two photographs from each program. The respective directors of each shared their exemplar programs at the 2018 Groves Conference, illustrating the power of intergenerational programs in creating a culture of care.

Preschool at Gorham House

Preschool at Gorham House, located near Portland, Maine, is unique from many others. The children in this program are part of a special intergenerational program, bringing together the young and the old to create meaningful moments each day. Bill Gillis, the founder of Gorham House, opened his first nursing home in 1980 and began bringing his children to work with him on snow days, school vacations, and holidays. When he saw the heartwarming relationships formed between his children and the residents, he decided to put a childcare facility in the nursing home. Initially, it was intended to allow staff with children to have accessible childcare; little did he know how much of a difference it would make to all involved. Ten years later, in 1990, Gorham House was built and designed with a preschool inside, just as Bill had envisioned. Almost 30 years later, Gorham House continues to embrace this unique intergenerational program, and the residents continue to welcome the children into their home each day.

Gorham House Preschool is a busy classroom with fifteen chil-

dren between the ages of three and five. With three full-time teachers, one being the director, the opportunities are endless. Their days include field trips, extracurricular activities, and personal interactions with the residents. The most cherished part of the day is when the children visit their "grand friends", nursing home residents. As the children visit their grand friends in their neighborhoods, the interactions are filled with smiles and laughter. Whether it be a game of balloon toss, BINGO, dancing with scarves, or just singing together, all involved gain a positive outcome from being a part of these interactions. Throughout their time, children begin to form individualized relationships with some of the residents, usually due to a common interest or similar personalities or because the child resembles someone that was special to grand friends when they were young. The residents and children will seek out one another during "Together Time" and continue to build on their relationships each week. The residents stop by the classroom door each day just to say hello or become guest readers who read to the children on a weekly basis. They join together for monthly luncheons, weekly music performances in the Great Room, and for those residents who are not quite comfortable leaving their rooms or neighborhoods, the children will stop by for a visit. The Gorham House is celebrating its 30th anniversary and is looking forward to giving the children and the residents at least 30 more years of laughter, smiles, and singing, all because one man realized the importance of creating an intergenerational program where the young and old can inspire one another every day.

The Cedars—Opening Minds through Art

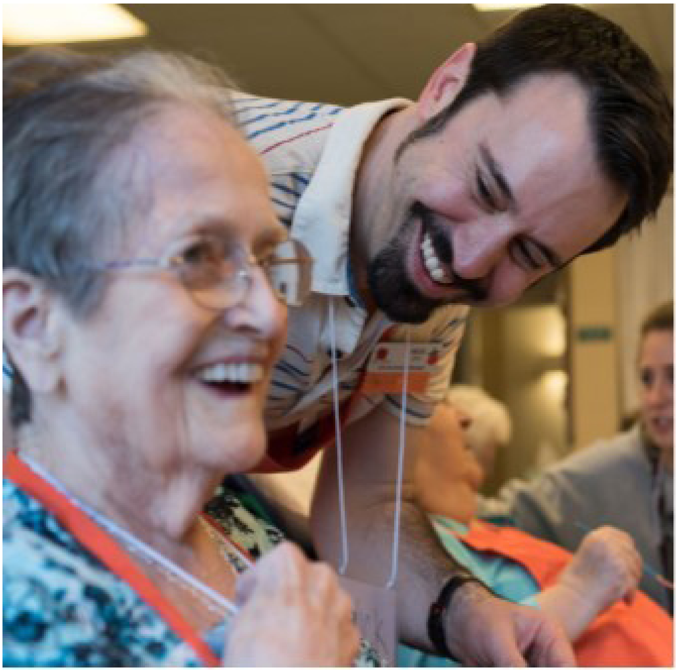
Opening Minds through Art (OMA) is a failure-free abstract art-making program explicitly designed to enable people living with dementia or related neurological diseases. It was created by artist and geriatrician, Elizabeth Loken, at the University of Miami, Ohio, and is being implemented at The Cedars, a retirement community located in Portland, Maine. The goals of the program are to provide people living with dementia (PLWD) the opportunity for choice and creative self-expression; facilitate meaningful productivity; bridge the intergenerational gap between senior citizens and the current generation moving into the workforce; breakdown stereotypes; and generate research into the use of art as a medium for positive engagement with PLWD. Through a person-centered philosophy, thoughtfully designed art projects, and one-on-one support, this program has successfully engaged long-term care residents, many of whom are PLWD, for the past four years at The Cedars.

The Cedars has partnered with the University of New England and the University of Southern Maine to provide student assistants for the OMA sessions in exchange for course credit and real-world experience. Students from these universities are paired with the same resident for the entire 13-week course. Before meeting their ‘elder teacher’, students are instructed in the OMA process and taught strategies for communicating and engaging PLWD. Over the course of the program, students learn how to refine their support and develop additional techniques for their specific elder teacher. The one-on-one pairing is essential to help both partners feel comfortable and confident when engaging in the weekly art projects (specifically designed to be failure-free) even though many have never done art or worked with a PLWD before.

When residents arrive at the weekly OMA sessions, they are greeted warmly by their student assistant and brought to their workspace. The residents and students begin to bond with each other by singing the opening song, the familiar and ever-comforting, *You are My Sunshine*. Art begins as students present their elder teacher with the project of the day, broken down into simple, easy to follow steps. The facilitators of the program, Nick Viti, Life Enrichment Manager and occupational therapist, and Pamela Moulton, local mixed media artist, provide the materials necessary for the current step. Once that step is completed, those materials are removed and replaced with tools required for the next step. Therefore, residents are never overwhelmed with too many materials, and the initiation of each step is made more comfortable - a common challenge for PLWD. Students never leave the residents' side during the session, instead raising their hand when ready for the next brush, paints, or bit of advice in assisting their elder teacher. The project ends in approximately an hour with residents naming their art and sharing their completed piece with their neighbors.

Not all artists are pleased with the result. Sometimes we hear the artist refer to their work as 'a mess'. However, students are trained in the use of professional 'art talk' to provide feedback that is sincere by referencing composition, texture, symmetry, color, and so on, which helps create value in the piece if the resident does not initially feel it. The use of abstract art means that artists are not asked to recreate familiar images. In this way, the artist and their student are free to explore the piece and develop their interpretation instead of focusing on how realistic it is. After hearing these comments and interpretations, we find that the residents' pride in their work increases, and they usually do see it as valuable themselves.

The program ends by singing of the closing song, *This Little Light of Mine.* Just as with the opening song, it is not long before the elder teachers and their student assistants are not just saying the words but singing the songs to each other. The bonding that occurs in a relatively short time is remarkable. Residents who may struggle to participate in large group activities thrive and become engrossed in artmaking. In this environment, PLWD who are too often identified by their disease, are no longer bound by their disability with the right modifications. They are *enabled* to make choices, express themselves creatively, and feel pride in their productivity. Students report that this is one of the most profound experiences of their education. From nervous novices, they emerge with a greater understanding of the needs, and more importantly, the abilities of PLWD. At the final session, the excellent work that everyone has done is recognized with a celebration and more than a few tears at the final parting.



Conclusion

Linking older and younger generations has the potential to support not only the generations involved but multigenerational families and communities in the future. Strengthening the connections between generations increases opportunities for exchanging knowledge and cultivates a culture of care within our society. For youth, time spent with the older generation helps them further understand the aging process and needs of older adults. As for older adults, spending time with youth enriches their daily lives and fulfills the desire for generativity. Humans long to be needed. Caring for others can create the same positive feeling as being the recipient of care. Intergenerational programs fill a void in society for both younger and older generations to feel cared for and learn to care for others.

References

Au, A., NG, C., Garner, B., Lai, S., & Chan, K. (2015). Proactive aging and intergenerational mentoring program to promote the well-being of older adults: Pilot studies. *Clinical Gerontologist*, *38*, 203-2010. doi:

10.1080/07317115.2015.1008116

Babcock, R. L., MaloneBeach, E. E., & Woodworth-Hou, B. (2016). Intergenerational intervention to mitigate children's bias against the elderly. *Journal of Intergenerational Relationships, 14*(4), 274-287. doi:10.1080/15350770.2016.1229542

Belgrave, M. (2011). The effect of a music therapy intergenerational program on children and older adults' intergenerational interactions, cross-age attitudes, and older adults' psychosocial well-being. *Journal of Music Therapy, 48*(4), 486-508. doi:10.1093/jmt/48.4.486

Bronfenbrenner, U. (1981). *Ecology of Human Development: Experiments by Nature and Design*, Harvard University Press, ProQuest Ebook Central, http://ebookcentral.proquest.com/lib/eastcarolina/detail.action?docID=3300702

Burgman, C. B., & Mulvaney, E. A. (2016). An intergenerational program connecting children and older adults with emotional, behavioral, cognitive, or physical challenges: Gift of mutual understanding. *Journal of Intergenerational Relationships, 14*(4), 353-359. doi:10.1080/15350770.2016.1229536

Canning, S. E., Gaetz, M., & Blakeborough, D. (2020). It takes time: Building relationships and understanding through an intergenerational ballet programme. *Dementia, 19*(2), 270-284. doi:10.1177/1471301218772895

Cohen-Mansfield, J., & Jensen, B. (2017). Intergenerational programs in schools: Prevalence and perceptions of impact. *Journal of Applied Gerontology, 36*(3), 254-276. https://doi.org/10.1177/0733464815570663

Corrigan, T., McNamara, G, & O'Hara, J. (2013). Intergenerational learning: A valuable learning experience for higher education students. *Eurasian Journal of Educational Research, 52*, 117-136.

Drury, L., Hutchison, P., & Abrams, D. (2016). Direct and extended intergenerational contact and young people's attitudes towards older adults. [Lisbeth Drury et al.] *British Journal of Social Psychology, 55*(3), 522-543. doi:10.1111/bjso.12146

Fair, C. D., & Delaplane, E. (2015). "It is good to spend time with older adults. You can teach them; they can teach you": Second grade students reflect on intergenerational service learning. *Early Childhood Education Journal, 43*(1), 19-26. doi:10.1007/s10643-014-0634-9

Flamion, A., Missotten, P., Marquet, M., & Adam, S. (2019). Impact of contact with grandparents on children's and adolescents' views on the elderly. *Child Development, 90*(4), 1155-1169. doi:10.1111/cdev.12992

Gaggioli, A., Morganti, L., Bonfiglio, S., Scaratti, C., Cipresso, P., Serino, S., & Riva, G. (2014). Intergenerational group reminiscence: A potentially effective intervention to enhance elderly psychosocial well-being and to improve children's perception of aging. *Educational Gerontology, 40*(7), 486-498. doi:10.1080/03601277.2013.844042

Gallagher, C., & Fitzpatrick, A. (2018). "It's a win-win Situation"–Intergenerational learning in preschool and elder care settings: An Irish perspective: Practice. *Journal of Intergenerational Relationships, 16*(1-2), 26-44. doi:10.1080/15350770.2018.1404403

Heyman, J. C., Gutheil, I. A., & White-Ryan, L. (2011). Preschool children's attitudes toward older adults: Comparison of intergenerational and traditional day care. *Journal of Intergenerational Relationships, 9*(4), 435-444. doi:10.1080/15350770.2011.618381

Isaki, E., & Harmon, M. T. (2015). Children and adults reading interactively: The social benefits of an exploratory intergenerational program. *Communication Disorders Quarterly, 36*(2), 90-101. doi:10.1177/1525740114529154

Kalisch, H. R., Coughlin, D. R., Ballard, S. M. & Lamson, A. (2013). Old Age Is a Part of Living: Student Reflections on Intergenerational Service-Learning. *Gerontology & Geriatrics Education, 34*(1), 99-113. doi: 10.1080/02701960.2012.753440

Lineweaver, T. T., Roy, A., & Horth, M. (2017). Children's stereotypes of older adults: Evaluating contributions of cognitive development and social learning. *Educational Gerontology, 43*(6), 300-312. doi:10.1080/03601277.2017.1296296

McAlister, J., Briner, B., & Maggi, S. (2019). Intergenerational programs in early childhood education: An innovative approach that highlights inclusion and engagement with older adults. *Journal of Intergenerational Relationships, 17*(4), 505-522, doi:10.1080/15350770.2019.1618777

Mead, M. (1971). *Coming to age in Samoa*. Morrow.

Murayama, Y., Ohba, H., Yasunaga, M., Nonaka, K., Takeuchi, R., Nishi, M., . . . Fujiwara, Y. (2015). The effect of intergenerational programs on the mental health of elderly adults. *Aging & Mental Health, 19*(4), 306-314. doi:10.1080/13607863.2014.933309

Opening Minds Through Art – The Cedars. https://www.thecedarsportland.org/health-services/skilled-nursing/innovative-programs/ Preschool at Gorham House. https://www.gorhamhouse.com/preschool/

Roodin, P., Hess Brown, L., & Shedlock, D. (2013). Intergenerational service-learning: A review of recent literature and directions for the future. *Gerontology & Geriatrics Education*, *34*(1), 3-25, doi: 10.1080/02701960.2012.755624

Spiteri, D. (2016). What do older people learn from young people?: Intergenerational learning in 'day centre' community settings in malta. *International Journal of Lifelong Education, 35*(3), 235-253. doi:10.1080/02601370.2015.113227

U. S. Bureau of the Census. (2019). *Older people projected to outnumber children for first time in U.S. history*. Retrieved from https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html

Caring for each other and another--the kitten--siblings became friends and allies.

Volume Figure 5: Williams, H. (circa 1811). *Portrait of the Dearborn Children: Julia Margaretta Dearborn, William Lee Dearborn, and Henry George Raleigh Dearborn* [oil on canvas]. Portland Museum of Art, Portland, Maine.

Henry Williams (United States, 1787 - 1830)
Portrait of the Dearborn Children: Julia Margaretta Dearborn, William Lee Dearborn, and Henry George Raleigh Dearborn, circa 1811
Oil on canvas, 29 x 35 inches
Portland Museum of Art, Maine. Bequest of Dr. Montgomery Blair, Jr.
1975.453.

Image courtesy of Luc Demers. Reproduced with permission.

Chapter 7

A Contextual View of Family Financial Caregiving

Pamela B. Teaster and Yuxin Zhao*
Virginia Tech

According to the National Population Projections promulgated by the U.S. Census Bureau 2020, all baby boomers will be aged 65 and older by 2030, with the number of older adults projected to make up nearly one quarter of the entire population by 2060 (Vespa et al., 2018). Between 2000 and 2016, life expectancy rose from 77.7 to 78.6 years, reflecting a 1.15% increase (Xu et al., 2009; Xu et al., 2018). Demographic factors reflecting subpopulation differences behind the increase in life expectancy have remained relatively unchanged, with females having a higher life expectancy than males. Race and ethnicity are also a factor, with the non-Hispanic white population having a lower death rate than non-Hispanic blacks (Xu et al., 2018). Increased life expectancy reveals that older adults are less likely to have a severe intellectual dysfunction and are actually "surviving" to a possibly "healthy" older age (Haveman et al., 2010). However, age-related functional deterioration alters some older adults' health status and threatens their independence. Reports show that 44.3% of individuals aged 75 or older have physical functioning disabilities, and 10% of individuals aged 65 or older have Alzheimer's dementia (Administration for Community Living, 2018; Alzheimer's Association, 2019).

Family caregivers provide care to loved ones who are unable to care for themselves due to illness, injury, or disability and who may need physical, emotional, and financial support (The White House Conference On Aging, 2010). Against this backdrop, the purpose of this paper is to

---

* *Correspondence to: Pamela B. Teaster, Professor & Director, Center for Gerontology, Virginia Tech; pteaster@vt.edu*

present information related to caregiving for an older adult, in particular, ways to manage his or her finances--tasks central to caring for an older adult and supporting his or her well-being.

Caregiving Demographics

Family members are central to providing care for older loved ones living in their own homes or living in an assisted living facility or nursing home. Many family caregivers juggle dual careers over extended periods of time with few additional family members available to help with care (Vespa et al., 2018). According to the Family Caregiver Alliance (2017), 34.2 million Americans reported providing unpaid care to an older person in the past 12 months, while 15.7 million Americans care for a family member diagnosed with Alzheimer's disease or other dementia. On average, family caregivers provide 24.4 hours per week of care, and nearly 25% spend more than 41 hours per week (Family Caregiver Alliance, 2017). Among family caregivers, up to 75% are women, and nearly 35% are individuals aged 65 years or older (Family Caregiver Alliance, 2017). According to a 2015 study by the National Alliance for Caregiving and AARP (National Alliance for Caregiving and AARP, 2015), the typical caregiver in the U.S. is a 49-year-old female caring for a 69-year-old female relative requiring care due to a long-term physical condition.

Tasks of Caregiving

Depending on the needs of an older adult, numerous caregiving tasks may be required. Providing care for an older adult can range from enhancing social interaction to the provision of care around-the-clock. Many caregivers must juggle providing care for young children while also providing care for an elder, and some are doing so while fulfilling full-time employment and schooling responsibilities. Tasks required for caregiving for a loved one depends on the ability of the older adult to perform activities of daily living (ADLs), including eating, bathing, dressing, walking, and using the toilet (Alzheimer's Association, 2019). In addition to these basic activities, there are instrumental activities of daily living (IADLs) with which an older person may need assistance. IADLs include driving, making telephone calls, and managing finances.

Money Management for Older Adults

Managing finances for an older adult can prove especially challenging, depending on abilities and needs, particularly his or her ability to make financial decisions (Wolff et al., 2016). Some older adults may only need assistance with traveling to a financial institution, while others may require complete help with managing funds, or financial caregiving. Some elders may resent having to share their financial information with a caregiver, often a family member, while others are more than happy to relinquish control to a trusted family member or friend. Factors that affect older adults' ability to make financial decisions, termed financial capacity, encompasses cognitive factors such as ability impairment to receive and evaluate information, as well as non-cognitive factors such as physical frailty (Marson et al., 2016). Factors influencing who assumes the financial management of an elder's affairs are often highly dependent on the relationship between family members and the elder (Belbase et al., 2020). A positive social network of family members and friends decreases the possibility of financial exploitation and abuse among older adults with or without dementia (James et al., 2014; Marson et al., 2016).

Transparency and advance planning are preferable when assuming the role of financial caregiver for an older adult. When done well, assisting an older adult with his or her finances is helpful to all concerned—creditors, other family members, and the older adult. When executed poorly (and sometimes illegally or immorally), management of an older adult's funds can engender lasting familial discord, wreck the remaining years of an older person's life, and sometimes, result in criminal or civil action.

Prevalence of Elder Financial Exploitation

Major studies confirm that there are more female than male victims and that perpetrators are typically friends or family members (e.g., Acierno et al., 2010; Metlife Mature Market Institute, 2011). However, research also indicates that the instances of elder financial abuse are far higher than earlier research indicated. Acierno et al. (2010) studied 5,776 older adults and found a 5% one-year prevalence for financial abuse by a family member. Similarly, a prevalence study by Lifespan of Greater Rochester (2011) in the state of New York revealed that the highest rate of any type of elder mistreatment was financial abuse, with a rate of 41 per 1,000 (4%), again suggesting that rates of underreporting were extremely high. A study by the MetLife Mature Market Institute (2011) of news articles citing financial exploitation of an older adult revealed an annual financial loss by victims of elder financial abuse estimated at least $2.9 billion dollars, with reports of elder financial abuse by family, friends, and neighbors comprising 34% of the news articles over a three-month period.

In 2019, the Consumer Financial Protection Bureau released the latest report about suspicious activity related to elder financial exploitation and found a quadruple increase from an average of about 1,300 reports filed per month to 5,300 filed per month from 2013 to 2017 (Consumer Financial Protection Bureau, 2019). Based on the report, over 180,000 suspicious activities targeted the older adult population (Consumer Financial Protection Bureau, 2019). Perpetrators included a variety of people ranging from scammers to family members, caregivers, and others. More than $6 billion of suspected financial exploitation targeted older adults, whose monetary losses averaged $34,200 (Consumer Financial Protection Bureau, 2019). One third of the older adults were aged 80 or older, and often, exploitation involved an older adult who was impaired or facing challenges at the end of his or her life. Adults ages 70 to 79 experienced the highest average monetary loss as compared with other age groups. On average, individuals aged 70 or older lost approximately $20,000 more than the younger age group aged 50 to 69 years (Consumer Financial Protection Bureau, 2019), losses to both individuals and society that demand a comprehensive approach to prevention and remediation, as explained by the theory below.

The Contextual Theory of Elder Abuse

The *Contextual Theory of Elder Abuse* (Roberto & Teaster, 2017) addresses the complexities of elder abuse within families as well as by trusted others who are not family members (Figure 1). This theory recognizes that, by virtue of their age, most older adults have forged well-de-

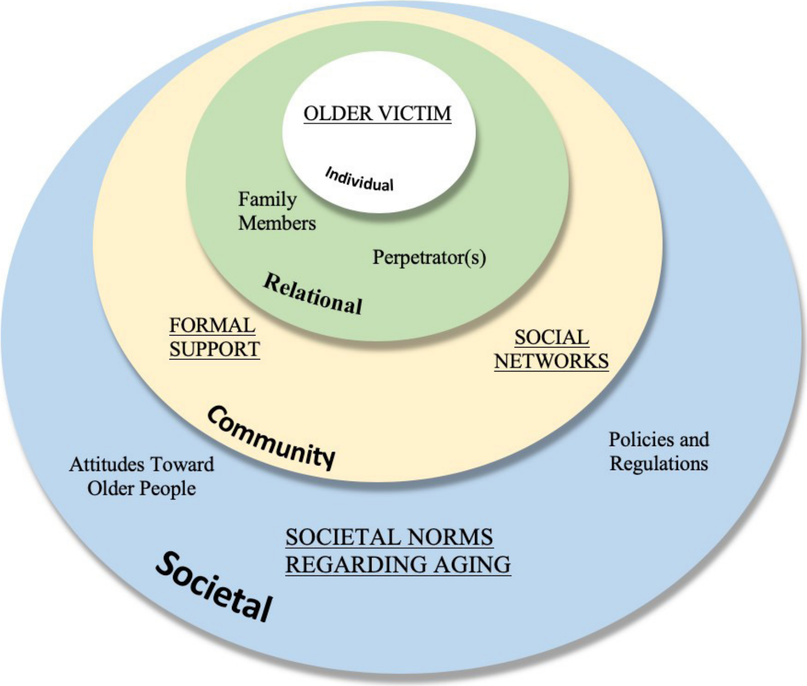


Figure 1. The Contextual Model of Elder Abuse
Roberto and Teaster, 2017

fined identities, which are influenced by distinct and often distant historical periods and, consequently, have lives inextricably intertwined with others. Older adults' lives intersect with partners, children, friends, faith communities, private programs and governmental agencies, and formal and informal care systems, all of which are shaped by pronounced attitudes and values intertwined in the relationships. Because of age-related changes and increasing reliance on others for care, some older adults, due to dependency, become vulnerable to exploitation by others, most often family members (Teaster, Vorsky, & Wangmo, 2012). However, family members can be a vulnerable elder's best line of defense against financial exploitation.

Building on Bronfenbrenner's (1986) model for the study of human development and the Social-Ecological Model promulgated by the Centers for Disease Control (2015), the *Contextual Theory of Elder Abuse* has at its center the older adult, consistent with a "person-centered" approach to the provision of financial caregiving (Holstein, Waymack, & Parks, 2011; Lithwick et al., 2000; Vladescu, 2000) (Figure 1). This framework recognizes that elder abuse is an individual, relational, community, and societal problem (Roberto & Teaster, 2017).

The following scenario is taken from real-life cases that the first author has encountered in her work and illustrates the levels of the *Contextual Theory of Elder Abuse*. The composite case study is presented in this manner not only to protect the privacy of the affected individuals but also to illustrate the paths that assistance can take (or, in some cases, does not take).

> *Donna is a 61 year-old former elementary schoolteacher with early onset Alzheimer's disease. Her husband died in a car accident when the children were in grade school and Donna's parents helped raise the children while she continued to work. She never remarried. Donna is becoming more and more forgetful – she frequently forgets what she is saying and misplaces more objects – more than several months ago. Donna tries to maintain some social contacts, particularly with people from her church, but she cannot now drive, having forgotten too often where she was going to go. Donna's daughter, Shelby, is her 30 year-old primary caregiver. Donna named Shelby her power of attorney for healthcare and finances; her two other children live two time zones away and have young children.*

Individual Context

The *individual context* involves both biological and personal factors that converge and affect how individuals behave. It includes personal characteristics (e.g., age, sex, gender, race/ethnicity) (Acierno et al., 2010;

Laumann et al.,2008), education, habilitation (e.g., community or long-term care setting; rural or urban geographic area), income level, physical health, mental health, and cognitive capacity (Lachs et al., 1997). Depending upon definition, personal attributes within the individual context may heighten, moderate, or reduce the risk for elder abuse. Neither the contributions of individual characteristics nor the complex interactions between and among them are fully comprehended. Timing, sequencing, spacing, density, and duration of key events all influence life transitions or turning points, a setting against which abuse may occur when an adult is old (Savla et al., 2013).

In the case study above, Donna's needs are becoming more and more pronounced, and she will continue to have greater needs. Church members will assist as they can, but she will need the help of a family member. Donna was wise to designate an agent under power of attorney, her daughter, Shelby, while she still had the capacity to do so. Like many people in her situation, she chose the child who lived close to her and who, in her mind, had more time to care for her, since she had no children. Below is an extension of the case study that illustrates the relational context of the model.

Relational Context

> *Shelby, never married and who works in middle management at a local Target, has been down on her luck for the past three years due to poor choices in a romantic relationship. Within the past year, though, Shelby, who continues to work at Target and called her mom during her breaks, recently moved in with her mother. While she was running errands for her mom, Shelby started using money from her mother's checking account to pay for "pick me up" clothes and jewelry purchases. She reasoned that her mom would want her to have it. As months went by and Donna's condition became worse and her need became greater, about monthly, Shelby began to take 3-day vacations to get "perspective."*

The *relational context* focuses on interactions among older adults and other people they encounter in order to explicate the role social networks play in lessening the risk for elder abuse and to identify relationships between and among victims and perpetrators. Relationships are variable and dynamic. Family members, friends, and neighbors may misinterpret perpetrators as the older adult's primary source of support rather than as an individual who is causing him or her harm. Also, changes in roles and the nature of the parent-children relationship affect both caregivers and care recipients. Though an adult child may be the designated provider of care, s/he may also be reliant upon an elderly parent for housing, finances, and emotional support (Jackson & Hafemeister, 2012; Teaster et al., 2012). If the availability of these resources is threatened, the adult child may attempt to take control of the situation by physically, psychologically, or financially abusing the elderly parent.

As the case study unfolds, we see that Shelby may have been a poor choice for surrogate decision-maker, even though she lives in close proximity to her mother. We learn that she makes poor choices and does not handle finances well. In addition, taking care of her mother appears stressful for Shelby, and to get away from the responsibility, she neglects Donna by leaving her alone too frequently and uses Donna's money unwisely and for purposes other than for her care. Sometimes the problems in the case of Donna and Shelby go unnoticed and unreported far too long and a victim's life can become endangered. The community context presented below shows what happens when problems are noticed.

Community Context

> *During one of Shelby's vacations, a church visitor and long-time friend, Peggy, visits visit Donna. When Donna answered the door, Peggy was alarmed to find that Donna did not recognize her, that Donna appeared disheveled, and that the house smelled of urine. Though she could not remember her name, Donna told Peggy that she was glad to see her and that she was hungry. After her visit, Peggy, called her minister and told her about the conditions in which she found Donna. The minister was familiar with the family and Donna's early onset dementia. The minister decided to reach out, separately, to both Donna and her daughter. She telephoned Donna and went to the home the next day. Nothing had changed, and Shelby was still out of town. The minister noticed a pile of bills on the kitchen table. She asked Donna if she could telephone Shelby, but when she called, Shelby did not answer.*

The *community context* involves an elder's sense of place and how he or she relates to others within the spaces in which they live, work, and worship. Although the structure and culture of communities may shield older adults from abuse, they may also inadvertently foster elder abuse. In the community context, questions raised about elder abuse include how settings affect the prevalence of elder abuse, the community's short-term responses and long-term supports for older persons, and the community response to perpetrators. Participation in community programs and use of available support services can reduce vulnerability and risk for elder abuse (Henderson, Buchanan, & Fisher, 2002; Penhale, 2010).

Older adults are more likely to rely on their communities' resources, as they have more physical and mental health vulnerabilities compared with the younger generations. A disadvantaged community is associated with limited health care facilities, poor infrastructures, reduced physical activities, and overall poor health status. Community networks provide a strong influence over interactions with and treatment of older adults, such as the many programs administered by the 622 Area Agencies on Aging around the country (as authorized by the Older Americans Act and funded in part by the Administration for Community Living). Without needed social interaction, older adults could experience loneliness and social isolation which in turn leads to functional decline and hastens death.

In Donna's situation, members of her faith community were made aware of a problem and are endeavoring to take action to protect one of its members. The church visitor, Peggy, illustrates the importance of having social networks, with other community members able to observe people in their changing circumstances. Because of her long-time association with Donna as member of their church, she can measure past conditions against present ones, taking note of when a caregiving situation has turned badly. The minister wisely goes to the home herself and decides to talk to both the potential victim, Donna, and the potential perpetrator, Shelby. When she cannot locate Shelby, she determines that she will report a suspicion of elder abuse to the local Adult Protective Services. She also telephones the Area Agency on Aging to arrange for home-delivered meals for Donna as well as in-home care.

Societal Context

> *The conditions that the minister observed in Donna's home prompted her to include, in the next meeting of the lay visitors from the church who conduct home visits with older adults, an exploration of their attitudes about older adults and their knowledge of services available to them. They determine that the problem of financial exploitation and older abuses goes beyond the lay visitors' group. They organize a church-wide initiative to make parishioners, young and old, more aware of their attitudes about older adults as well as what to do if caregiving supports are needed. The minister reaches out to the national leadership of their church. She is pleased to find that a group of experts, who happen to be of the same faith, had developed a Lenten series on elder abuse, and the minister and the church members use it as a tool to explore possible ageist treatment of older people. They even go so far as to attend a convention of their national church, where they propose a resolution to address the problem of elder abuse on a national scale—a resolution that passes when voted upon by the representatives in attendance.*

The *societal context* for aging and elder caregiving involves overarching ideological values and norms that discourage or encourage abuse. Within this context are large-scale changes in power and control, including but not limited to age-related changes in social positions and financial resources (Straka & Montminy, 2006) and ageism (Butler, 1975). For example, national initiatives of denomination, as above, or major actions of government such as the Elder Justice Act, (United States Government Printing Office, 2010; Public Law 111-148), the central piece of legislation on the topic, has the potential to play an important national role in prevention and intervention efforts. The act has engaged numerous federal agencies to become more aware of the problem of elder financial exploitation (e.g., Department of Justice, Social Security Administration, Centers for Medicare and Medicaid Services).

In the scenario above, a minister is both reacting to an individual situation in which she has found a home-bound congregant and making sure that other lay visitors explore their attitudes about older adults. She is proactive in making sure that the visitors are aware of services for older people who need more assistance with care than they are presently receiving. The local church takes action about the problem, helping all its members explore their attitudes about older people and caregiving. They then take a further step, going so far as to address the problem at a national level.

Preventing and Intervening in the Financial Exploitation of Older Adults

Growing recognition of the need to prevent financial exploitation of older adults and their families has led to joint efforts by financial institutions, law enforcement, social services agencies, and legislators to find ways to prevent, detect, and respond to this problem (Comizio et al., 2015; Carey et al., 2018). As a result, there has been a steady rise in the number of national research institutes, government programs, and local advocacy groups offering education, consulting, training, and legal services on financial issues regarding older adults and their families. Below, we mention a few notable examples and how they might be beneficial in the case study presented above.

Consumer Financial Protection Bureau. The Consumer Financial Protection Bureau (CFPB) offers resources and information for older families to avoid unfair, deceptive, or abusive practices (https://www.consumerfinance.gov). Specifically, CFPB provides transparent information to consumers about regulations involving financial institutions such as banks, credit unions, payday lenders, and mortgage services. CFPB generates rules and guidelines in order to prevent consumers from taking out loans larger than what they can afford that may result in the foreclosure of their home. Customers are encouraged to report issues with any financial institutions on the CFPB's website, and CFPB will investigate the complaint. Had Shelby want to invest her mother's money wisely, she could have consulted the CFPB website to determine safe ways to do so (and places to avoid). If Shelby stops caregiving for her mother and another family member or trusted friend assumes Donna's care, he or she could do the same.

Fraud Watch Network. AARP offers an online Fraud Watch Network to assist families to track scams by adding to a fraud map of the United States (https://www.aarp.org/money/scams-fraud/tracking-map/?intcmp=AE-SCM-FRD-SUBNAV-MAP). People may report instances of scams online and share the information with others in their community who may also be targeted. If, during the course of Donna's care, a caregiver suspects that some people in the community are attempting to de-fraud older adults by falsely charging for services that they do not provide, then the caregivers might consult the fraud map to determine if others in the area are being affected similarly or if the services are legitimate.

Who Gets Grandma's Yellow Pie Plate. Educational resources and training programs related to financial management are also available. An excellent example, from the University of Minnesota Cooperative Extension Service, is Stum's workbook, *Who Gets Grandma's Yellow Pie Plate*, which shows families how to transfer personal property (https://extension.umn.edu/who-gets-grandmas-yellow-pie-platetm-workshop-facilitators-toolkit/who-gets-grandmas-yellow-pie-0). The workbook can help families plan ahead and to understand issues most sensitive within their family, determine what members want to accomplish, and decide an equitable means within the context of their family to identify the significance of property that is imbued with different meanings for different family members. By using the recommendations from the workbook, family members can recognize distribution options and their potential consequences, thus managing (and reducing) conflicts that may otherwise arise. By using information from this program, Shelby's family members might have better worked together to provide Donna's care and finances and might have avoided Shelby's misuse of Donna's funds and inattention to her care.

Conclusion

It is critical to manage one's finances throughout one's lifecourse. Doing so becomes especially critical in older adulthood because of changes in relationships and roles as well as the onset of chronic disease and cognitive impairments. Both formal and informal caregivers may become involved with taking care of the finances of an older adult.

As illustrated by the information and the scenario above, the level of help required to manage the money and real property of an older adult is uniquely influenced by personal, relational, community, and societal factors. In some instances, a surrogate decision-maker such as an agent under power of attorney or guardian may be necessary, and in some cases, changed. Most families rise to the occasion to assist openly and honestly when needed. Still, mismanagment of funds can occur. It is the shared responsibility of individuals, families, communities, and society to understand the important aspects of managing the finances of an older adult in order to reduce financial abuse and physical harm from occurring and to intervene as swiftly and appropriately as possible whenever it does occur.

References

AARP - Fraud Map. (n.d.). Retrieved April 11, 2019, from AARP website: https://action.aarp.org/site/SPageNavigator/FraudMap.html;jsessionid=00000000.app217a?NONCE_TOKEN=7551FCB20140FA57C0956C326738C894

Acierno, R., Hernandez, M.A., Amstadter, A.B., Resnick, H.S., Steve, K., Muzzy, W., & Kilpatrick, D.G. (2010). Prevalence and correlates of emotional, physical, sexual, and financial abuse and potential neglect in the United States: The National Elder Mistreatment Study. *American Journal of Public Health*, *100*(2), 292-297. doi: 10.2105/AJPH.2009.163089

Administration for Community Living. (2018). 2017 Profile of Older Americans. Retrieved April 5, 2019, retrieved from https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2017OlderAmericansProfile.pdf

Alzheimer's Association. (2019). 2019 Alzheimer's Disease facts and figures. Retrieved from https://www.alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf

Belbase, A., Sanzenbacher, G. T., & King, S. E. (2020). Cognitive impairment and social security's representative payee program. *Journal of aging & social policy*, *32*(3), 201-219. https://doi.org/10.1080/08959420.2018.1444315

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, *22*(6), 723.

Butler, R. N. (1975). *Why survive? Being old in America*. Harper & Row.

Carey, C., Hodges, J., & Webb, J. K. (2018). Changes in state legislation and the impacts on elder financial fraud and exploitation. *Journal of Elder Abuse & Neglect*, *30*(4), 309-319 https://doi.org/10.1080/08946566.2018.1479670

Center for Disease Control. (2015). The Social-Ecological Model: A Framework for Prevention |Violence Prevention, Injury Center, CDC. Retrieved May 6, 2019, from https://www.cdc.gov/violenceprevention/publichealthissue/social-ecologicalmodel.html

Comizio, G., Kowalski, A., & Bain, L. (2015). *Elder financial abuse on the rise: What financial institutions can do to address increasing regulatory scrutiny designed to protect at-risk customers.* Washington, DC: Paul Hastings LLC. http://www. paulhastings. com/docs/default-source/PDFs/stay-current-elder-financial-abuseon-the-rise-what-financial-institutions-can-do-to-address-increasing-regulatoryscrutiny. pdf.

Consumer Financial Protection Bureau. (2019). *Suspicious Activity Reports on Elder Financial Exploitation: Issues and Trends*. Retrieved from https://files.consumerfinance.gov/f/documents/cfpb_suspicious-activity-reports-elder-financial-exploitation_report.pdf

Family Caregiver Alliance. (2017). Caregiver Statistics: Demographics. Retrieved April 5, 2019, from https://www.caregiver.org/caregiver-statistics-demographics

Haveman, M., Heller, T., Lee, L., Maaskant, M., Shooshtari, S., & Strydom, A. (2010). Major health risks in aging persons with intellectual disabilities: An overview of recent studies. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(1), 59–69. https://doi.org/10.1111/j.1741-1130.2010.00248.x

Holstein, M. B., Waymack, M., & Parks, J. A. (2011). *Ethics, aging, and society: The critical turn*. Springer.

Jackson, S. L., & Hafemeister, T. L. (2012). Pure financial exploitation vs. hybrid financial exploitation co-occurring with physical abuse and/or neglect of elderly persons. *Psychology of Violence*, *2*(3), 285–296. https://doi.org/10.1037/a0027273

James, B. D., Boyle, P. A., & Bennett, D. A. (2014). Correlates of susceptibility to scams in older adults without dementia. *Journal of elder abuse & neglect*, *26*(2), 107-122. https://doi.org/10.1080/08946566.2013.821809

Lachs, M. S., Williams, C., O'Brien, S., Leslie, H., & Horwitz, R. (1997). Risk factors for reported elder abuse and neglect: A nine-year observational cohort study. *The Gerontologist*, *37*(4), 469–474. https://doi.org/10.1093/geront/37.4.469

Laumann, E. O., Leitsch, S. A., & Waite, L. J. (2008). Elder mistreatment in the United States: Prevalence estimates from a nationally representative study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *63*(4), S248–S254. https://doi.org/10.1093/geronb/63.4.S248

Lifespan of Greater Rochester. (2011). *Under the radar: New York state elder abuse prevalence study - Self-reported prevalence and documented case surveys.* Retrieved from http://www.lifespan-roch.org/documents/ElderAbusePrevalenceStudyRelease.pdf

Lithwick, M., Beaulieu, M., Gravel, S., & Straka, S. M. (2000). The mistreatment of older adults: Perpetrator-victim relationships and interventions. *Journal of Elder Abuse & Neglect*, *11*(4), 95–112. https://doi.org/10.1300/J084v11n04_07

Marson, D. C., Kerr, D. L., & McLaren, D. G. (2016). Financial decision-making and capacity in older adults. In *Handbook of the Psychology of Aging* (pp. 361-388). Academic Press.

Metlife Mature Market Institute (2011). *The MetLife study of elder financial abuse: Crimes of occasion, desperation, and predation against America's elders*. Retrieved from https://ncvc.dspacedirect.org/handle/20.500.11990/641

National Alliance for Caregiving (NAC) and the AARP Public Policy Institute. (2015). *Caregiving in the U.S. 2015*. Retrieved from https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf

Penhale, B. (2010). Responding and intervening in elder abuse and neglect. *Ageing International*, *35*(3), 235–252. https://doi.org/10.1007/s12126-010-9065-0

Roberto, K.A. & Teaster, P.B. (2017). Theorizing elder abuse. In X. Dong (Ed.), *Elder abuse: Research, practice, and policy* (pp. 21-41). Springer Science.

Savla, J. T., Roberto, K. A., Jaramillo-Sierra, A. L., Gambrel, L. E., Karimi, H., & Butner, L. M. (2013). Childhood abuse affects emotional closeness with family in mid- and later life. *Child Abuse & Neglect*, *37*(6), 388–399. https://doi.org/10.1016/j.chiabu.2012.12.009

Straka, S. M., & Montminy, L. (2006). Responding to the needs of older women experiencing domestic violence. *Violence Against Women*, *12*(3), 251–267. https://doi.org/10.1177/1077801206286221

Teaster, P. B., Wangmo, T., & Vorsky, F. B. (2012). Elder abuse in aging families. (pp. 409-430). In R. Blieszner & V.H. Bedford (Eds.). *Handbook of Families and Aging* (2nd Ed). ABC-CLIO.

The White House Conference On Aging. (2010). Care for the family caregiver: A place to start. Retrieved April 5, 2019, from http://www.caregiving.org/data/Emblem_CfC10_Final2.pdf

Vespa, J., Armstrong, M. D., & Medina, L. (2018). Demographic turning points for the United States: Population projections for 2020 to 2060. *US Department of Commerce, Economics and Statistics Administration, US Census Bureau.*, 25–1144. Retrieved from https://www.census.

gov/content/dam/Census/newsroom/press-kits/2018/jsm/jsm-presentation-pop-projections.pdf

Vladescu, D. (2000). An evaluation of a client-centered case management program for elder abuse. *Journal of Elder Abuse & Neglect*, *11*(4), 5–22. https://doi.org/10.1300/J084v11n04_02

Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA internal medicine*, *176*(3), 372-379. https://doi:10.1001/jamainternmed.2015.7664

Xu, J., Kochanek, K. D., & Tejada-Vera, B. (2009). Deaths: Preliminary data for 2007. *National Vital Statistics Reports*, *58*(1), 51. Retrieved from: https://www.ncbi.nlm.nih.gov/pubmed/25075874

Xu, J., Murphy, S. L., Kochanek, K. D., Bastian, B., & Arias, E. (2018). Deaths: Final data for 2016. *National Vital Statistics Reports*, *67*(5), 76. Retrieved from: https://stacks.cdc.gov/view/cdc/12095

When ocean was full of fish, men shared catch to sustain their families and others.

Volume Figure 6: Wyeth, N. C. (1943). *Dark Harbor Fishermen* [tempura on hardboard]. Portland Museum of Art, Portland, Maine.

Newell Convers Wyeth (United States, 1882 - 1945)
Dark Harbor Fishermen, 1943
Tempera on hardboard (Renaissance Panel), 35 x 38 inches
Portland Museum of Art, Maine. Bequest of Elizabeth B. Noyce, 1996.38.63.
Image courtesy of Luc Demers. Reproduced with permission.

Chapter 8

Maine's Anne Longfellow Pierce: Still Giving Gifts of Care

Christine A. Readdick and John William Babin
Florida State University

Gifts given early and often to Anne Longfellow and her brothers and sisters were the loving attentions and provisions of parents, grandparents, other relatives, and family helpers in a handsome red brick house on Back Street (now Congress) in Falmouth (now Portland), Maine. Anne was the fourth-born child of eight who enjoyed the distractions and engagements she shared with her siblings as well, including, Henry Wadsworth Longfellow, the poet, with whom she shared an especially close and lifelong relationship.

During the colonial era of the establishment of the United States, Anne was born in 1810 to Zilpah Wadsworth and Stephen Longfellow. Of British descent both families played roles during the Revolutionary War and in the attainment of Maine statehood. Anne's father was a lawyer and served as representative of Maine in the Massachusetts legislature prior to statehood and in the Maine legislature after statehood was achieved[1].

Four-year-old Anne is first described by her mother as "very precise", always speaking and walking "by rule", "anxious always to behave with strict propriety"[2]. Gazing at the earliest picture of Anne, painted when she was a young woman of twenty, her fair face is framed with beautiful dark curls, her head turned slightly to the side, her dark eyes and slight smile greet the eyes of the painter directly, one assumes (see Figure 1). From this cameo it is not difficult to imagine Anne, not so many

**Correspondence to: Christine A. Readdick, Professor Emerita, Florida State University; readdick@fsu.edu*

years earlier, as a pert and precocious preschooler, happy to be part of her bustling family and household.

Figure 1
Portrait of Anne Longfellow Pierce, painted by Joseph Greenleaf Cole, 1830. Collections of Maine Historical Society, courtesy of MaineMemory.net, item #15634

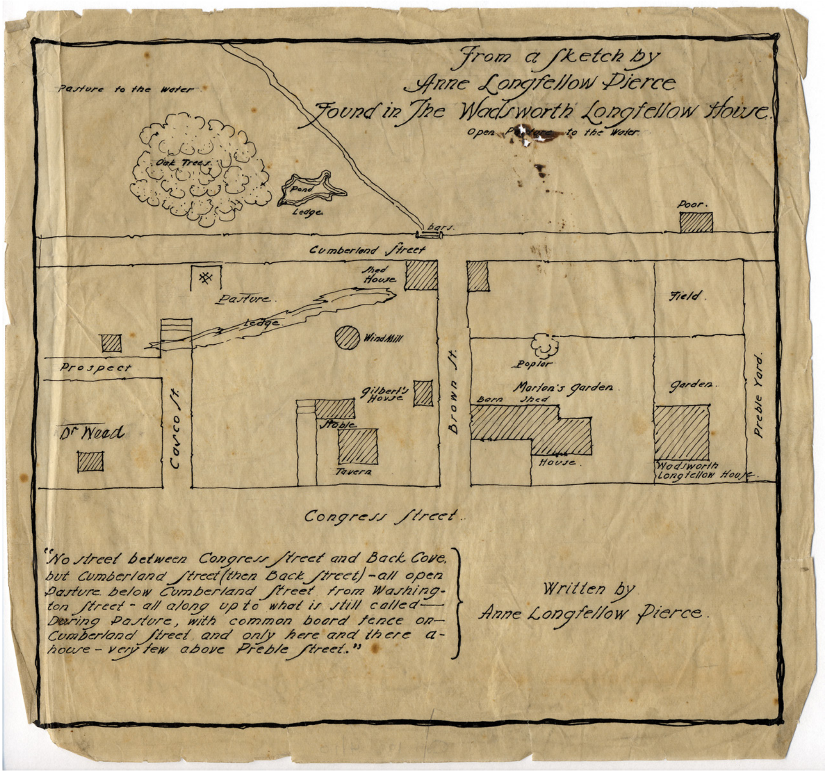
In a remembrance of early life in the family, Anne recalled, at the age of sixty-nine:

> Books and satchels were the ornaments of the parlor table in the evenings, and silence the motto, till the lessons were learned—then fun and games were not wanting, and when they grew too fast…for the parlor, the old kitchen rang with our shouts and glee….[3]

Zilpah's father, Peleg, built the family home in 1785-86 on a promontory of the growing town of Falmouth, facing east toward Casco Bay and the port and west toward Back Cove. Situated on one and a half acres, their family compound included the home, assorted outbuildings, and a barn surrounded by gardens and fields with pasture and animals beyond[4]. This was a perfect setting for outdoor play and exploration for

Anne and her brothers and sisters (see Figure 2). The senior Wadsworths moved upstate in 1807, then renting the original home to Zilpah and Stephen. In 1827 Peleg deeded the Portland family home to his daughters, Zilpah and Lucia. All of the Longfellow children, except Henry and Stephen, the oldest of eight, were born in this house; all grew up here.[5] In the summer the children often spent time at their grandparents' farms, with the Wadsworths in Hiram and the Longfellows in Gorham.[6]

Figure 2



From a ſketch by
Anne Longfellow Pierce
Found in The Wadſworth Longfellow Houſe.

"No ſtreet between Congreſſ ſtreet and Back Cove, but Cumberland ſtreet (then Back ſtreet) – all open Paſture below Cumberland ſtreet from Waſhington ſtreet – all along up to what iſ still called— Deering Paſture, with common board fence on— Cumberland ſtreet and only here and there a-houſe – very few above Preble ſtreet."

Written by
Anne Longfellow Pierce.

Anne L. Pierce Sketch of Longfellow House Site, circa 1823. Collections of Maine Historical Society, courtesy of MaineMemory.net, item #100210

Anne's mother and father both stressed the importance of education for all of their children. During early childhood, the Longfellow girls enjoyed learning manners, music, sewing, and writing with private teachers. In later childhood, Anne attended a proper school for young ladies in Portland with her older sister Elizabeth, where they studied reading and writing, geography, and the arts, but also, at the behest of their father, math, including geometry and algebra. Anne excelled in math.[7]

Anne and her sibling enjoyed not only the care of their mother and father, but also the care, sometimes described as strict, of their Aunt

Lucia, Zilpah's sister who lived with them in the family home.[8] Despite enduring frail health, Zilpah shared her love of music, poetry, and nature with her children. Henry recalled his mother gazing out of the window in a thunderstorm, "enjoying the excitement of its splendor."[8] Lucia, in counterpoint, provided structure and established expectations for the children's behavior. In addition, daily hired family help included a handyman, who sometimes gave the children a ride to school on his horse, and a changing cast of cooks and maids who assisted the family in their tasks of daily living.[9] And, it was in this context of shared care, that Anne herself acquired the sentiments and skills necessary for her lifelong role of family, and later, community caregiver.

For Anne, in her diaries and letter writing, and for Henry, in his letters and poetry, there is evidence of an idyllic family life. Samuel, the youngest child in the family and author of a biography about his brother, the poet Henry, shared memories of play in the hay loft, visits to the dove chamber, and "steedless" rides in a yellow sleigh.[10] Strong images of both the sentiments of care and caring activities in daily life can be seen in a sweet note Henry wrote to his father, recounting his little brother, Alex, falling asleep beside him as he studied in the parlor.

> "Poor little boy, he wants to go to bed! I called him by name—he only raised his head and without opening his eyes answered 'what'. Stephen is just carrying him up to bed…."[11]

In his own poetry, Henry called children "living poems"[12] and thrilled to the "voices soft and sweet" and "patter of little feet" of his daughters descending on him in his study for Children's Hour[13].

Yet, family life was tinged by the trials and tragedies of the day, including illness and death and fire and civil war, drawing on this deep reservoir of care. Anne was nineteen when Elizabeth, her older sister by two years, became ill with scrofula, a tuberculosis infection of the lymph nodes in the throat. Anne, along with Aunt Lucia, provided her sister with tender care and companionship until her death. Writing to an uncle about her sister's death, she pined:

> "my dear and long-loved sister…. I felt, I hoped, I trusted—so dear was her life to me that Elizabeth would recover. I fondly believed my good nursing would eventually restore her to health. Her sufferings were extreme"[14].

One hopes that many happy memories stored, like those cited above and another held by her mother, that of Anne and Elizabeth running home together from church in the rain with handkerchiefs over their bonnets[15], were buoying, as well, to Anne.

Anne fell in love and was engaged to to George Pierce, a young lawyer who worked with her father. After a three-year engagement, the result of her own bout with poor health (she describes herself as "Ricketty"[16]), she married in 1832 and established "that dear, dear little home of mine"[17] on Cumberland Street with George, only to have him succumb after two weeks of extreme suffering from typhus, a bacterial disease carried by insects, three years later[18]. She returned to the family home and lamented the loss of their dear life together for her remaining years. Back home Anne assumed caregiving for her younger sister, Ellen, who died also from typhus, at age 16, during Portland's typhus epidemic in 1835[19].

During these times it can be seen how important Zilpah, her mother, was to Anne. When she mourned for George, and her little sister as well, Anne said,

> "I love to be with her and in her customary cheerfulness and the interest she feels in the welfare of others and the things around her. I am taught many lessons which I know I particularly need."[20]

An example of the reciprocal giving and taking of care between Anne and her mother can be seen in Anne's baking 16 mincemeat pies to please her mother and guests during the Christmas holidays in 1838 (hoping to at least match her Aunt Lucia's reputation for delicious pies).[21] While a recipe of such does not exist, it is known that Anne baked an English plum pudding from a recipe in Miss Beecher's Domestic Receipt Book.[22]

As her parents aged, Anne assumed more responsibilities with Lucia for their care. In 1849, when Anne was 39 years old, her seventy-three year old father, Stephen, succumbed to peritonitis, an inflammation of the abdominal wall, after a decade of declining health, and in 1851 Anne's mother died, also at seventy-three years of age, succumbing to weak lungs and cumulative effects of childbirth difficulties.[23] When her next younger brother, Alex, a civil engineer married and left home at the age of 37 years, Anne professed, "No gentleman in the house seems to make no family."[24]

Butler, in her account of the life of Anne, makes note of a major shift in family caregiving responsibilities for Anne that occurred between the death of her dear parents and the departure of her brother Alex, who remained in Portland. Stephen, the oldest son in the family who had returned home to receive the care of Anne and Lucia, died at 45 years of age, from alcoholism. Upon her elder bother's death, Anne, now 40 years old, became guardian of Stephen's son (her nephew) Henry, called Hen, who at that time was 10 years old. Prior to this, Anne frequently provided day care for Hen and his sister when they were "dropped off for the day" by their parents.[25]

Anne with the financial support and encouragement from her brother, the poet, cared for Hen until he left home for college. Anne and Henry felt the care of Hen to be an important family "duty". Perhaps, reflecting the illness of his father and troubles at home that necessitated guardianship, Hen was a "handful" in spite of the good intentions of his aunt and his great-aunt who appeared to shower him with the same love and expectations as others had enjoyed growing up in the family home. Anne gave him little birthday parties, invited Hen's school chums for noisy play, and listened to his prayers; and each Christmas she made Hen a stocking, filled it with goodies, and hung it faithfully on his bedstead.[26] Speculation that Hen's mischief might be due to being raised by two women who had had no children of their own and, hence, held to unreasonable expectations for his deportment, seems misplaced.

After her mother's death, Anne accrued even more responsibilities in the care and maintenance of the old family home, her mother having bequeathed her half ownership of the home to Anne.[27] Summers remained a time for family members' travel, siblings and nieces and nephews often arriving. Henry, as well as her youngest brother, Samuel, a theologian and minister, often visited for weeks at a time.[28] With and without guests, Anne oversaw all the tasks of home management from dusting and washing to redecorating and purchasing a cooking stove to planning meals and cooking for her extended family.[29]

Anne, in turn, was regarded fondly by these visitors, including two of her great-great nephews who recounted taking a coach ride with her, driven by two horses, and being rewarded with sugar plums for "being very good boys"[30]. Fannie, her sister-in-law and wife of Henry, described Anne as "gentle" upon the occasion of her first visit to the Longfellow home.[31] Henry, admitted to being "idle as a painted ship upon a painted ocean" on the occasion of a summer visit a few years before his death.[32] Although, after a stint of company in 1841, Anne confessed in a letter to her sister, Mary, in Massachusetts, "'there is no rest for the wicked' is my favorite text of the time". [33]

Not surprisingly, Anne's performed acts of care beyond her immediate family and home. As a child, she and her brothers and sisters attended church at the First Parish Meetinghouse. The Longfellow family had their own pew, and in the winter the children would bring their own foot warmers to help them endure the long sermons and cold, cold church.[34] As time passed, Anne taught Sunday school and helped with the annual Nativity re-enactment, that is still produced by the congregation today. Returning from a trip to Europe with Henry, Anne brought materials, likely trims and ribbons, she had purchased to incorporate into costumes for this important community event.[35]

Other community engagements included serving on Portland's Female Orphan Asylum Board and supporting the Association for the Relief of Aged, Indigent Women.[36] In response to losses of so many buildings due to the disastrous Portland fire of 1866, Anne opened up her house to a milliner, who set up shop.[37] On the first independence day celebration after the conclusion of the U.S. Civil War, an accidentally set flash fire, fanned by strong winds, had destroyed not only city hall, customs house, post office, all of the town's banks, and many of its hotels, shops and office buildings, as well as 1,200 residences, leaving 10,000 folk, including the milliner, homeless.[38]

Anne's greatest loving kindnesses were centered in the family home. Anne called the Longfellow home on Congress Street "dear old home" and "[I] am happier here than anywhere. An affectionate presence seems to enfold me here…. A benediction will ever rest on us children under the old roof tree…so long as memory of our dear parents lives," Anne wrote to her sister Mary in 1851, after the death of both her mother and father.[39] Accordingly, in 1895, as sole owner of the property since the death of her Aunt Lucia in 1864, Anne wrote a deed to pass on the house to the Maine Historical Society, of which her father had been one of its founders, as a "Longfellow Memorial", with precise instructions for its appointment, both indoors and out.[40] Down to the detail, she noted where each household object was to be placed to best reflect life as shared mid-century in the Longfellow family.[41] She asked that a library to house the Society's collections be built where the old barn used to be, so the Society would have a permanent home. Features that she dictated be added to the property included a "children's gate" and garden, reflecting her own love of gardening.[42] Today Anne's home remains, just as it was when she and her family lived, loved, and cared for each other—a final gift of care extended to us all.

Footnotes

[1] Babin, J.W. & Levinsky, A.M. (2015). Henry Wadsworth Longfellow: The Fireside Poet of Maine, pp. 27-28. Charleston, SC: The History Press.

[2] Butler, J. (2000, September 23). The life and times of Anne Longfellow Pierce, p. 5. Maine Historical Society.

[3] Butler, p.5.

[4] Pierce, A.L. (ca. 1893). Anne L. Pierce sketch of Longfellow House site. Maine Historical Society. Retrieved from https://mainememory.net/artifact/100210

[5] Maine Historical Society. The Longfellow House and Portland. Retrieved from https://wlhouse.mainememory.net/page4021/display/html

[6] Babin & Levinsky, p. 27.

[7] Butler, pp. 8-9.

[8] Babin, (Personal communication, December 31, 2020).

[9] Higginson, T.W. (1902). Henry Wadsworth Longfellow, (p. 9). Houghton,

Mifflin and Company.

[10] Babin, (Personal communication, January 31, 2020).

[11] Butler, p. 20.

[12] Babin & Levinsky, p. 36.

[13] Longfellow, H.W. (1893). "Children" (p. 200). The complete poetical works of Henry Wadsworth Longfellow. Houghton, Mifflin and Company.

[14] Longfellow, "The Children's Hour", (p. 201).

[15] Butler, p. 9.

[16] Butler, p. 9.

[17] Butler, p. 11.

[18] Babin, (Personal communication, January 7, 2021).

[19] Butler, p. 12.

[20] Butler, p. 12.

[21] Butler, p. 20.

[22] Butler, p. 16.

[23] Babin, (Personal communication, January 7, 2021).

[24] Babin, (Personal communication, January 7, 2021).

[25] Butler, pp. 22-24.

[26] Maine Historical Society (2020-2021). "Anne Longfellow Pierce" Henry Wadsworth Longfellow, Maine Historical Society. Retrieved from http://www.longellow.org.

[27] Butler, p. 22.

[28] Babin, (Personal communication, January 7, 2021).

[29] Babin, (Personal communication, January 7, 2021).

[30] Butler, p. 27.

[31] Butler, p. 16.

[32] Butler, p. 3.

[33] Butler, p. 17.

[34] Butler, p. 27.

[35] Butler, p. 25.

[36] Babin & Levinsky, p.60.

[37] Babin, (Personal communication, July 21, 2020).

[38] Butler, p. 25.

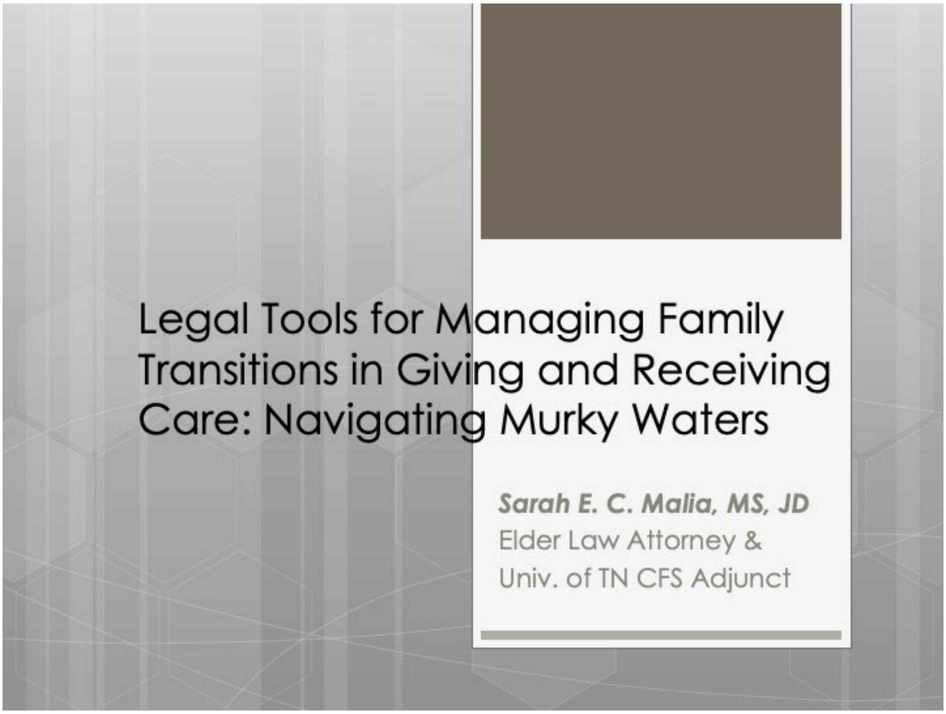
[39] Greater Portland Landmarks (n.d.). Portland's Great Fire of 1866. Retrieved from https://www. portlandlandmarks.org/great-fire-of-1866.

[40] Butler, p. 27.

[41] Butler, p. 26.

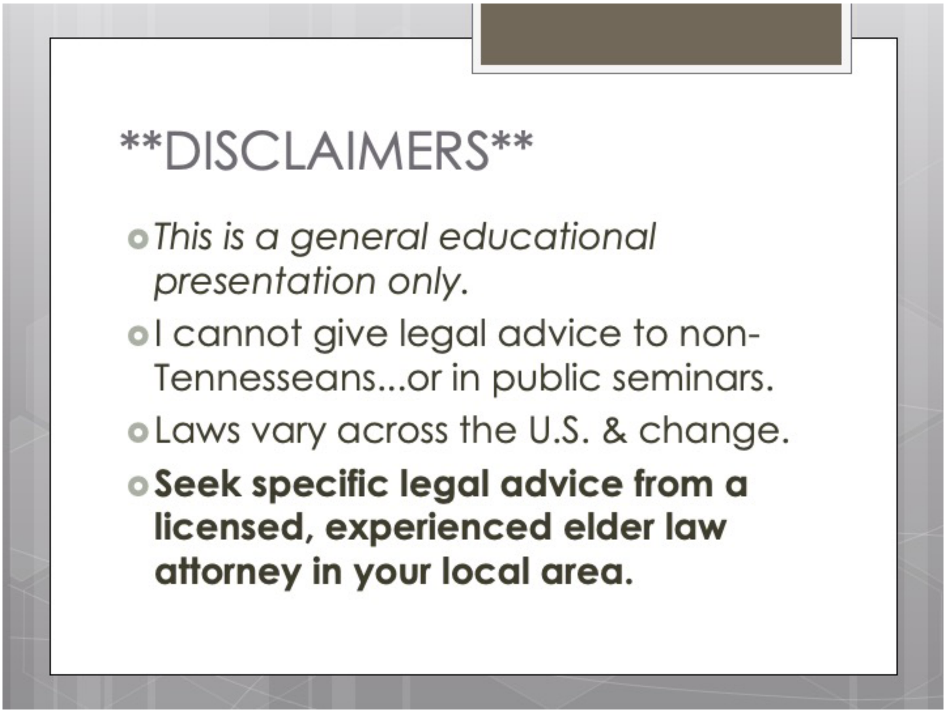
[42] Babin, (personal communication, January 8, 2021).

Chapter 9



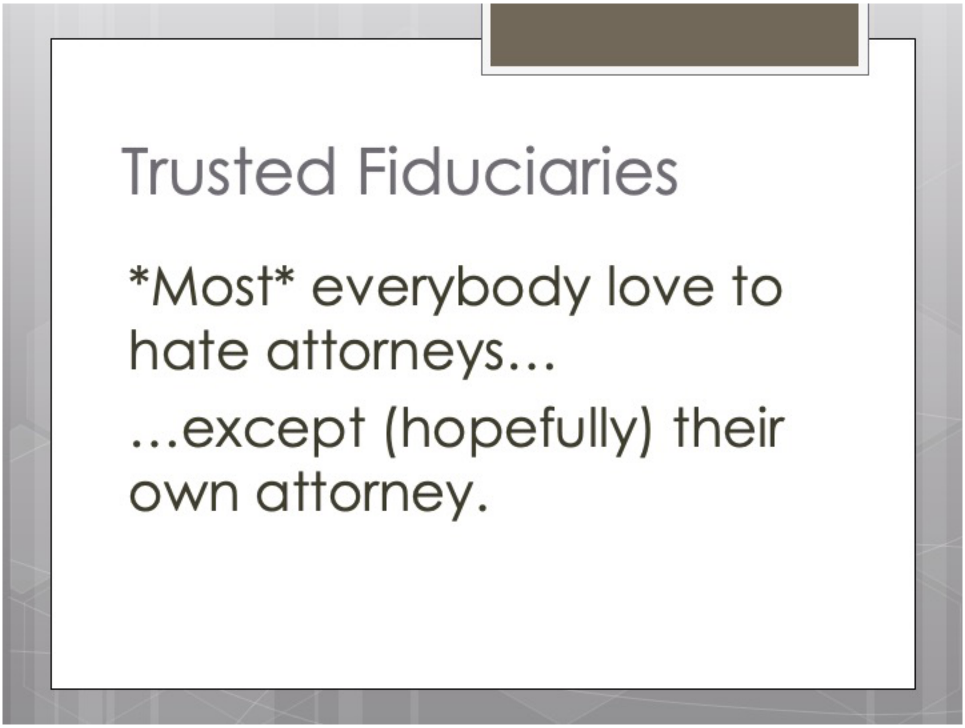
Legal Tools for Managing Family Transitions in Giving and Receiving Care: Navigating Murky Waters

Sarah E. C. Malia, MS, JD
Elder Law Attorney &
Univ. of TN CFS Adjunct



DISCLAIMERS

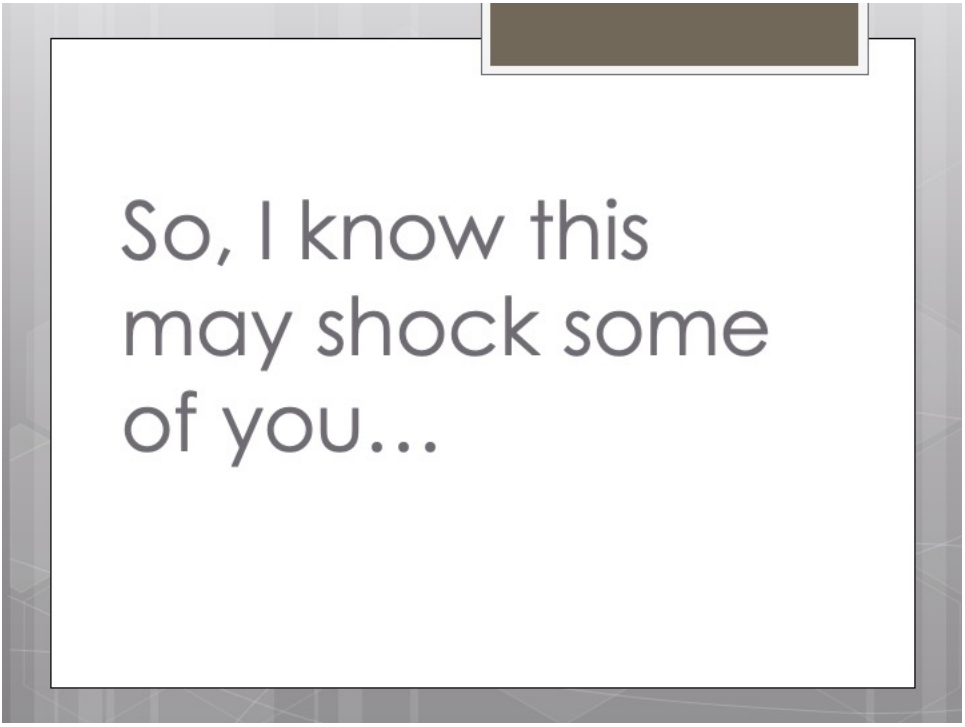
- *This is a general educational presentation only.*
- I cannot give legal advice to non-Tennesseans...or in public seminars.
- Laws vary across the U.S. & change.
- **Seek specific legal advice from a licensed, experienced elder law attorney in your local area.**



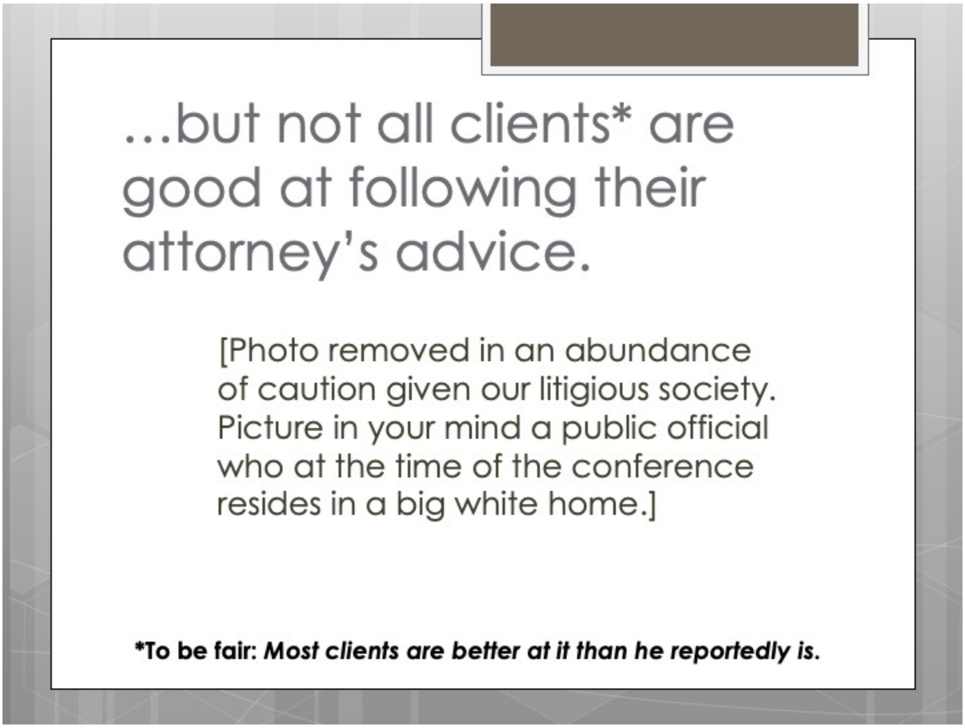
Trusted Fiduciaries

Most everybody love to hate attorneys…

…except (hopefully) their own attorney.



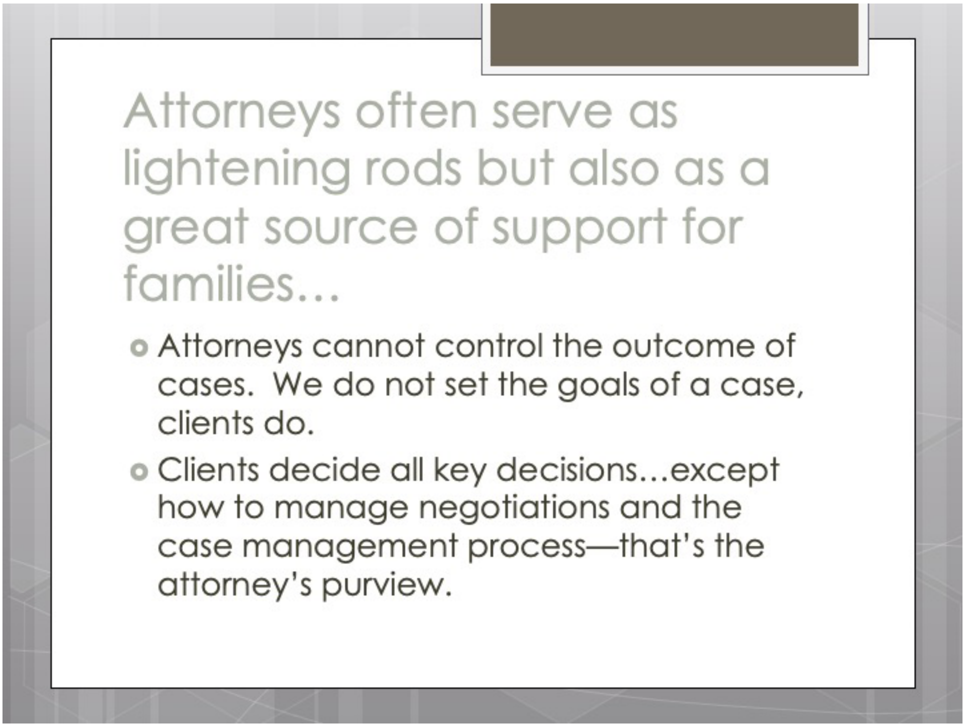
So, I know this may shock some of you…



…but not all clients* are good at following their attorney's advice.

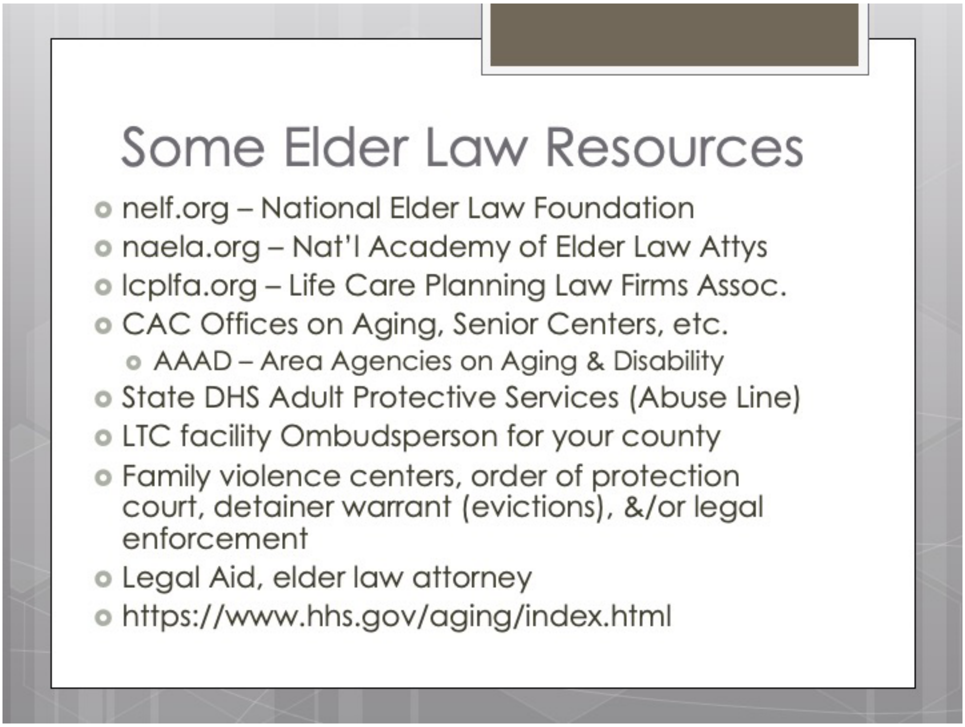
[Photo removed in an abundance of caution given our litigious society. Picture in your mind a public official who at the time of the conference resides in a big white home.]

To be fair: *Most clients are better at it than he reportedly is.



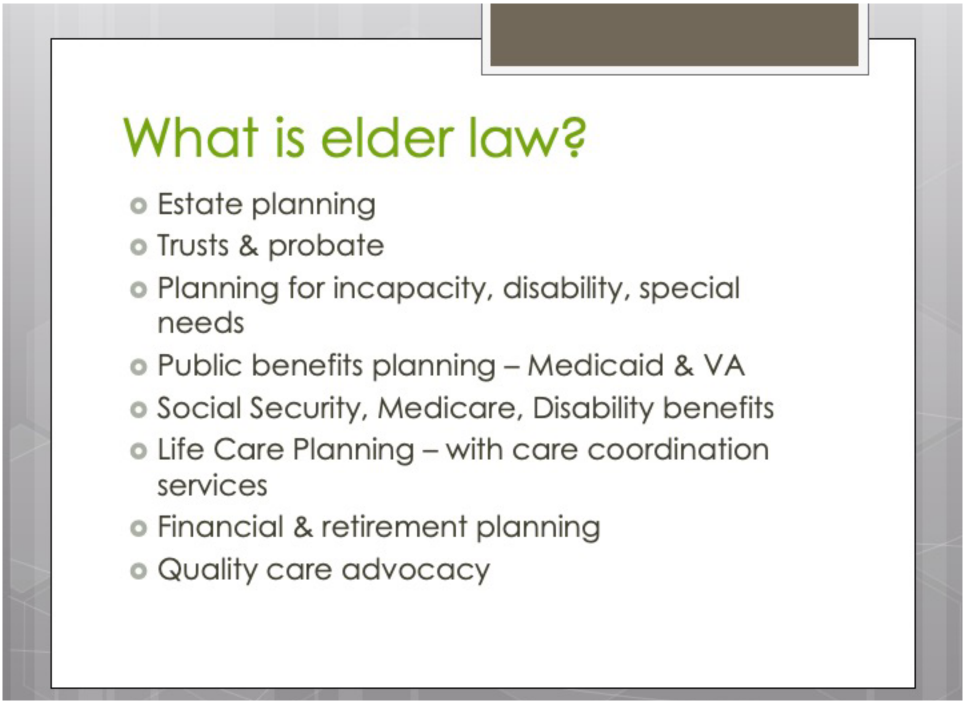
Attorneys often serve as lightening rods but also as a great source of support for families…

- Attorneys cannot control the outcome of cases. We do not set the goals of a case, clients do.
- Clients decide all key decisions…except how to manage negotiations and the case management process—that's the attorney's purview.



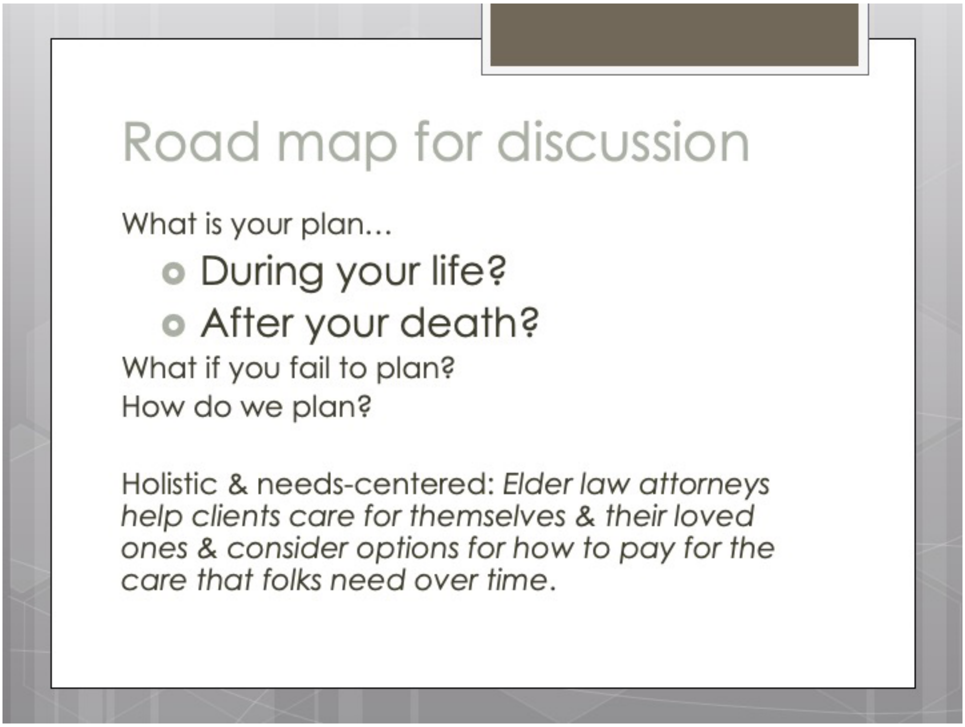
Some Elder Law Resources

- nelf.org – National Elder Law Foundation
- naela.org – Nat'l Academy of Elder Law Attys
- lcplfa.org – Life Care Planning Law Firms Assoc.
- CAC Offices on Aging, Senior Centers, etc.
    - AAAD – Area Agencies on Aging & Disability
- State DHS Adult Protective Services (Abuse Line)
- LTC facility Ombudsperson for your county
- Family violence centers, order of protection court, detainer warrant (evictions), &/or legal enforcement
- Legal Aid, elder law attorney
- https://www.hhs.gov/aging/index.html



What is elder law?

- Estate planning
- Trusts & probate
- Planning for incapacity, disability, special needs
- Public benefits planning – Medicaid & VA
- Social Security, Medicare, Disability benefits
- Life Care Planning – with care coordination services
- Financial & retirement planning
- Quality care advocacy



Road map for discussion

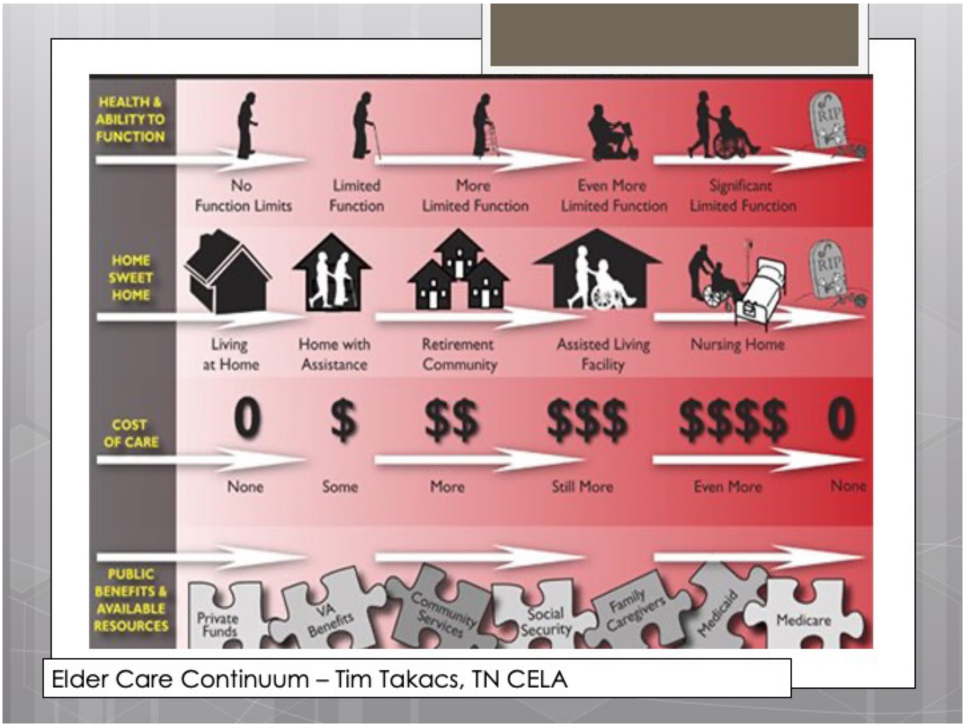
What is your plan…

- During your life?
- After your death?

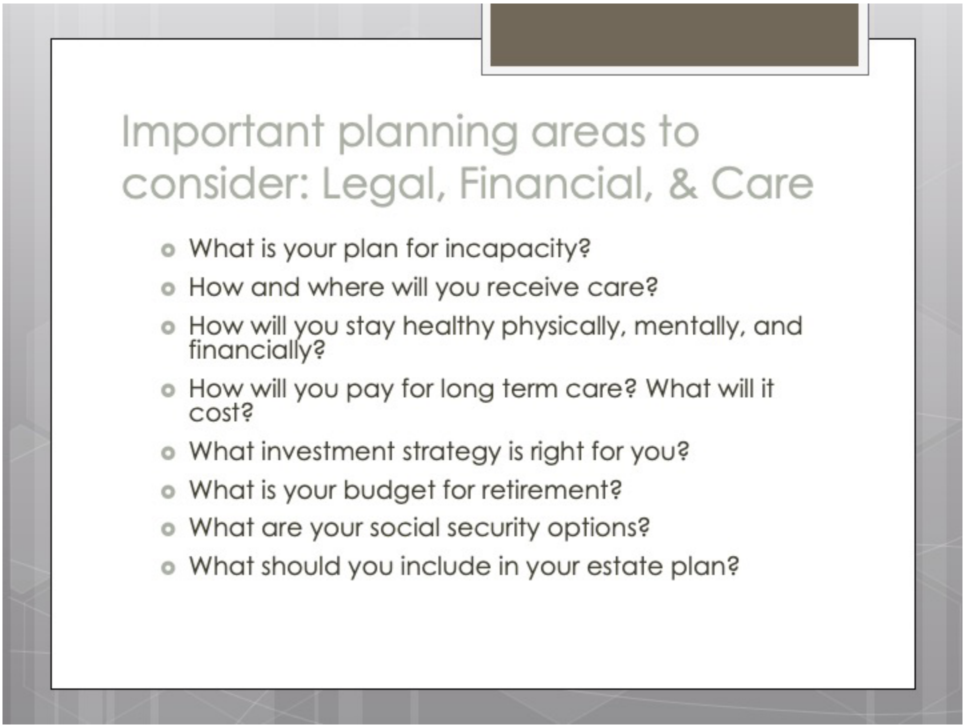
What if you fail to plan?

How do we plan?

Holistic & needs-centered: *Elder law attorneys help clients care for themselves & their loved ones & consider options for how to pay for the care that folks need over time.*

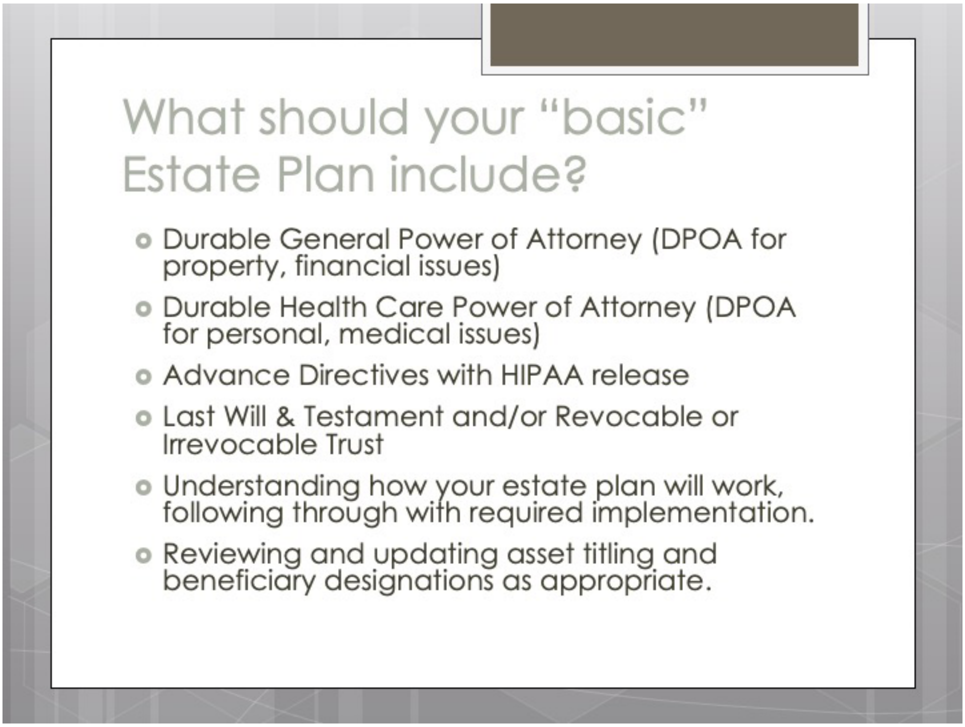


Elder Care Continuum – Tim Takacs, TN CELA



Important planning areas to consider: Legal, Financial, & Care

- What is your plan for incapacity?
- How and where will you receive care?
- How will you stay healthy physically, mentally, and financially?
- How will you pay for long term care? What will it cost?
- What investment strategy is right for you?
- What is your budget for retirement?
- What are your social security options?
- What should you include in your estate plan?

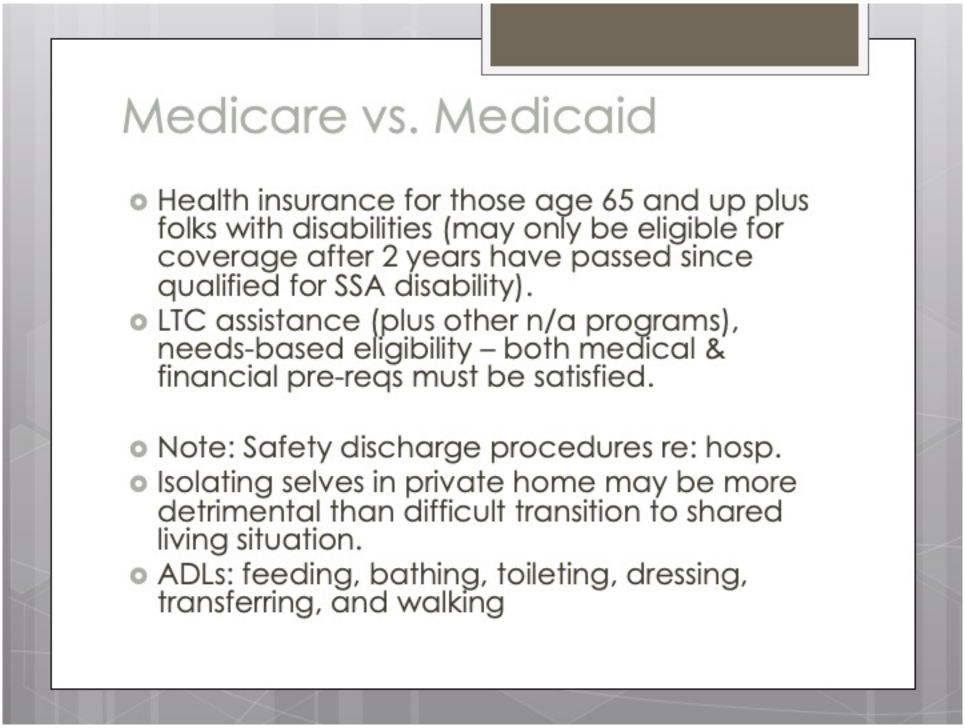


What should your "basic" Estate Plan include?

- Durable General Power of Attorney (DPOA for property, financial issues)
- Durable Health Care Power of Attorney (DPOA for personal, medical issues)
- Advance Directives with HIPAA release
- Last Will & Testament and/or Revocable or Irrevocable Trust
- Understanding how your estate plan will work, following through with required implementation.
- Reviewing and updating asset titling and beneficiary designations as appropriate.

More sophisticated planning may include…

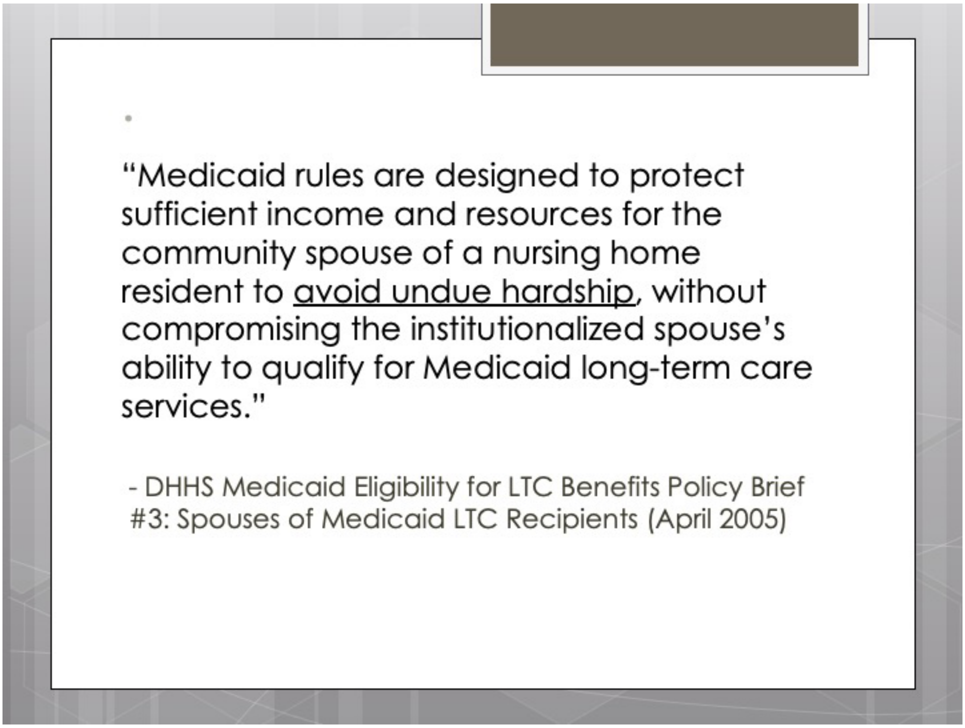
- Irrevocable Trusts, such as family asset protection trusts or special needs or supplemental trusts (SNTs)
  - SNTs: Self Settled vs. Third Party
  - SNTs: Might help with Medicaid eligibility and certain SSA/Medicare means-based benefits
  - Asset protection trusts: Require relinquishing control of assets to trustee
- Family caregiver agreements
- Contracts
- Asset restructuring and/or gifting (with professional assistance!)
- Deeds or retitling accounts and policies
- Trust/estate administration services



Medicare vs. Medicaid

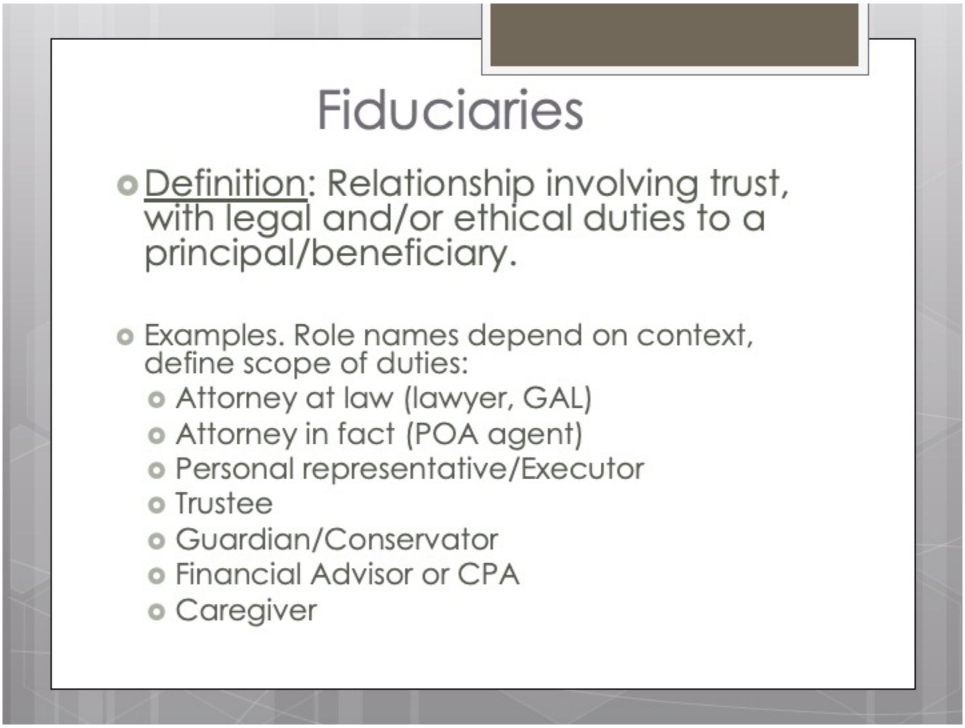
- Health insurance for those age 65 and up plus folks with disabilities (may only be eligible for coverage after 2 years have passed since qualified for SSA disability).
- LTC assistance (plus other n/a programs), needs-based eligibility – both medical & financial pre-reqs must be satisfied.

- Note: Safety discharge procedures re: hosp.
- Isolating selves in private home may be more detrimental than difficult transition to shared living situation.
- ADLs: feeding, bathing, toileting, dressing, transferring, and walking



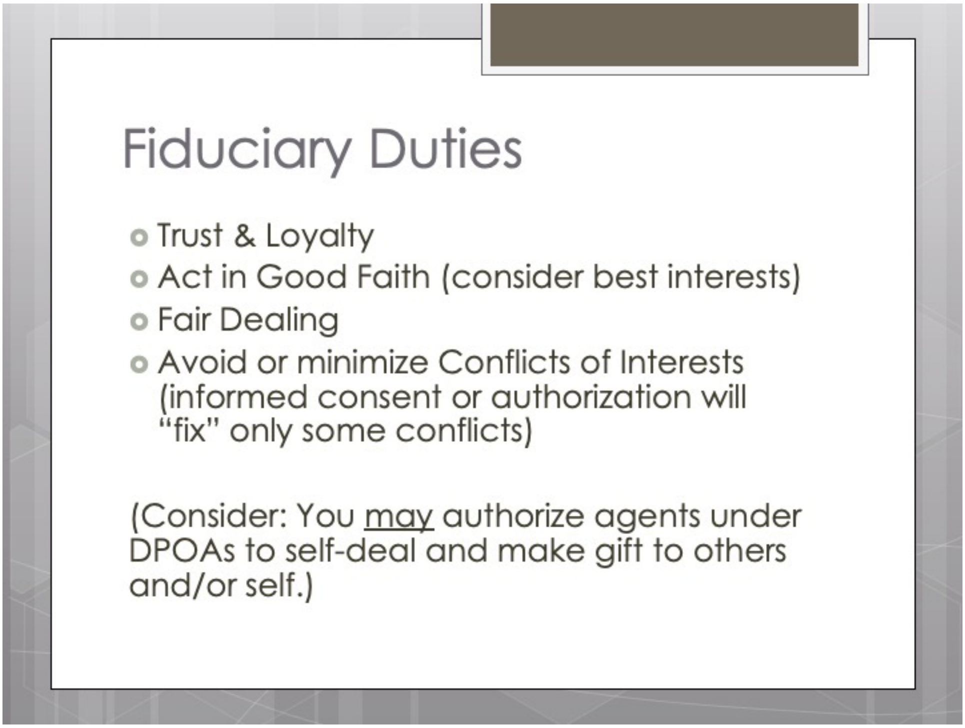
"Medicaid rules are designed to protect sufficient income and resources for the community spouse of a nursing home resident to avoid undue hardship, without compromising the institutionalized spouse's ability to qualify for Medicaid long-term care services."

- DHHS Medicaid Eligibility for LTC Benefits Policy Brief #3: Spouses of Medicaid LTC Recipients (April 2005)



Fiduciaries

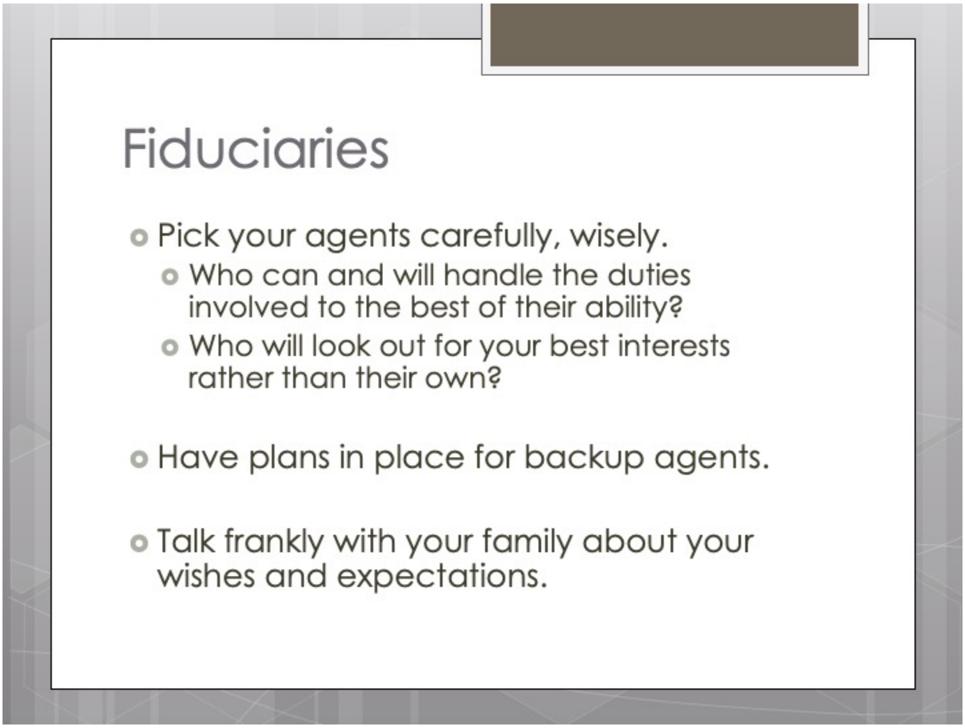
- Definition: Relationship involving trust, with legal and/or ethical duties to a principal/beneficiary.
- Examples. Role names depend on context, define scope of duties:
  - Attorney at law (lawyer, GAL)
  - Attorney in fact (POA agent)
  - Personal representative/Executor
  - Trustee
  - Guardian/Conservator
  - Financial Advisor or CPA
  - Caregiver



Fiduciary Duties

- Trust & Loyalty
- Act in Good Faith (consider best interests)
- Fair Dealing
- Avoid or minimize Conflicts of Interests (informed consent or authorization will "fix" only some conflicts)

(Consider: You may authorize agents under DPOAs to self-deal and make gift to others and/or self.)

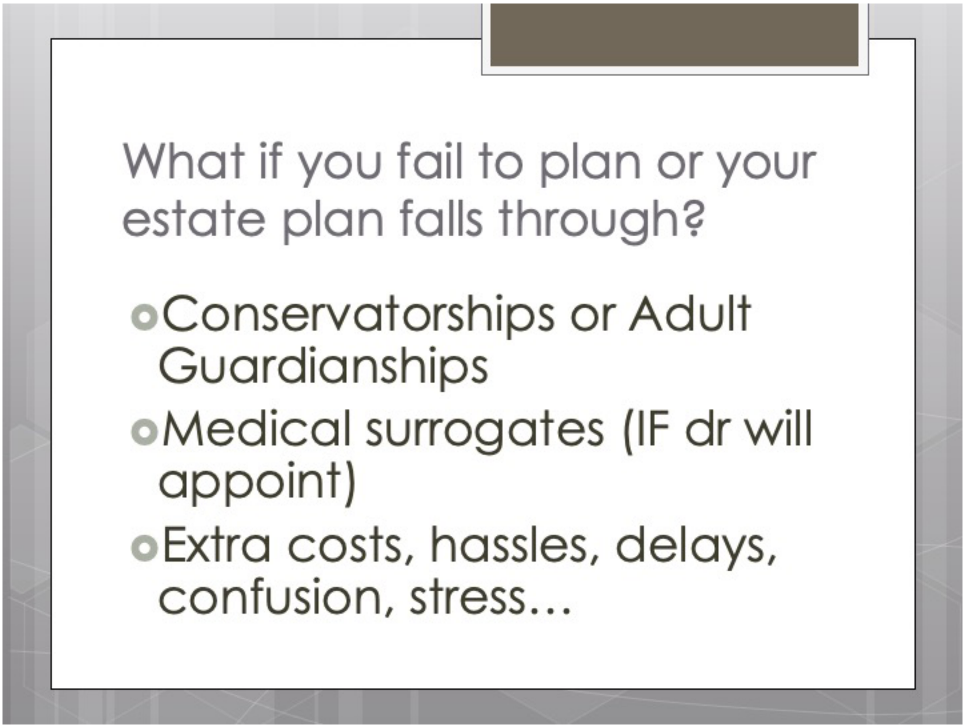


Fiduciaries

- Pick your agents carefully, wisely.
  - Who can and will handle the duties involved to the best of their ability?
  - Who will look out for your best interests rather than their own?

- Have plans in place for backup agents.

- Talk frankly with your family about your wishes and expectations.



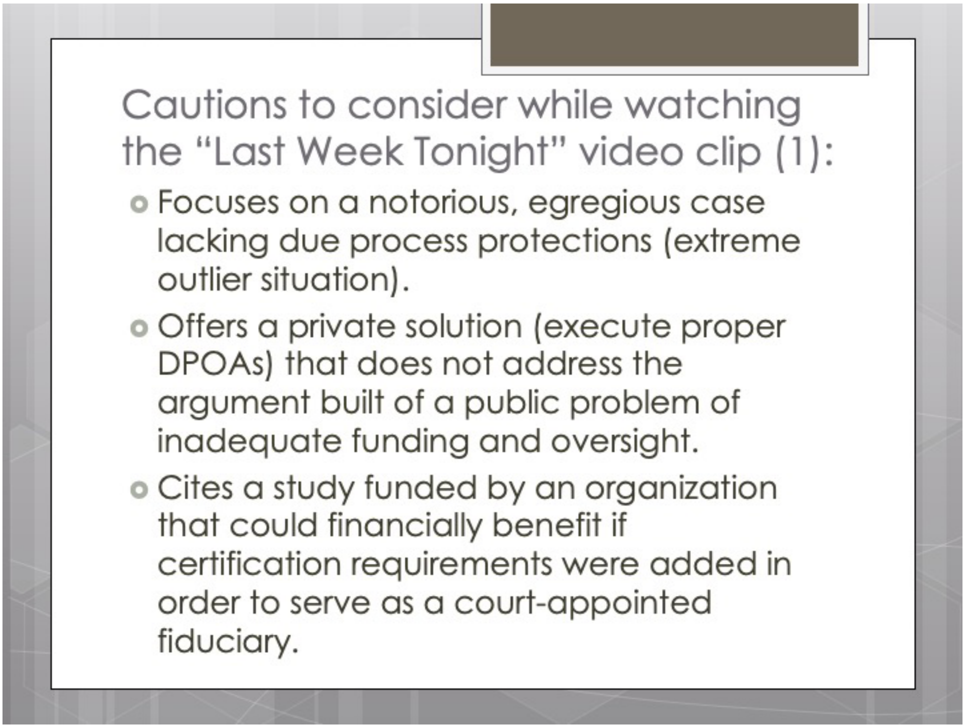
What if you fail to plan or your estate plan falls through?

- Conservatorships or Adult Guardianships
- Medical surrogates (IF dr will appoint)
- Extra costs, hassles, delays, confusion, stress…

John Oliver's "Last Week Tonight"

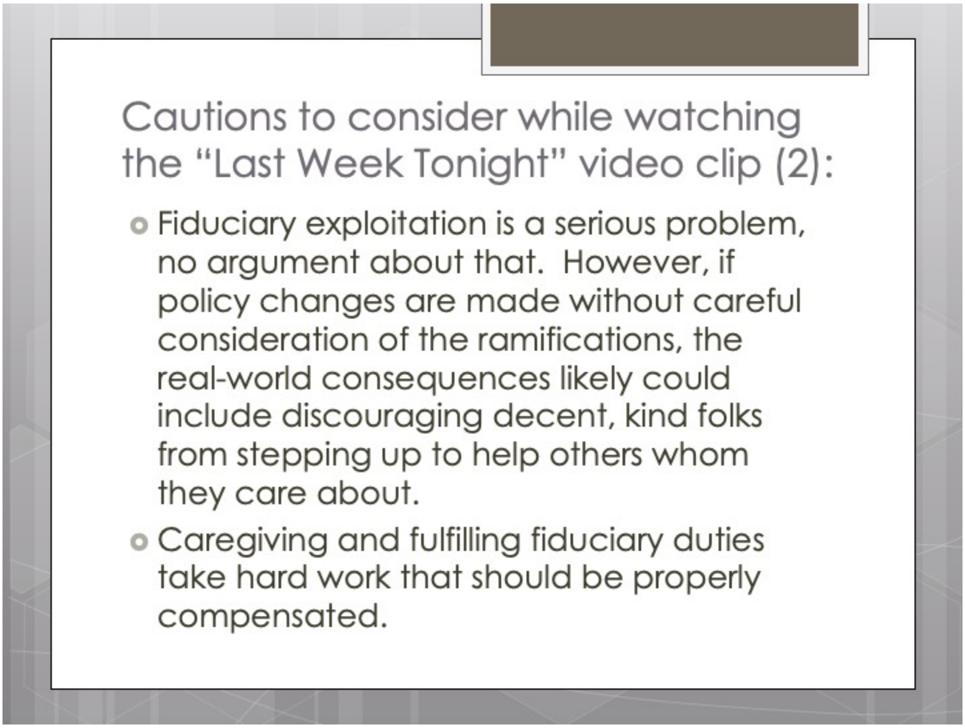
Guardianships (June 3, 2018)

https://www.youtube.com/watch?v=nG2pEffLEJo



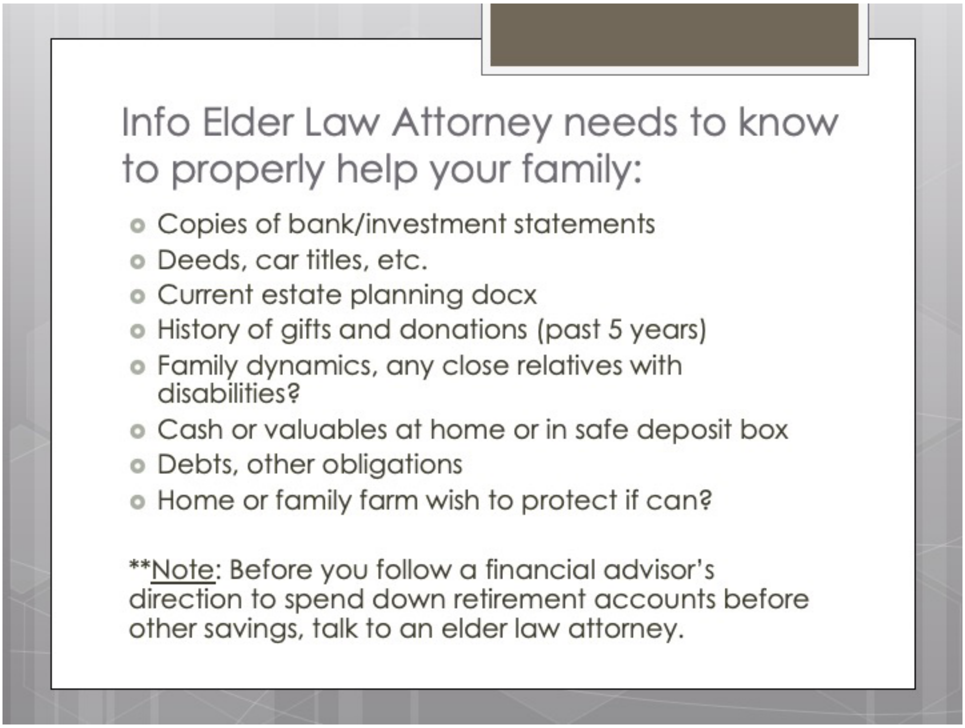
Cautions to consider while watching the "Last Week Tonight" video clip (1):

- Focuses on a notorious, egregious case lacking due process protections (extreme outlier situation).
- Offers a private solution (execute proper DPOAs) that does not address the argument built of a public problem of inadequate funding and oversight.
- Cites a study funded by an organization that could financially benefit if certification requirements were added in order to serve as a court-appointed fiduciary.



Cautions to consider while watching the "Last Week Tonight" video clip (2):

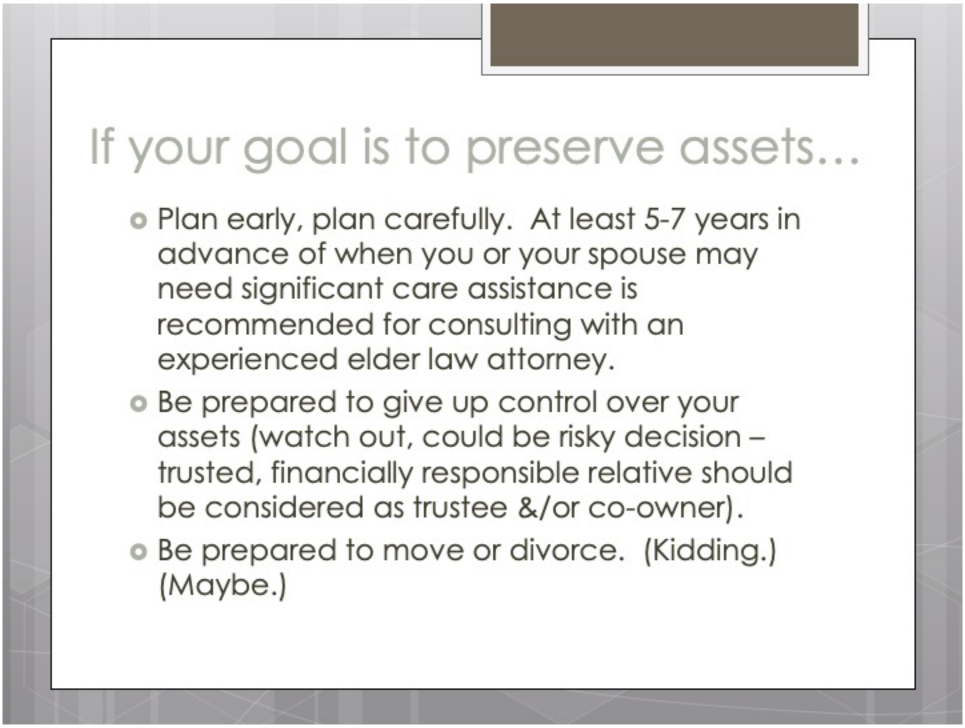
- Fiduciary exploitation is a serious problem, no argument about that. However, if policy changes are made without careful consideration of the ramifications, the real-world consequences likely could include discouraging decent, kind folks from stepping up to help others whom they care about.
- Caregiving and fulfilling fiduciary duties take hard work that should be properly compensated.



Info Elder Law Attorney needs to know to properly help your family:

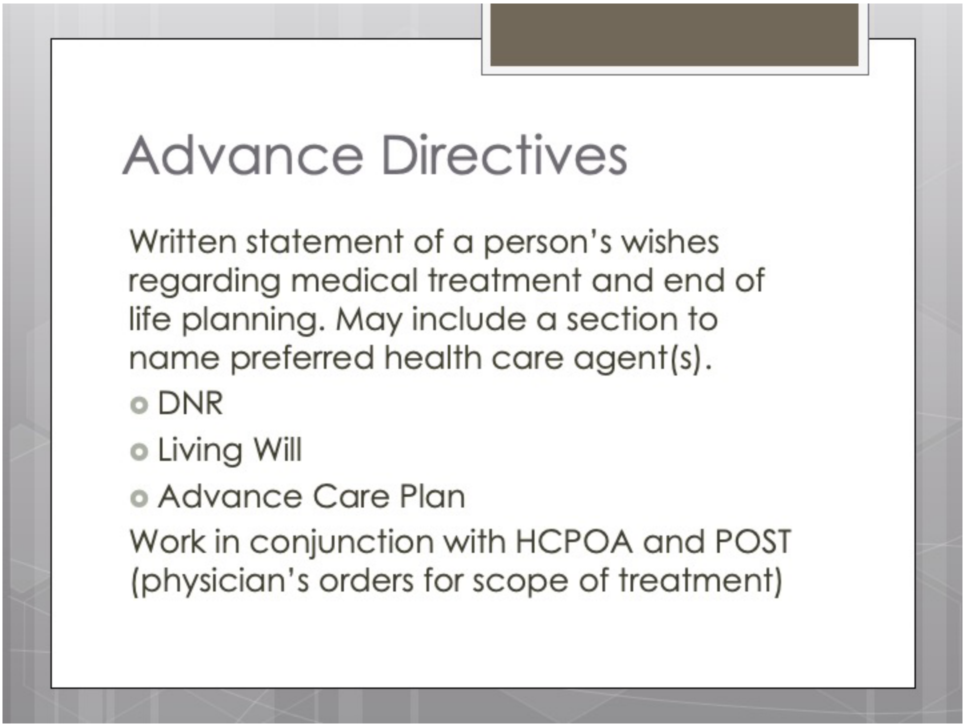
- Copies of bank/investment statements
- Deeds, car titles, etc.
- Current estate planning docx
- History of gifts and donations (past 5 years)
- Family dynamics, any close relatives with disabilities?
- Cash or valuables at home or in safe deposit box
- Debts, other obligations
- Home or family farm wish to protect if can?

**Note: Before you follow a financial advisor's direction to spend down retirement accounts before other savings, talk to an elder law attorney.



If your goal is to preserve assets…

- Plan early, plan carefully. At least 5-7 years in advance of when you or your spouse may need significant care assistance is recommended for consulting with an experienced elder law attorney.
- Be prepared to give up control over your assets (watch out, could be risky decision – trusted, financially responsible relative should be considered as trustee &/or co-owner).
- Be prepared to move or divorce. (Kidding.) (Maybe.)



Advance Directives

Written statement of a person's wishes regarding medical treatment and end of life planning. May include a section to name preferred health care agent(s).

- DNR
- Living Will
- Advance Care Plan

Work in conjunction with HCPOA and POST (physician's orders for scope of treatment)

"We're all getting older every second."

Plan now. Live now. Keep moving.

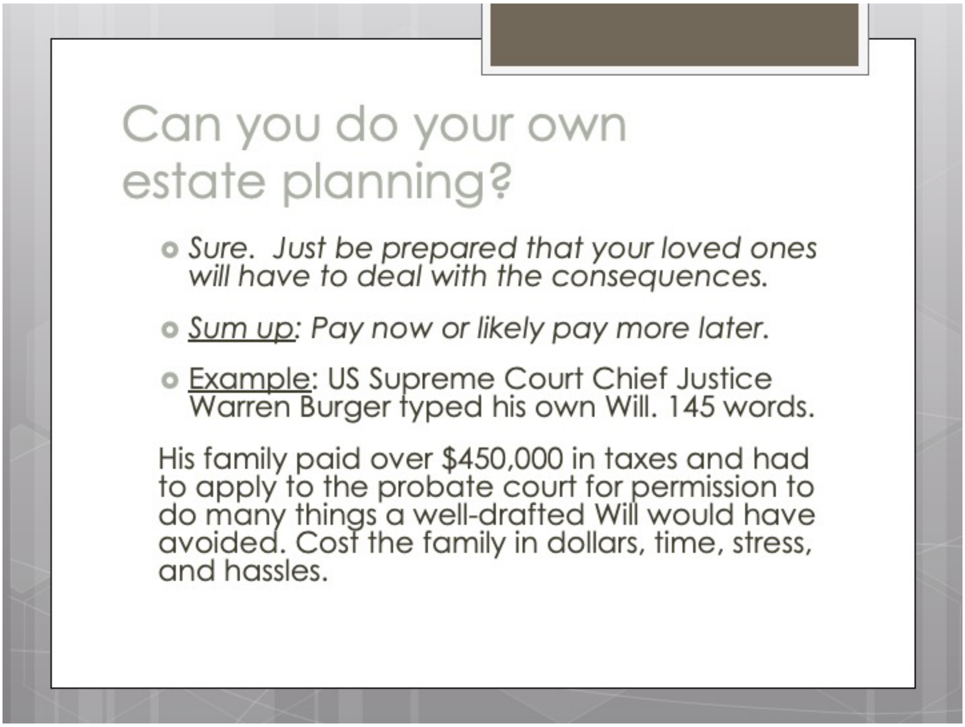
Good advice for:

- Folks of all ages.
- Especially those who embrace the Scarlett O'Hara approach to living by putting off thinking about the hard stuff until tomorrow, another day.

When should you update your plan?

Life Marker Events: *After you are very happy or very sad.*

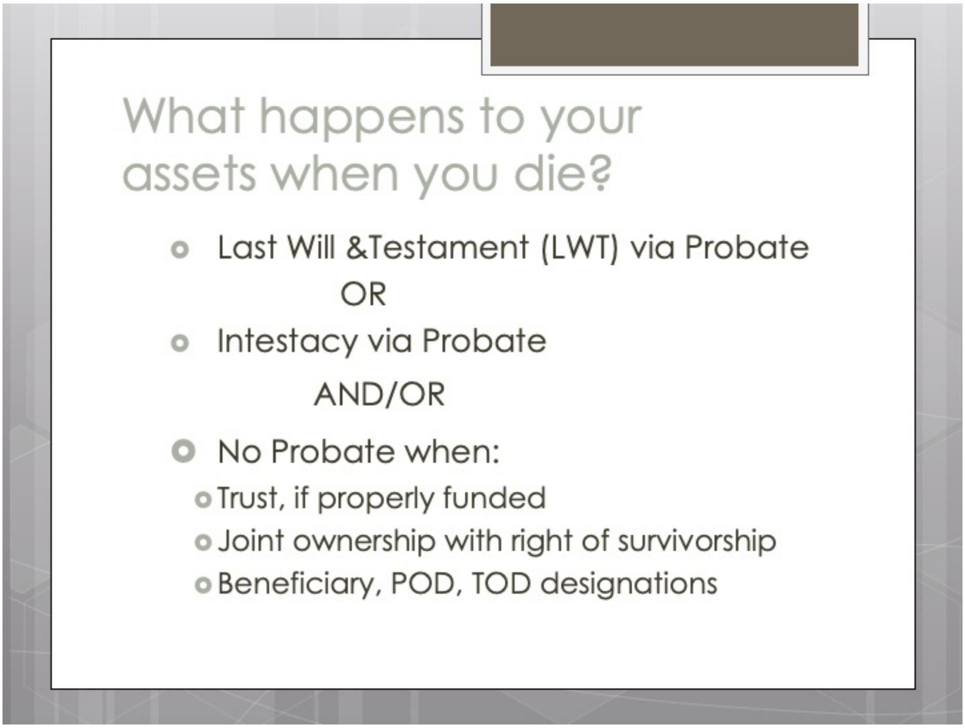
- Loss of a spouse or close relation/beloved
- Receipt of inheritance
- Change in your assets
- Remarriage or divorce
- Major health change
- Birth of a descendant
- Beneficiary with disabilities
- Move to another state
- Change your mind about your plan
- Change in the law



Can you do your own estate planning?

- *Sure. Just be prepared that your loved ones will have to deal with the consequences.*
- *Sum up: Pay now or likely pay more later.*
- Example: US Supreme Court Chief Justice Warren Burger typed his own Will. 145 words.

His family paid over $450,000 in taxes and had to apply to the probate court for permission to do many things a well-drafted Will would have avoided. Cost the family in dollars, time, stress, and hassles.



What happens to your assets when you die?

- Last Will &Testament (LWT) via Probate

  OR

- Intestacy via Probate

  AND/OR

- No Probate when:
  - Trust, if properly funded
  - Joint ownership with right of survivorship
  - Beneficiary, POD, TOD designations

Sarah E. C. Malia, Elder Law Attorney

P.O. Box 12395
Knoxville, TN 37912
sarahecmalia@gmail.com
(865) 456-1383

Additional Resources

- **Ageless Alliance** http://www.agelessalliance.org
- **American Bar Association, Commission on Law & Aging** ttp://www.americanbar.org/groups/law_aging.html
- **Consumer Financial Protection Bureau** www.consumerfinance.gov/older-Americans/
- **Department of Justice** www.doj.gov, https://www.justice.gov/elderjustice/victims-families-caregivers
- **National Center of Elder Abuse** http://ncea.aoa.gov/FAQ/Type_Abuse/#financial
- **Administration for Community Living** https://www.acl.gov/aging-and-disability-in-america
- **Administration on Aging** for help planning for & finding eldercare, call 800-677-1116 or go to https://eldercare.acl.gov/Public/Index.asp

Chapter 10

Conversations About Faith Traditions and Caregiving

*Jean Pearson Scott**
Texas Tech University
and Martha LaRiviere
Antioch University New England
With Aftab Ahmed
Covenent Health System
and Stefanie Posner
Temple Israel

The study of care across the life span would not be complete without an appreciation and understanding of the spiritual and religious significance of caring for one another. Acts of caring reveal our humanness and make manifest the deep spiritual/religious dimensions of our personhood. Nearly all great religions value and encourage care for one another through a variety of religious practices including prayer and meditation, and concrete acts of compassion and care. Central to many religions is the practice of loving and caring for others. One form of love is to care for other persons in times of need. Some would assert that the act of caring is most basic to what it means to be fully human. The Christian faith, for example, exemplifies the significance of care for others in that Jesus, the Incarnate God, healed the sick and fed the hungry and commanded that his disciples love others by responding to their needs. Forty years ago, Kelsey noted in his book, *Caring*, that care and compassion for others is a theme of how we love one another and is inspired by the love of a supreme being (1981).

In both giving care to others and in receiving care, we experience love. Indeed, as love in action, caring is one means of affirming worth and making meaning in our lives. Caring is shaped by traditions

---

**Correspondence to: Jean Pearson Scott, Professor Emeritus, Texas Tech University, jean.scott@ttu.edu.*

of a religious community and one's sense of spirituality. In considering professional spiritual care providers (chaplains, pastoral counselors, and religious leaders), many are required to receive clinical education in order to provide meaningful spiritual support to persons of diverse spiritual backgrounds. The chaplain's role underscores how important it is for those professionals to have listening skills as well as a broad-brush if not fine-tuned understanding of many faiths for the purpose of giving meaningful, if even one-time support, to someone in crisis in a hospital setting.

This chapter is a follow up to a panel discussion held at the 2018 Groves conference in Portland, Maine. The chapter captures thoughts about caring from Jewish, Christian, and Muslim religious perspectives and the experiences of a hospital chaplain trained in pastoral care. These contributions are offered as food for thought about the significance of care from religious and spiritual perspectives.

Family Caregiving in the Muslim Faith:

A Conversation between Aftab Ahmed, retired, Covenant Health System and Jean Pearson Scott

Lubbock, TX, October 15, 2020

I met Aftab for the first time after he accepted my invitation to be interviewed about caregiving from his faith tradition. Aftab grew up in England; however, he has lived most of his life in Texas. Presently, he is retired, widowed, and divides his time between his home and the home of his daughter and her family in another city about seven hours away. His opening comment to me is that family caregiving is a core value for Muslims. Just as Islam is a way of life; caring for family is intertwined with living one's faith day to day. Muslim family environments are typically close knit and bonded, a characteristic that transcends the many countries and cultures where Muslims live. Care for older family members, for example, is the responsibility of the family unit. A nursing home is not an option; care is spread across the family with tasks usually carried out according to traditional gender roles and norms of modesty. Women are more likely to provide meals than men and same-sex care is preferred for hygiene and intimate tasks of daily living (e.g., a male would assist a male with bathing). Although care is an assumed responsibility of family members, older members value independence and do not want to be burdensome to their loved ones.

Aftab noted that lack of "cultural programming" in health care facilities was a deterrent to use and optimal caregiving for Muslim families. Specifically, he pointed out that ignorance of the language, values (e.g. modesty and dietary preferences), and unfamiliarity with Islam limited the quality of care and acceptability of formal health care.

The *Quran i*s the source of holy scripture that teaches about the practice of religious life and provides prayers to recite for many occasions over the lifespan. Muslims pray five times a day. There are prayers specifically for healing. A prayer for humanity encompasses the whole person – body, mind, and spirit. To pray for wholeness or health is to include the psychological, physical, social, and spiritual. Aftab described raising children as a way of life for Muslim families. In the family, there are prayers before and after meals; families go to the Mosque for prayers and instruction. Muslim family life includes care of children and healing.

A poignant moment in the interview was Aftab's description of Azan, a prayer at the birth of a child. The imam or the baby's father will offer this prayer. The words of Azan are whispered into the newborn's ear – the first words the newborn hears declare him/her a child of Allah; the infant, a servant of Allah, is invited to come to prayer for all of his/her earthly life. The infant hears in those first moments of life that there is no God but Allah. Later, boys will be circumcised at two to three weeks of age.

Adhan (alternative word for Azan) for a newly born baby (Gatrad & Sheikh, 2001) is described as follows: It is customary for the father, or a respected member of the local community, to whisper the Adhan into the baby's right ear. These words include the name of Allah the Creator and is followed by the Declaration of Faith: "There is no deity but Allah; Muhammad is the Messenger of Allah." Both of these fundamental pronouncements serve as the pivot around which the life of a Muslim rotates, hence their symbolic significance at birth. Ideally Adhan should be performed as soon as possible after birth; the entire ceremony takes only a few minutes (2001, F-6).

Finally, dying is considered a part of life. The imam may visit a patient who is dying in a hospital or at home though it is preferred to die at home where family are available to care for family members who are dying. In the Muslim faith, it is important that those who die are buried quickly preceded by prayers and preparation of the body. Muslims do not use cremation. The way of life of those of the Muslim faith is exemplified in the life of care and love for one's family.

Aftab shared several prayers that are offered for persons who are sick or in pain (Dua for Mercy, Forgiveness, Healing of Pain, 2020):

> Whoever among you suffers some sickness, or his brother suffers some sickness, let him say:
> 'Our Lord Allah Who is in heaven, hallowed be Your name, Your will is done in heaven and on earth; as Your mercy is in heaven, bestow it upon the earth. Forgive us of our sins. You are the Lord

> of the good. Send down Your mercy and healing upon this pain', and he will be healed. (Sunan Abi Dawud 3892).

Surah Al-fatiha in the *Quran* is also recited for those that you care for and in illness:

> In the name of Allah, Most Gracious, Most Merciful.
> Praise be to Allah, the Cherisher and Sustainer of the worlds;
> Most Gracious, Most Merciful;
> Master of the Day of Judgment.
> Thee do we worship, and Thine aid we seek.
> Show us the straight path;
> The way of those on whom Thou hast bestowed Thy Grace, those whose (portion) is not wrath, and who go not astray. Amen.

Here is a prayer expressing care for the family (Authentic Dua & Dhikr, 2017):

> O Allah! I seek your refuge from incapacity, laziness, cowardice, miserliness, decrepit old age, and punishment of the grave. O Allah! Grant my soul its dutifulness, and purify it, You are the One to purify it: You are its Guardian and its Lord. O Allah! I seek Your refuge from knowledge that does not benefit, and from a heart that is not humble, and from a soul that is never satisfied, and from a supplication that is not answered.

Family Caregiving in the Jewish Faith:

A Conversation between Stefanie Posner, Education Director, Temple Israel and Christine Readdick
Tallahassee, Florida, November 2, 2020

The questions guiding our conversation were "What traditions in the Jewish faith address family caregiving—the giving and receiving of care in families?" and "What are some specific examples of scripture, song, and celebration that provide expectations for family members across the lifespan, that is what is taught about teaching family members to care—fostering care in and for children, sibling care, care for the ill and elderly, give-and-take in spousal relations, extending care to those beyond the family, even caring for the earth?"

Stefanie, who is of Lithuanian heritage and raised in the Jewish Orthodox tradition and now practices her faith in the Reform tradition, said, "In Judaism there is plenty of text about raising children—about the gift that children are. For example, in the Talmud, it is written, 'Childhood is a garland of roses and their very breath is free of sin.'" The very openness of the child leads us to nurture, care for, and love him or her;

in the Orthodox tradition, often in very large families, a mother or father never hits or hollers at their children, extending kindness and nurturance instead.

When teaching children how to live according to an ethic of care or to abide by specific tenants of the Jewish faith, the Jewish parent will be sure to see that each child is learning. If one child "doesn't get it", it is considered not to be the fault of the child, but rather the teacher. Stefanie said, "It is nothing that the child has done that is wrong, it is that the adult needs to see and do something differently." In fact, if you think about it, she observed, Jews were the first "leave no child behind" practitioners, remembering ever that it is in life the child who will carry on the religion, the Jewish faith. And in scripture in the book of Proverbs, the child is reminded to "listen to our fathers, mothers".

In this same vein, there is a story in the Jewish tradition, about a very old man who was planting a carob tree, and a neighbor walked by and asked, "Why are you planting this carob tree? It will not bear fruit for you." And the old man looked up from his digging and replied, "I am doing it for my children." This tale reflects a belief that just because an act does not benefit the actor does not mean that the act should not be performed.

The Jewish holiday of Shavuot commemorates the giving of the Torah, the first five books of the Hebrew Bible from the Almighty/Sovereign to the Jews at Mount Sinai. "To whom shall I give the Torah—whom can I trust to follow its teachings?", the Almighty asked. The Jews exclaimed, "Our children will serve as our guarantors. And so, the Almighty, trusting their word, said, "Teach them to your children."

A beautiful song "Oyfn Pripetshik", written by Mark Warshawsky, speaks to the role of old men who are delighted to teach the alphabet to little children so that they, too, would be able to read the Torah. Ever the goal is "your child teaches their child". A lovely version performed by Einat Betzalel with L'Ochestre Festival can be viewed and listened to on YouTube (Warshawsky, 2015).

Stefanie observed that there are a total of 613 commandments in the Jewish faith—lots of do's and don'ts. One, "visit the sick", is reflective of the Jewish faith as "very community-oriented," focused on "coming together." This admonition to visit the sick goes back to a story about Abraham who at 99 years of age circumcised himself, and, as might be expected, was more than a bit ill. At that time, it was believed that God would send angels for comfort, but, in this case, God himself came.

The lesson in this story is that "if God can go visit, you can go visit!" Even if the person who is ill is sleeping when you visit, upon waking she will feel the burden of sickness lifted. It is further believed that each visitor takes up 1/16th of the person's suffering, extending compassion and kindness. This coming together is still practiced by "sick circles", members of the community gathering food and candles and visiting the ill. Here, it is assumed that not only the person who is ill but also the family of that person, knowing that other people care, feel their burdens lessened.

I asked Stefanie if saying a blessing or grace over meals is practiced in the Jewish faith. Stefanie laughed and said, "We give thanks for each and everything we eat!", even a snack of a single apple. One basic blessing is the Hamotzi, offering thanks for bringing forth wheat, "Blessed are You, Lord our God, Ruler of the universe, who brings forth bread from the earth." From the Jewish perspective, "a meal is only a meal, if you have bread", she added. In order that the blessing be received, children rush to wash their hands and immediately "tear into" the bread, in what to an outside observer might look a little unmannerly, she noted. A blessing is said at the meal's end as well.

Baby naming ceremonies are held for baby girls and boys, with different traditions for each, but each acknowledging the importance of the new baby within the family and within the Jewish community. Newborn baby girls are welcomed with a name. On the eighth day of life baby boys receive not only a name but also circumcision in the tradition of Abraham. Within Orthodox and Hasidic communities, families celebrate both the child's Hebrew birthday and Gregorian birthday, whereas most Conservative and Reform communities today celebrate only the Gregorian birthday.

As Education Director, Stefanie is involved in the teaching of children in Hebrew School at Temple Israel, where the youngest children learn the commandments through play, arts and crafts, and songs. Conversations about being a good friend, over time are elevated to consideration of "how can being a good friend be a 'holy' thing to do?" to "what is a relationship with God like?" That Jews are always "looking to learning" is apparent in lifelong study of the Mishnah, rabbinic writings known as the Oral Torah in which practical dilemmas from everyday life as well as philosophical conundrums are discussed, as well as the Talmud, written Jewish law and theology.

Finally, caring during illness or at life's end is often expressed in recitation and singing of scripture, such as Psalm 121, "I will lift up mine eyes to the hills, from whence cometh my help" or the 23rd Psalm, "The Lord is my shepherd, I shall not want." This psalm may be sung on the occasion of a loved one's "unveiling", the one-year anniversary of death. This version "Adonia Ro'i" is sung beautifully by Cantor Rachel Goldman (Goldman, 2017).

Family Caregiving from a Christian Perspective:

Jean Pearson Scott, Interim Rector, St. Stephen's Episcopal Church
Lubbock, TX

Central to the Christian faith is the divine mystery of the Incarnation - that God became flesh, in the form of a human being named Jesus, who lived on earth, fully human and fully divine. God came into the world to show us how loved we are and to get us back in step with the divine plan through repentance of sins and profession of faith. Jesus offers himself in self-sacrificial love to die by crucifixion though he committed no crime. He became the scapegoat for our wrongdoing and complicity in harm to others and the creation. In gratitude for God's great mercy, disciples of Christ promise to live the way of love - by living life to its fullest through loving God and loving others as ourselves. Caring for others was of high importance in Jesus' ministry and in his teachings to his disciples. The Bible recounts many of Jesus' healings and encounters with persons with diseases. When Jesus warns his disciples of the coming judgment, he is clear that those who show mercy "to the least of these" will inherit the heavenly kingdom: "…I was naked and you gave me clothing, *I was sick and you took care of me*, I was in prison and you visited me…" (Matthew 25: 36). Jesus' disciples will be known by their love and care for one another.

One of the first religious rites in the Christian faith is the baptism of an infant, small child, or adult family member – the age varies among Christian groups. Baptism is the official welcome of a person into the faith community and the recognition of the person as Christ's own forever. When infants and children are baptized, parents and the faith community make promises to support and nurture the child in the teachings of the faith. Promises made by adults on behalf of the infant or child include, for example, the promise to "seek and serve Christ in all persons, loving your neighbor as yourself" (Book of Common Prayer, 1986, p. 305). Baptism is a communal act. In the churches that use infant baptism, there is the expectation that with maturity, adults will make a public affirmation of their faith and responsibilities to their baptismal promises. Confirmation is usually held beginning at 16 or 17 years of age or in adulthood. Confirmands are expected to receive instruction in the full membership in the church and renew their baptismal vows.

Although I did not realize it at the time, the church served as a school in caring – my family attended many a potluck supper for special events, Sunday School classes, vacation Bible school, choir practices, youth group, outreach projects, and, for me, church summer camps. All of these were important in my spiritual formation. Many persons in the church modeled for me the care that Christians give for not only those who are sick, but the care that shapes a child's entire development and spiritual life.

Caring for one another is an expression of love for one another. The promise to care for one another is reflected in the major observances celebrated by families and the whole congregation. Other events including marriage and death have special services associated with them. Traditional marriage vows affirm the promise to care for one another throughout life: "Will you love her, comfort her, honor and keep her, in sickness and in health…" (Book of Common Prayer, 1986, p. 424). Services of healing are held weekly at some churches. Prayer groups are organized to hold those who are sick in prayer. Liturgical resources include prayers for persons who are sick and for persons desiring unction. As a priest in the Episcopal Church, I use oil to make the sign of the cross on the forehead of the one desiring anointing.

There are liturgies prescribed for persons who are nearing death. These are very meaningful ways of expressing one's faith and finding meaning in the death of a loved one. The burial service emphasizes the resurrection of Jesus and the promise of eternal life for all persons. The Christian faith is a post-resurrection faith. We live into the promise of resurrection now and beyond the grave. For many persons including Christians, illness may present a crisis of identity–who am I when I can no longer be as active or as independent as I used to be? There are often spiritual crises–why does God not intervene? why are my prayers unanswered? have I been forgiven of my sins? The local church provides pastoral ministry by "being with" those who need care; being the "face of Christ" for someone in need. Even a brief visit, a prayer, a moment to check-in is a valued act of spiritual care for others.

Learning to be a Resident Chaplain at Maine Medical Center: Education in Spiritual Care.

Conversation with Martha LaRiviere, Marriage and Family Therapist, Ph.D. Candidate at Antioch University, New England

Clinical Pastoral Education (CPE) "is interfaith professional education for ministry. It brings theological students and ministers of all faiths (pastors, priests, rabbis, imams and others) into supervised encounter with persons in crisis. Out of an intense involvement with persons in need, and the feedback from peers and teachers, students develop new awareness of themselves as persons and of the needs of those to whom they minister…." (ACPE, n.d.). Chaplains in hospitals, skilled care facilities, hospice, and other spiritual care settings are often required to have clinical pastoral education (CPE) units. At the time of the Groves Caregiving conference, Martha LaRiviere was a CPE student. She received approval from her supervisor at Maine Medical Center to share an example of her spiritual care experience in the form of a verbatim. What follows is a summary of Martha's CPE experience and an example of a verbatim transcript with her assessment of the visit and her supervisor's comments.

Maine Medical Center (MMC) in Portland, Maine, has hosted a training program for men and women who want to become chaplains or ministers. I joined the group hoping to learn how to incorporate spiritual care into my future work as a family therapist. My job at MMC was to see any of my assigned patients that welcomed a conversation with a chaplain resident.

As I sought out those that could use some quiet spiritual care, I met a wide range of patients. One woman was raised in a communist country to be "religion-free." Others were eager to sing familiar church hymns, or who simply welcomed a visitor. I tried to become an appreciative witness to patients and to quietly validate their emotional and spiritual journeys. It was not my mission to proselytize or to provide specific guidance.

One patient that I met towards the end of my training was watching television as I entered his hospital room. A football game was on and Army was playing Navy. After a nonverbal greeting, I sensed that it would be alright to slide into the easy chair and join with him for a while. After quietly cheering for Army, we slipped into a chat about his wait for a family member to come to pick him up and take him home. "I've got work to do," he said, "and my dog needs me." This patient was not waiting for a sermon or even some positive thinking. It appeared that having someone who made no demands upon him, but was interested in his story, was close to what he needed.

The spiritual care I learned to apply had no script. I learned, a little at a time, to feel unconditional acceptance, to offer a presence when patients had fears and missed home. There is a song with which I am familiar entitled "I Need Thee Every Hour" (Bonner Family, 2016). Its refrain repeats the phrase, "I am here. I am here." That line, "I am here", sums up my desire to be there for those who wait for the resolution of their hardships.

Verbatim From Patient Visit

Preliminary Data:

Male patient, 59, white, Protestant; in a committed relationship, Pyelonephritis (bacterial infection of the kidney), recently admitted. This visit was a consultation and his first spiritual care visit.

How I chose to visit this patient:

I saw seven patients on this day, but this is the visit that touched me the most. This man was someone whose record said Protestant, a vague term, and he made it very clear that he was not a church-going man. Our discussion took us pretty deep into spiritual matters. The term "Protestant" obscured his own very personal relationship with the sacred.

Pastoral/Spiritual Care Plans and Preparation:

I made this visit my priority of the day. I checked in at the nursing station to see if there were any changes in his health. There was no change, and he was in a good deal of pain. As a trainee, I was becoming more comfortable meeting with absolute strangers but was still hesitant.

Impressions:

I entered the room, puzzling out which bed was his. A helpful staff person pointed out the patient who was perched on the edge of the bed with his feet just above the floor. He had arranged his belongings on his meal table. Absent were any cards or flowers for him. There was a curtain drawn between him and his roommate, who, he said, required care during the night, making it difficult to sleep. He, too, needed care at night. He looked exhausted and uncomfortable. His eyes did not focus on anything in particular, and I wished I had read the health record more thoroughly. He sat restlessly, seeming to be trying to cope with the pain. I asked for his permission to visit with him.

An account of our Interaction:

C1 (the chaplain):	Hello. My name is Martha; I am from Spiritual Care. May I come in?
P2 (the patient):	(softly) Yes, come in.
C3	May I sit down and stay for a few minutes? I am here to visit and to see how you are faring.
P4:	Yes.
H5:	(Housekeeper came in to set up a small plastic bag on the side of his mobile tray and set up a box of tissues on the other end of the tray).
C6:	I see you have a roommate.
P7:	Yes, and it is very noisy at night.
C8:	(observes that the patient's eyes are red and not clearly focused. Why?) You do look tired. It must be difficult to sleep away from home.

P9: Yes. I slept only an hour last night, and maybe 4 hours for the whole week.

C10: Well, that is pretty rough. It's tough to be away from home.

P11: I just want to have the pain go away. I'm so tired, and my girlfriend can't be here.

C12: I'm sorry to hear that. (pause) You must miss her.

P13: She doesn't have a car, and it is too far away. It's lonely.

C14: It is hard to be separated and away from her.

P15: Who did you say you were?

C16: I am from the Spiritual Care department. I notice that you have named your religion "protestant."

P17: I have a relationship with Jesus, but I don't go to any church.

C18: That's all right. So, you feel close to Jesus?

P19: Yes. I read the Bible, and you can learn everything about Jesus there. There are great stories, but most of them are about people who make mistakes.

C20: I guess that's true. We humans do make a lot of mistakes. Maybe we learn from them.

P21: But, Jesus, he walked on water and turned the water to wine. He knew what he was doing.

C22: It sounds like you know your Bible real well.

P23: Before I lost all my sight.

C24: (Aha! That solves my confusion over the lack of eye contact.)

P25: I read it all the way through.

C26: Not many people have done that. Do you have any favorite scriptures? Would you like me to read to you?

P27: Yes. You choose.

C28: (pulling out my smartphone). OK. Here's one I like. I read 1 Corinthians 13:4-8 (which begins, "Charity suffereth long, and is kind; charity envieth not; charity vaunteth not itself, is not puffed up).

P29: (tears run down patient's eyes). There is one about a door.

C30: Let me find it. OK. Here it is. (Reads Matthew 7:7 and is grateful for the scripture search engine.) The verse says, "Ask, and it shall be given you; seek, and ye shall find; knock, and it shall be opened

unto you."
P31: (Weeps).
C32: It is beautiful.
P33: Thank you for your visit.
C34: I am so honored to meet you. May I shake your hand?
P35: Yes.
C36: Good-bye.

Summary of LaRiviere's Verbatim

ML comments in black standard print

[The education director of the Spiritual Care Office responded to my verbatim report. Her comments are italicized and in brackets.]

Goal:

- My goal was to see where the patient wanted to go with the visit. I wanted to be alert to any emotional connection I felt. I did not want to play cowboy with the direction of the conversation. [☺]
- I found myself asking questions about his beliefs.
- He took the bait and ran with it, so I tried to keep up. *[Yay!]*

Spiritual Assessment

- This man's God was clearly Jesus. He wanted a direct connection with him and nothing between them. His beliefs seem to give him a sense of meaning into what sounded like a quiet and perhaps lonely life. *[+grief]*
- The patient is somewhat resigned to his string of medical difficulties.
- I think that his hope is on the immediate issue and not the big picture.
- I believe many of the same things that this man did, although I am firmly committed to my religious organization *[+]*

Personal and Psychological Dynamics

- This is a mature person who has carried a great deal of physical distress. It seems to have made him weary, but he still is staying somewhat optimistic.
- His psychological needs may be comfort and companionship as a way of staving off the debilitating aspects of loneliness. *[Yes]*
- I don't think this patient has put it into words, but he feels it emotionally.
- I am always thinking about fixing things, and of course, cannot do it with this patient or really any of the others. I did what I could and felt (on my end) very moved by him. *[Spiritual Care leader*

underlined "very moved by him" and said, "You might have missed that if you had been "fixing him!"]

Sociological

- The hospital stay is making the separation between him and his significant other almost insurmountable.
- He is currently in too much pain to take action to relate to those around him in the hospital.

Exploration

- My role in this interchange was like a traveler to new lands where I meet someone like me, but I could make no assumptions and could not meet his deep pain. *[But you stepped toward him]*
- Dynamically, we had barriers regarding sight, health, and time. I tried to capture what I could in a short visit.
- I would definitely been more thorough and read his health record carefully. I wish I had felt freer with my curiosity/concern about his girlfriend's trials. *[but – you stayed with his feelings about her absence.]*
- His loneliness felt familiar to me as I have felt lonely often.

Pastoral/Spiritual Care Opportunity

- I would love to have others follow up with this patient. I am particularly concerned about his isolation in social, emotional, and even spiritual ways, even though he may be reluctant to share himself in these ways. *[This could be a good referral to the Call Chaplains.]*

Theological Reflection

- I must have made some assumptions about what this patient needs. Is his loneliness a problem for him? It looked that way to me, but I would have to talk to him more to know. *[good catch!]*
- Theologically, I was thrilled to find a connection with him through his love of the Savior and the beautiful words of the scriptures.
- My image is of the Savior gathered with the children as they visited with him. I felt that he had a childlike simplicity in his beliefs. *[good]*

[This verbatim shows significant development. Many fewer questions and I sense you were more yourself in the role.]

Conclusion

The Abrahamic faiths offer a structure for praying, praising, and worshiping a God of compassion. Jews, Muslims, and Christians strive to live their lives consistent with the teachings of their faith. As it is clear in the interviews in this chapter, care is a demonstration of the love that a person has for God. As care is practiced in the family, loved ones learn of a compassionate and loving God. Each religion has its own unique practices, prayers, songs, worship and festive traditions. Yet, there are clearly common themes reflected in the comments of Stefani, Aftab, and Marie regarding how care is viewed in the Abrahamic faiths.

Care is **inclusive** in that persons who are vulnerable (children, widowed, aged, poor, those with mental illness, and developmentally challenged, etc.) are given priority as persons who particularly need the care of their families and faith community. The mission to care for vulnerable relatives and others in need gave rise early to faith-based hospitals, nursing homes, and hospice, to name a few. These services aim to help families with care needs and acknowledge the spiritual and religious aspects of healing. As was noted in Aftab's comments; however, health facilities' policies and understanding of diverse religious traditions may be a deterrent for acceptability and full use of health care by persons from more diverse religious backgrounds. All the more reason to have professional spiritual care providers who are attuned to religious traditions and spiritual needs of patients.

Care is *communal***.** Although caregiving is often defined by cultural and gender norms, religious precepts emphasize that the faith community has a duty to care, particularly when family situations are challenging. For example, a member of a synagogue may give respite care to a caregiver who needs time away from a spouse who suffers from dementia. Christian churches may offer services specifically to pray for those who are in need of healing. Communities of faith often sponsor community services whose mission is care.

Care involves *presence***.** Fundamental to care is the ability to be fully attentive to the experience of the one who needs care. As a part of pastoral education, spiritual counselors are taught to offer a non-anxious presence. A non-anxious presence is created by being focused on the patient. Along with focus, spiritual care professionals focus on attentive listening; learning to listen without judging or offering advice. Often the best spiritual care is an attentive listener.

Spiritual growth is an important aspect of care. Throughout life the impact of illness or trauma on one's faith and sense of identity is an event that has spiritual implications. Individuals may find themselves seriously questioning their faith, questioning God, confused about who they are now that they are in the middle of life's transitions (e.g. adolescence, have been traumatized, or are a survivor of disease, etc.). These events represent spiritual challenges that can be problematic or more likely, they can be opportunities for spiritual growth. Religious faith and spiritual understandings may function as a foundation for resilience and new life.

Mutuality is a unique characteristic of care. Being a receiver of care aids us in turn in becoming providers of care. So often we hear the ones who gave care declare that they, themselves, were the ones who benefitted from the encounter – we truly are enlivened, discover meaning in life, and grow spiritually when we risk giving and receiving care.

References

Accredited Clinical Pastoral Education (n.d.). *Programs: Frequently asked questions*. https://acpe.edu/education/cpe-students/faqs

Authentic Dua and Dhikr (2017, April 10). *The supplication narrated by Zayd Arqam – radiyallaahu anhu*. https://authentic-dua.com/category/dua-dhikr/cowardice/

Bonner Family (2016, May 5). *The Bonner family presents 'I am here*." an original arrangement of the hymn "I Need Thee Every Hour," (with lyrics by Anne Hawks and Robert Lowry, and tune by Lowry) [Church of Jesus Christ of Latter-day Saints, Mormon Channel] YouTube. https://www.youtube.com/watch?v=L86XIMxw6mY.

Dua for mercy, forgiveness, and healing of pain. (2020, July 21). https://muslim.sg/articles/dua-for-sick-person-in-hospital-in-english

Episcopal Church (1986). *Prayer book and hymnal: Containing* the *book of common prayer and hymnal 1982.* Church Pension Fund.

Gatrad, A. R., & Sheikh, A. (2001, January). Muslim birth customs. *Archives of Disease in Childhood: Fetal and neonatal edition. 84*(1), F6-F8. 10.1136/fn.84.1.F6 https://fn.bmj.com/content/fetalneonatal/84/1/F6.full.pdf

Goldman, Paul (2017, February 21). *Rachel Goldman's recital*. [Video] YouTube. https://www.youtube.com/watch?v=OjRR-UVrdEw

Kelsey, M. (1981). *Caring: How can we love one another?* Paulist Press.

Warshawsky, M. (2015, November 28). *Oyfn Pripetshik – Einat Betzalel and L'Orchestre Festival*. [Video] YouTube. https://www.youtube.com/watch?v=k-6vPN00apc

Chapter 11

New—and Needed—Care Manager Education Supports Aging and Disabled Populations

Leisa R. Easom
Georgia Southwestern State University

America needs a better prepared workforce to address a broader scope of needs and services for its aging and-or disabled populations. Within the last decade, the population of people ages 65 and older has grown from 37.2 million in 2006 to 49.2 million in 2016 (a 33 percent increase) and is projected to almost double to 98 million by 2060 (tinyurl.com/ya6lbmde).

This older adult cohort also must cope with multiple chronic illnesses, including cardiovascular disease, cancer and dementia (tinyurl.com/y9h2nypa). Similarly, parents of children with disabilities face worries about healthcare management in the years ahead when they might not be present—or able—to advocate for and protect their children. Families caring for older adults and children with disabilities need to know what programs and services are available, how to connect with them and who can help manage their family members' care over the long term.

While each family is unique in how it deals with different stresses and issues, a trained care manager can advise families on available support programs and how to access these programs both

Leisa R. Easom, R.N., Ph.D., is associate dean and professor in the College of Nursing and Health Sciences at Georgia Southwestern State University in Americus, G.A. She can be contacted at leisa.easom@ gsw.edu.

[Originally published as Eason, L. R. (2019). New—and needed—care manager education supports aging and disabled populations. *AgingToday, xl*(2), 1-3. Reprinted with permission.]

in the community and nationally (tinyurl.com/yc8k4fu8).

Traditional healthcare providers are not educated to address these needs. Thus, families need a new category of healthcare worker—a care manager—who is trained to navigate our nation's convoluted healthcare system.

Education Deficit Creates Service Gaps

The healthcare workforce is critical to the healthcare system infrastructure, but insufficient or absent educational training for this workforce has created gaps in healthcare service. In traditional healthcare training settings, physician and nursing instruction is based on the medical model, which focuses on detecting and treating disease. There is little or no training that focuses on caregivers, budgetary and management skills and "soft" skills, such as effective communication.

What is missing are healthcare workers who can plan, organize, arrange staffing, direct people to community resources and assist with decision making—in other words, care managers. In past years, nurses or social workers have evolved into care managers as they completed additional training or benefited from experiential learning over years of employment.

As noted by Zimmerman and Osborn-Harrison in "Person-Focused Healthcare Management" (New York: Springer, 2016), the system for producing, delivering and paying for healthcare requires a new healthcare worker to oversee and guide families so that people being treated as patients fare better than they do currently.

Navigating this system is complicated at best and formal undergraduate education has not previously been available to prepare a healthcare worker to address the wide interdisciplinary area of patient needs and supports. Now, however, healthcare workforce training for long-term-care management is available in an academic interdisciplinary setting as an undergraduate degree.

Research and Teamwork Forge a New Degree

The Bachelor of Science in Long-Term Care Management originated in the Rosalynn Carter Institute for Caregiving at Georgia Southwestern State University in Americus, and was created after holding focus groups and conversations with caregivers, and consulting with employers that offer long-term services and supports. Research also included in-person discussions with CEOs of a hospital and a long- term-care residential institution; and, to learn more about the most needed workforce skill sets, an electronic email survey was circulated to all known Georgia area agencies on aging, hospitals, home health agencies and nursing or assisted living facilities.

Of the 116 surveys returned, 81 percent indicated a need for employees with long-term-care management education, and most reported that this type of degree would fit into current positions. The majority (65 percent) of those surveyed indicated an annual salary compensation of $45,000 to $50,000 for such an employee in Georgia, but a review of care manager salaries nationwide revealed an annual salary range of $40,000 to $105,000 (tinyurl.com/y9h9gy85).

Employers noted that the needed healthcare workforce skill set should include management and budgetary skills, cultural diversity knowledge, social skills, communication skills, awareness of caregiver and care receiver needs and an awareness of and ability to connect people to support programs in the community. Based upon employer feedback, only an interdisciplinary approach to training can prepare graduates of such a program to meet the wide range of needs experienced by individuals with chronic illness and-or disability who are living in the community or in residential institutions.

In next steps, an interdisciplinary team was formed between Georgia Southwestern State University's College of Nursing and Health Sciences, the School of Business Administration, the Department of Psychology and Sociology and the Rosalynn Carter Institute for Caregiving. This team met for two years to plan content for a four-year course of study that would develop the skill set needed by employers offering services to older adults, and that would offer long-term-care management training to program participants.

An Accessible, Well-Rounded Curricula

Acknowledging the need for flexibility in training, this Bachelor of Science degree is now offered online and-or in classroom settings. The training includes courses in business, psychology, sociology, nursing, caregiving and long-term-care management.

Students also take a capstone internship course, which ensures an opportunity to apply theory to practice. In the internship portion of the program, students complete 150 hours of on-site training with an agency of direct service in long- term care, such as an area agency on aging, an institutional residential setting, a hospital, a home health agency and others.

Program graduates can join the national organization, the Aging Life Care Association, which has established standards of practice and a code of ethics for care managers. After two years of supervised work in the field as a care manager, care managers are eligible for certification through a national exam for Certified Managers of Care (CMC). The test is administered by independent testing centers, and candidates are tested on specific content domains unique to care management. To maintain certification, CMCs are required to participate in continuing education and professional development; certification is renewed every three years to ensure that care managers are practicing at the highest professional level (tinyurl.com/ycpvfswz).

A New Path Forward

Currently, the healthcare workforce cannot meet the needs of individuals and families attempting to navigate our nation's complex healthcare system. Given the vast quantity of older adults in America with chronic illness, and large numbers of individuals with disabilities, this degree offers a much needed and innovative educational pathway for people who want to support and work with these growing cohorts.

Chapter 12

Tai Chi and Qigong: Slow Dances of Self-Care for Family Caregivers and Care-Receivers

*Julia A. Malia**
University of Tennessee
James E. Malia, & Sarah E. C. Malia

In the early 1970s and again in the late 1980s, I, Julia was a student at Iowa State University in Ames. Every non-rainy morning during warm weather, I observed Chinese students and older-generation Chinese family members moving together in synchronized patterns on the lawn of graduate student housing. They performed the relaxed, smooth, beautiful patterns of Tai Chi with no identifiable teacher, just a sharing and passing of deeply ingrained body knowledge, one generation to another.

Decades later, Julia and her family presented Tai Chi and Qigong workshop sessions each morning at the 2018 Groves Conference with dual purposes in mind: (a) we, Julia, Jim, and her daughter Sarah, wanted to make people aware of the health benefits that regular practice of Tai Chi and Qigong can bring to their lives, especially when people are under stress such as being a family caregiver (Boss, 2002; Boss, 2006; Boss, 2011), and (b) we wanted to give attendees at our Groves Conference a gentle but energizing way to begin each conference day. During our sessions at the conference and on the subsequent video recording that we made to accompany this chapter (Readdick, 2020), we demonstrated how to practice four different routines: (a) Shibashi I (Qigong), (b) Tai Chi for Arthritis, (c) Yang 24 Form Tai Chi, and (d) Four Forces (Qigong cool-down).

This chapter provides general background information about Tai Chi and Qigong, along with more specific information about the four rou-

**Correspondence to: Julia A. Malia, Associate Professor Emerita, University of Tennessee, Knoxville; jmalia@utk.edu*

tines that we demonstrated on the video. We conclude with information about how to learn more about these topics and, if desired, how to incorporate Tai Chi and Qigong practice into your daily life.

Roughly speaking, Qigong includes various series of energy-building exercises that take place in a small square footage of floor space, at most stepping front, back, or to the side while doing X number of repetitions of each exercise. Then Tai Chi takes the building blocks of Qigong and combines certain movements into various dances (called forms), including multiple steps in different directions around a larger but still modest area of square footage within a typical home or practice area (see Readdick, 2020). More details are included below.

We, the three members of our immediate Malia family can offer personal testimonies regarding the benefits that Tai Chi and Qigong bring to us individually. Julia and Sarah started weekly Tai Chi classes in 2007 with local teachers, Bill and Linda Pickett, and found the regular practice to be helpful stress management tools in our high-pressure professional and personal lives. In 2011, James was in a bicycle accident that broke his neck. He always has been physically very active, but suddenly he had to be extremely careful of movements during his painful 3-month recovery in a neck brace. When Julia and Sarah suggested that James join them in a new series of the Picketts' classes, he found the movements to be a way to safely promote his healing, and he has continued regular practice ever since.

Compassion fatigue often haunts family caregivers (Boss, 2002; Boss, 2006; Boss, 2011). Frequently, caregivers rely on sedentary activities such as watching television or reading as their primary means of taking a break from the tasks associated with caring for their family member(s), and they often feel trapped because they believe they shouldn't leave their family member(s) home alone (Boss, 2002). Julia's only aunt died of a heart attack while she was her husband's caregiver at home; he was an Alzheimer's patient and outlived her by a number of years. She had just taken steps to enroll him in a care facility's waiting list, finally admitting that it was getting to be too much for her to do at home. It clearly was.

Two truly useful activities for caregivers who want to take care of themselves even when they do not leave home are Tai Chi and Qigong. These activities do not require a lot of space or special equipment or attire—just comfortable clothing and flat shoes, some room to move around freely, and some basic instruction to guide them. Even more beneficial may be joining a class so that they can take time away to be social and enjoy the special energy that comes from moving in a slow, controlled, graceful dance in synchrony with others. The students whom we have taught Tai Chi and Qigong over the past 5+ years have formed a strong social network of support for each other and us. They have co-created with us what we call our "Tai Chi family," a branch extended from our deeper affiliated kin ties with the Picketts and others.

Family caregivers are in an excellent position to pass on what they are learning to their care recipients—if they make the effort to learn how to safely teach what they have learned and adapt it to accommodate physical and/or intellectual limitations that their care recipients are experiencing (See Lam & Miller, 2006). The movements should be gentle, soothing, and painless, modified to fit the range of motion comfortable for each individual.

Our 2020 video recording, *Tai Chi and Qigong: Slow Dances of Self-Care for Family Caregivers and Care Receivers* was filmed especially for this chapter by Dr. Christine (Coco) Readdick and Josh Kukus of Florida State University's College of Human Sciences in order to demonstrate what we are discussing in this text. Viewing it is evocative for Julia of those 1970s and 1980s glimpses of daily Tai Chi activity on a campus lawn: gentle, slow, continuous movements of people practicing Tai Chi together to develop and maintain health-promoting routines. It is gratifying that our own immediate family perform these activities together and are working in various ways and venues to pass on insights and tools for self-care to others who are interested.

Doing the Practice

Stand tall; arms are at your side;
lengthen your spine; drop your shoulders;
knees are loose and slightly bent; loosen your joints;
place the tip of your tongue at the roof of your mouth just behind your front teeth;
clear your mind and focus on the moment;
take a deep breath and begin.

These instructions put the practitioner into the proper position and state of mind to commence a traditional Tai Chi or Qigong routine as an exercise in moving meditation. When everything is going smoothly, the mind relinquishes control while staying alert and focused, and the body takes over to direct the flow of hands and arms, feet and legs, head and torso. The slow, gentle movements are relaxing and yet stimulating at the same time.

Tai Chi and Qigong activities are exercise and wellness routines that originated in ancient China. Each is a low-impact, weight-bearing exercise that involves slow, gentle movements, deep breathing, and meditation. Tai Chi and Qigong may be practiced separately or together to enhance physical and mental health. Tai Chi and Qigong routines generate energy that is “rooted in the feet, powered by the legs, controlled by the waist, and expressed in the hands and fingers” (Pickett & Pickett, 2007-present). Because of the gentle ways in which the routines are practiced and their adaptability to individual capabilities and limitations, they may be performed by people of most any age or health condition. Indeed, according to the Picketts, simply visualizing the routines without moving your body can reap up to 25% of the physical benefits gained by actually doing the movements.

We each have become certified teachers of Tai Chi and have incorporated Qigong into our teaching. Our initial training and teacher certification were through the Tai Chi for Health Institute (TCHI) developed and directed by Dr. Paul Lam. (It should be acknowledged that Sarah was asked to serve on and is a current member of the international TCHI board of directors, a nonprofit division with volunteer board members).

As shared by Dr. Lam in his autobiography, *Born Strong* (Lam with Bawden-Davis, 2015), he is a retired family physician who developed severe arthritis very young as a result of deprivations suffered as a child during the Cultural Revolution in China. To regain and maintain his health, Lam devoted himself as a young man to learning and regularly practicing Tai Chi. He went on to become a gold medal winner in Yang 24 Form at the Third International Tai Chi Competition in Beijing in 1992.

After immigrating to Australia, in addition to practicing family medicine, Lam worked with a team of Tai Chi and medical experts to create several Tai Chi programs designed to promote health and well-being by combining authentic traditional Tai Chi and Qigong, up-to-date medical knowledge, and effective skills-based teaching methods (Lam with Miller, 2006). Dr. Lam has taught his programs throughout the world. Today millions (including the Malias) have learned and practice these routines for health and enjoyment (Lam with Bawden-Davis, 2015).

Qigong

Qi (pronounced “chee”) means “energy” or the animating power that flows through all living things, and *gong* means “work” as well as the benefits that accrue through perseverance and practice. Hence, *Qigong* means working with your energy to enhance its flow, which can help you achieve vital health and well-being. The practice began in China several thousands of years ago as a standard exercise to achieve and maintain good health (Ross, 2014). Today Qigong is part of the Chinese National Health Plan and is an integral part of Chinese daily living (Mahoric, 2019).

Qigong can be a single movement that is repeated multiple times or a more complex series of movements. Sometimes there is only breathing and meditation. Generally, the routines are relatively easy to learn, and there have been thousands of Qigong routines developed and practiced over the centuries (Mahoric, 2019). Because of their relative simplicity, Qigong routines are quite adaptable, allowing individuals of varying ability and physical conditions to learn and benefit from the regular practice of the routines. All are designed to improve balance, relaxation, breathing, posture, and general well-being.

Some Qigong routines are designed to ameliorate specific medical conditions (e.g., breast cancer, Lu with Schaplowsky, 1999; other cancers, Klein et al., 2017; and back complaints, Baumgarden et al., 2018) in addition to the general health benefits of the practice of Qigong. Sifu George Picard (Founder and Chief Instructor of the Glenridge Martial Arts Academy in St. Catharines, Ontario, Canada) has pointed out that 1 in 2 persons now contract cancer at some point in their life, compared with 1 in 33 in 1908 (Picard, 2009, 2010). He works with traditional Western medical practitioners to teach patients ancient self-healing methods from Chinese medicine and with researchers from major medical universities (for instance, Harvard Medical School) to systematically investigate the results (Picard, 2009, 2010). During the Covid-19 pandemic, James and Julia have participated in his Zoom sessions that teach 24-Posture Therapeutic Qigong to the general public (The Village of Healing and Wellness, n.d.).

Qigong energy exercises traditionally are practiced with Tai Chi (Ross, 2014). The Picketts and Malias use Qigong activities as warm-ups prior to teaching or performing Tai Chi and as cool-downs at the close of each session.

Tai Chi

Tai Chi is a slow-moving exercise that is meditative in nature. It began in ancient China 500 years ago or more (Wayne with Fuerst, 2013). It engages a practitioner on multiple levels: physical, intellectual, emotional, and spiritual. Tai Chi builds on Qigong principles and practice, and, in contrast to Qigong, initially was applied more for self-defense purposes (Wayne with Fuerst, 2013). The term *Tai Chi* means "vast universe", "supreme ultimate", or "total balance"; and when the word *Chuan*, meaning "fist", is added to the name, the whole phrase is understood to mean a martial arts discipline (Ross, 2014). As practiced today for health purposes, Tai Chi Chuan may be considered a soft martial art, meaning that participants learn to react to external forces by yielding to and redirecting force to gain or retain control. Many Tai Chi forms are derived from observing nature to understand how animals in the wild control their movements, transfer weight, and maintain balance during combat or to preserve their lives (Ross, 2014; Wayne with Fuerst, 2013). Tai Chi forms are a series of intentional positions ("forms") with movements between that flow one into the next as in a dance of continual slow, smooth movements. Although deemed "low impact," it takes great focus and intent to develop *song* (controlled relaxation) and *Jing* (mental quietness or serenity) while building core strength, endurance, and even a sweat (Lam et al., 2002, 2008).

The purpose of Tai Chi is to generate internal energy and to maintain control of one's movements. The regular practice of Tai Chi routines stimulates mindfulness, helps bring on serenity, and relaxes and loosens joints; the movements of Tai Chi are designed to create inner strength and to generate power for healing and wellness (Mahoric, 2019).

Tai Chi routines are more complex to learn than Qigong and typically involve a single repetition of a series of movements as well as unique positions and stances, all of which make up a prescribed routine. Routines were originally developed by individual practitioners within unique Chinese villages or families. Over time, the most popular routines were adopted by other villages and formed specific styles, such as Sun and Yang styles, named after their founding families (Wayne with Fuerst, 2013). In more contemporary times, the routines were standardized and spread throughout large parts of China and the rest of the world.

The earliest Tai Chi forms were believed to have been developed in the 1670s in China's Chen village. The Chen style of Tai Chi includes spiraling movements, low stances, and whole-body coiling. It is characterized by soft and slow movements alternating with fast and hard ones that are accompanied by explosive releases of power *(fa jing)* (Ross, 2014). The original old frame form developed by Chen Wang-ting is still practiced today (Wayne with Fuerst, 2013). Chen Style is reminiscent of various martial art forms and most likely to be used as Tai Chi Chuan.

Sun Style, in contrast, is the youngest, most recent of the major Tai Chi styles, developed by Sun Lu-tang in the early 20th century. Sun Style is characterized by high, upright stances; consistently slow, gentle movements; compactness of movement; and flexible stepping–meaning that when one foot moves forward or backward the other foot follows for stability. Generally, Sun Style is easier for beginners and most everyone as we age or develop health issues that require safety modifications (Lam with Miller, 2006; Pickett & Pickett, 2007-present; Ross, 2014).

The Tai Chi for Health forms that we teach are based on the work of Dr. Lam, who has trained instructors from throughout the U.S. and many other countries around the world. For instance, we are fortunate that our teachers, Bill and Linda Pickett, live in Knoxville with us; Bill is one of Dr. Lam's Master Trainers, and Linda is one of his Senior Trainers.

Step-by-step instructions and full demonstrations for many of the Tai Chi forms (e.g., for arthritis, osteoporosis, diabetes, back pain, rehabilitation, and energy as well as traditional Yang Style 24 and Sun Style 73 Forms) are available through the Tai Chi for Health Institute (see the first electronic resource in reference list). We recommend starting with Tai Chi for Arthritis (TCA) as it is taught and used most often, and it forms the basis of other more complicated Tai Chi routines that Dr. Lam has designed.

There are ample research studies that document the many benefits available through the regular practice of Tai Chi and Qigong (e.g., Cohen, 1997; Jarmey, 2003; Lam with Miller, 2006; Lu with Schalowsky, 1999; Wayne with Fuerst, 2013). For example, Tai Chi can be helpful to ameliorate or prevent such conditions as arthritis, lower back pain, low bone density, breast cancer and its side effects, heart disease and heart failure, hypertension, Parkinson's Disease, sleep problems, and strokes (Wayne with Fuerst, 2013) and for fall prevention (Lam et al., 2013). Additional benefits documented in various studies include the following: reduced stress; improved mood; better sleep; weight loss; improved cognition in older adults; better management of fibromyalgia, chronic pain, and COPD symptoms; improved balance and strength in people with Parkinson's Disease and in older adults in general; reduced pain from arthritis; and improved cardiorespiratory function in older adults (Wayne with Fuerst, 2013).

At the end of this chapter is a short list of books and websites where you can find research details and learn more about the history and practice of Tai Chi and Qigong. Readers also may use these resources to help them learn Tai Chi and Qigong routines for their personal practice. Dr. Lam and his certified Master and Senior Trainers also have focused on using the Internet to offer webinars and online virtual workshops during the COVID-19 pandemic. While books, DVDs, and YouTube videos can be very helpful for initially learning or refreshing one's memory of a routine, working in-person with an instructor ultimately is the most effective and rich experientially. You can explore your community to see who locally teaches Tai Chi and/or Qigong and what kinds of classes they offer. When picking an instructor and a class, it is critical that it be led by someone you are comfortable with and that the classes are held in an environment that is supportive of your well-being and your goals for learning Tai Chi and/or Qigong. If for some reason the instructor and/or location do not feel right for you, they probably are not, and you should explore other alternatives.

One does not have to have a diagnosed health issue to benefit from Tai Chi (Pickett & Pickett, 2007-present; Wayne with Fuerst, 2013). It is an excellent stress management tool for anyone—quietly invigorating as well as relaxing. As Dr. Lam (Lam & Phillips, 2008) has described, "Tai Chi can be an exercise, an art, or a tool. The ultimate aim of Tai Chi is to help us restore and improve the balance within ourselves and with the outside world" (p. 60)—what family caregivers and their care-receivers so often desperately need.

Safety issues for Qigong and Tai Chi practitioners include the need to keep all movements within the individual's personal comfort zone (Lam with Miller, 2006). Tai Chi relies on gentle motions that massage the person's energy system and, in doing so, the person's internal organs and muscles as well (Pickett & Pickett, 2007-Present). All of the forms can be adapted to restricted ranges of motion, even for persons seated or in wheelchairs or with balance issues (Lam with Miller, 2006).

Qigong and Tai Chi Together

The relationship between Qigong and Tai Chi can be subtle and complicated. Both are health-promoting practices that have similar roots. Each in its own way is about the stimulus and management of the vital energy that sustains each of us. Qigong may be thought of as the internal expression of Tai Chi, while Tai Chi is the most well-known moving form of Qigong (Ross, 2014). Qigong tends to be simpler and less complex in execution; Tai Chi can be more intricate and complicated in practice.

Regardless of the level of complexity, the regular exercise of these practices, either individually or in combination, will improve health and make one more flexible, strong, and balanced. The internal principles of Qigong and Tai Chi need to be adhered to when practicing. Without this focus, these routines are merely exercise routines.

Components of Tai Chi (and Qigong) Movements Instruction: Tai Chi Walking

The following components of Tai Chi (and Qigong) movements provide a way to learn units of movement that one can practice and build on over time and experience.

1. <u>Posture</u>: Tai Chi stance is based most often on maintaining an erect spinal column to promote energy flow while keeping your shoulders relaxed and your knees somewhat bent ("soft knees") so you don't have locked knee joints. Stand with your feet about shoulder width apart. Imagine that there is an invisible cord attached from the universe above you to the crown of your head. Without losing the tension in that cord, let your knees bend slightly so that your body is suspended comfortably from that cosmic thread. The vertebrae in your neck will feel like they have spread apart a bit so that your neck is stretching up as your chin tucks in somewhat. Imagine the

cord extends through your body deep into the ground. Your body remains upright, centered in line with your legs and feet; your feet are solidly rooted, stable. You can move fluidly in any direction now.

2. Abdominal Breathing: While maintaining your posture, take several deep, slow breaths into and out of your abdomen. Many Tai Chi movements have abdominal breaths coordinated with them. When in doubt: Breathe. (Holding one's breath is a common beginner mistake.)
3. Open-Close: Refreshing little breaks are built into many Tai Chi forms as you take in an abdominal breath that causes a chest-high invisible ball of energy that you are holding between your upward-pointing hands in front of your chest, open and facing each other across the width of your body (prayer stance, hands upward or tilted more outward as comfort requires) to expand outward and then to collapse slowly back to its original size as you breathe out. Often you will do three open-close breathing movements during each little break. (You can focus on and "play with" the ball of energy between your hands pretty much anywhere and anytime that you need to pause, meditate, relieve stress, and build energy.)
4. Single-Pole Pivoting: Imagine that there is a supple pole running from the point where the cosmic cord attaches to the crown of your head down through your chest and abdomen. This single pole coordinates your head, chest, and abdomen so they swivel together as you change directions with your feet. This coordinated movement of your body with your feet helps prevent you from putting torquing pressure on your knees or ankles while leaving your arms free to move independently. As you stand in relaxed suspension (head erect, shoulders down, knees bent), swivel one foot on its heel outward a few inches and simultaneously swivel your hips, shoulders, and head along the invisible pole running through you so your body stays aligned with the moving foot. Swivel back again, and then do this movement on the other side. Repeat on each side several times, then do one open-close breathing movement.
5. Shifting Weight to the Side: Stand with your weight balanced evenly between your feet, which are about shoulder-width apart. (a) Without moving your feet, shift your weight to be more on your right foot, then shift your weight to be more on your left foot. Shift back to your weight being evenly distrib-

uted between both feet. (b) Now you will widen your stance by shifting your weight to your left foot, picking up your right foot by lifting the heel first, then the ball, and finally your toe. Move your right foot a few inches to the side and place it down by touching first the toe, then the ball, and finally your heel. Shift your weight to the right so that you are evenly balanced on your feet. Reverse the process to move back to your original stance. (c) Now do the move to your left by shifting your weight to your right foot, picking up your left foot by lifting the heel first, then the ball, and finally your toe. Move your left foot a few inches to the side and place it down by touching first the toe, then the ball, and finally your heel. Shift your weight to the left so that you are evenly balanced on your feet. Reverse the process to move back to your original stance.

6. <u>Shifting Weight Forward and Backward</u>: To shift your weight forward and backward, start by standing in your original centered stance. (a) To move your right foot forward, shift your weight to your left foot and pick up your right foot by lifting the heel first, then the ball, and finally your toe. Move your right foot a few inches forward and place it down by touching first the heel, then the ball, and finally your toe. Shift your weight forward so that you are evenly balanced on your feet. Reverse the process to move back to your original stance. (b) Now do the move with your left foot by shifting your weight to your right foot, picking up your left foot by lifting the heel first, then the ball, and finally your toe. Move your left foot a few inches forward and place it down by touching first the heel, then the ball, and finally your toe. Shift your weight forward so that you are evenly balanced on your feet. Reverse the process to move back to your original stance.

Many of these components go together to create the basis of what is called *Tai Chi walking*, which is slow and very focused walking, whether forward, backward, or to the side. Tai Chi walking is an integral part of the beginning of Yang Style 24 and Sun Style Forms. Walking at heart is controlled falling, and Tai Chi walking maintains *very* controlled falling.

Mindful adherence to the central principles of Tai Chi and Qigong enables a practitioner to gain maximum benefit from any practice session and to solidify these gains over time. The movements are done slowly so that the practitioner can better integrate mind and body. They are done smoothly to facilitate serenity and gather inner energy. Movements should be done as though one is pushing against a gentle, invisible resistance, as though one is moving through water. One's posture should be upright to strengthen stabilizer muscles and to provide more space for internal organs, thus strengthening the inner core. Movements often require a transfer of weight from one part of the body to another. These weight transfers should be done with deliberation and focus in order to maintain balance and harmony. Routines should be done in a relaxed manner that can be achieved by consciously stretching your joints from within. And finally, movements should be done in a state of mental quietness with focus on the present and yourself.

Gaining skill and competence in the doing of Qigong and Tai Chi routines are achieved with consistent time and effort. Like when one is learning to play a musical instrument, the Tai Chi practitioner learns the intricacies of the arm, leg, and trunk movements associated with each form to "play" their body in order to fine-tune the form and gain maximum benefit. To acquire the precision and subtlety of the movements and unique forms is a life-long learning process and a journey we think is well-worth taking.

By cultivating a deep relaxation on the inside, one's movements can be developed so that they become flowing and effortless. Other than good shoes and loose, comfortable clothing, no specific equipment is required. The practices are applicable to most physical capability levels and can be adapted to accommodate physical limitations. The routines may be practiced most anywhere with flat, even ground or flooring. In fact, some of the most useful Tai Chi practicing that Julia has done is when she has been immobilized in a medical or dental procedure: She visualizes the form, which allows her mind to relax and take her awareness away from the annoying or distressing procedure. Before or during a stressful meeting, interview, or presentation, subtly practicing several open-close breathing movements or playing with the invisible ball of energy between one's hands can calm and center the practitioner.

Malia Groves Video Recording

The four routines that we demonstrate in the Groves-related video recording (Readdick, 2020) are: (a) Shibashi I (Qigong), (b) Tai Chi for Arthritis, (c) Yang Style 24 Form Tai Chi, and (d) Four Forces (Qigong). The first three and a half minutes of the video includes introductory information.

Shibashi I (Minutes 3:30-11:59 on the recording). Among the countless Qigong routines available to learn and practice, Shibashi I is an 18-movement routine that was created in 1979 by Professor Lin Hou Sheng from China. The Shibashi I routine is one of the most popular and widely practiced Qigong routines in the world. It is a simple, easy-to-learn routine that synchronizes gentle movements with deep abdominal breathing. The gentle rocking motions and stretching movements improve circulation and digestion. The routine's chest exercises and controlled breathing are good for lung health. It is a calm, beautiful, and flowing exercise. Shibashi movements encourage the stretching and stimulation of smaller muscles and ligaments, and they ensure that the joints are protected as one slowly builds up the muscles that help protect the joints. Shibashi I is unlike other forms of exercise, which work on the larger muscle groups and can often put the body under stress. The gentle stretching and releasing of the movements, combined with deep, relaxed breathing, encourages tension held deep in the body's tissues to soften and release (Mahoric, 2019).

Many of the students we teach report that they begin very quickly to sense their *qi* when doing this routine and derive great satisfaction in working with that sensation. Participants report finding it to be deeply relaxing.

Tai Chi for Arthritis (Minutes 12:00-17:16 on the recording). The Tai Chi for Arthritis (TCA) routine was created in 1979 by Dr. Lam and his team of Tai Chi and medical experts (Tai Chi for Health Institute, 2018). Its prime purpose was to help people with arthritis to improve their condition and general health or to prevent the development of arthritis in the first place. Additionally, it is an excellent overall routine for anyone in that it builds great internal power that is particularly effective for relaxation and healing. TCA incorporates movements from Sun Style Tai Chi, and it integrates Qigong exercise during movement changes (Tai Chi for Health Institute, 2018). The routine works by improving flexibility, which reduces stiffness and keeps joints mobile. It helps build muscular strength, which keeps joints stable and helps a person be more active, with the attendant benefits that come with regular activity. And it improves cardiorespiratory fitness by strengthening the heart and lungs, building stamina. The regular practice of TCA improves balance, mobility, and psychological health; it increases flexibility and muscular strength, decreases pain, and helps prevent falls. Dr. Lam's TCA routine specifically has been recommended and endorsed by the National Council on Aging, the Center for Disease Control and Prevention, and the Arthritis Foundation.

Yang Style 24 Form (Minutes 17:17-21:37 on the recording). Yang Style was created in the early 19th century by Yang Lu-chan and is characterized by slow, gentle movements, with an emphasis on being grounded and rooted (Ross, 2014; Wayne with Fuerst, 2013). Yang Style is a strong promoter of health and is generally considered easier to learn than other older styles, especially compared to Chen Style. The simplified 24 Form version of the original Yang Style 108 Forms was developed in 1959 by the National Physical Culture and Sports Commission of the People's Republic of China (Ross, 2014). The resulting simplified version is relatively easy to learn, accessible to people with a wide range of abilities, provides a standard for international competitions and physical education classes, while also being an effective routine for building general health. The Yang Style 24 Form provides an apt demonstration of Tai Chi fundamentals with an emphasis on grace and beauty. Today it is the most widely performed Tai Chi form in the world (Ross, 2014).

Four Forces (Minutes 21:38-23:30 on the recording). We do not know the history or derivation of the Four Forces routine. It was taught to James several years ago by a colleague, Dr. Mary Pope, who learned it at a workshop she attended a couple years prior to teaching it to him. It is a simple but extremely soothing routine that can take one to a meditative state if performed with focus and multiple repetitions. In the classes we teach together, we gather the students as a group behind us at one end of the room and continue moving forward through its alternate side repetitions until we run out of space. Repeating the Four Forces feels as though we flow across the room. We tend to use it at the end of class as a cooldown routine to calm the energy stirred up during instruction and practice and to help participants leave in a relaxed, contented state.

Summary: Infinite Variations, Find the Right Fit

When beginning to explore Tai Chi and Qigong, it is important to keep in mind that, although there is a standard way for doing the various routines, how they actually are implemented will depend on who is teaching or demonstrating it. There will be subtle or not so subtle differences. Each instructor and practitioner will have a unique way of actually doing a particular routine, of making it their own. Think of the many varieties of religious organizations that are represented in your community. Many will have similar names, but the actual services and practices will vary from congregation to congregation or structure to structure as well as from one type of religion to another. Tai Chi and Qigong are no different. Your challenge will be to find the instructor and approach that fits for you.

Conclusion

For eons, people in China have used Qigong and, later, Tai Chi as a means to enhance their health and well-being. Today the practice of Tai Chi and Qigong has expanded throughout the world, and now millions benefit from the regular practice of these ancient arts. For those who are interested, there are ample resources available to help them learn about the art and practice of Tai Chi and Qigong.

Tai Chi and Qigong are useful activities for caregivers who want to take care of themselves even when they feel they cannot safely leave their duties at home. The pamphlet entitled *10 Tips for Caregivers* (Easom, n.d.) from the Rosalynn Carter Institute for Caregiving recommends "maintain[ing] your physical and emotional health over the long haul. ... Take care of yourself first" as its Tip #1. Harvard Medical School lists Tai Chi as one of the five best exercises "you can ever do" (Harvard Medical School, n.d., p. 1). Strength training, walking, and Kegel exercises, which are incorporated in many Tai Chi forms, are listed as three other of the five best exercises (swimming is the 5th, and one might argue that Tai Chi is akin to swimming on land).

As Boss (2002, 2006, & 2011) has pointed out, family caregivers can easily come to a point at which they experience compassion fatigue when their lives feel overwhelmed by the requirements of the role. All too frequently, family caregivers rely on sedentary activities as their primary means of escaping for a while from the tasks associated with caring for their family member(s). If caregivers believe that they shouldn't leave their family members' homes, they may feel trapped—or guilty if they do leave. We believe that learning and regular practice of Qigong and/or Tai Chi routines can be pivotal to maintaining family caregivers' health and sense of balance in their lives, whether they practice at home or find a nearby class to join while taking time away from home. Qigong or Tai Chi may be modified for and enjoyed by care-receivers (seated or standing), and family caregivers and care-recipients learning or practicing together may not only form bonding experiences but also good memories.

References

Baumgarden, J., Klein, P, & Picard, G. (2018). Qigong and a tale of two back complaints. *Medicines*, *5*, 60; doi:10.3390/medicines5030060. Retrieved December 17, 2020, from http://www.mdpi.com/journal/medicines

Boss, P. (2002). *Family stress management: A contextual approach* (2nd ed.). Sage.

Boss, P. (2006). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss.* Norton.

Boss, P. (2011). *Loving someone who has dementia: How to find hope while coping with stress and grief.* Jossey-Bass.

Cohen, K. S. (1997). *The way of Qigong: The art and science of Chinese energy healing.* Ballantine Books.

Easom, L. R. (Ed.). (n.d.). *10 tips for caregivers.* Rosalyn Carter Institute for Caregiving.

Harvard Medical School. (n.d.). *Special health report: Starting to exercise.* Harvard.

Jarmey, C. (2003). *The theory and practice of Taiji Qigong*. North Atlantic Books.

Klein, P., Picard, G., Schneider, R., & Oh, B. (2017). International expert panel consensus guidelines for structure and delivery of Qigong exercise for cancer care programming. *Medicines*, *4*, 54; doi:10.3390/medicines4030054. Retrieved December 17, 2020, from http://www.mdpi.com/journal/medicines

Lam, P., Tai Chi Productions, & the Arthritis Foundation. (2002, 2008). *Arthritis Foundation Tai Chi Program Instructor Guid*e. The Arthritis Foundation.

Lam, P., with Bawden-Davis, J. (2015). *Born strong: From surviving the Great Famine to teaching Tai Chi to millions.* Tai Chi Productions.

Lam, P. & Kaye, N. (2006). *Tai Chi for beginners and the 24 Forms.* Limelight Press.

Lam, P., Kircher, P., & Miller, M. (2013). *Tai Chi for Fall Prevention.* Tai Chi for Health Institute. www.taichiforhealthinstitute.org/tai-chi-for-fall-prevention

Lam, P., with Miller, M. (2006). *Teaching Tai Chi effectively.* Tai Chi Productions.

Lam, P., & Phillips, P. (2008). *Tai Chi for diabetes: Living well with diabetes.* Rockpool Publishing.

Lu, N., with Schaplowsky, E. (1999). *Traditional Chinese medicine: A woman's guide to healing from breast cancer.* Avon Books.

Mahoric, M. (2019, May 30). *What are the differences between Qigong and Tai Chi?* Qigong Energy Healing. https://qigongenergyhealing.com/blog-qigong-energy-healing/qigong-vs-tai-chi

Picard, G. (2009, 2010). *Heal yourself with QiGong: An ancient solution to a modern problem.* Spiral Graphics.

Pickett, B., & Pickett, L. (2007-present). Personal communications during their various Tai Chi/Qigong classes that we have taken.

Readdick, C. (2020). *Tai Chi and Qigong: Slow dances of self-care for family caregivers and care-receivers.* [Video]. You Tube. https://youtu.be/uVwg7ObXQBc

Ross, D. (2014). *Essentials of Tai Chi and Qigong*. The Teaching Co.

Tai Chi for Health Institute (2018). *Tai Chi for Arthritis*. https://taichiforhealthinstitute.org/programs/tai-chi-for-arthritis/

The Village of Healing and Wellness (n.d.). www.thevillageofhealingandwellness.com

Wayne, P. M., with Fuerst, M. L. (2013). *The Harvard Medical School guide to Tai Chi: 12 weeks to a healthy body, strong heart, and sharp mind.* Shambala Publications (Harvard Health Publications).

Electronic Resources

- The video featuring the Malias that is referenced within the chapter can be found at https://youtu.be/uVwg7ObXQBc
- Dr. Paul Lam's website contains a wealth of information about all aspects of Tai Chi and a variety of products that can help aspiring students learn Tai Chi. The website includes a list of Tai Chi for Health Institute-certified instructors across the globe. https://taichiforhealthinstitute.org/
- For a demonstration of the Yang 24 Form with instruction: https://www.youtube.com/watch?v=B8xiWA-j7zY
- These two websites give general information about Qigong, its practice, its benefits, and supporting research: https://www.qigonginstitute.org/ and www.thevillageofhealingandwellness.com
- This is information about the Shibashi I and II (Qigong) routines: https://taichi18.com/
- More information about Qigong vs. Tai Chi: https://qigongenergyhealing.com/blog-qigong-energy-healing/qigong-vs-tai-chi

Chapter 13

Social insurance in the 21st century

Ben Chin
Maine People's Alliance

It is an exciting time to develop new policies. For those of us interested in ensuring all seniors and people with disabilities have access to quality long term care, we are in good company. Similar efforts have sprung up to ensure universal access to higher education, childcare, paid family and medical leave, and income itself. At the same time, because the activism for these reforms emphasizes the needs of affected populations, most policy development focuses on programmatic concerns. Issues related to financing and administration tend to come second. Thus, most of the debate concerning long term care typically centers around benefit generosity, reimbursement rates for providers, and models of care. Taxes and related administrative mechanisms get less attention, with policy developers usually carrying forward existing models. With respect to long term care, the default policy paradigm is social insurance, where—in popular parlance—beneficiaries "get out" what they "pay into the system." A host of specific financing and administrative mechanisms accompany that model. Below, I explore their origins, and evaluate their usefulness.

In short, I argue that it no longer makes policy or political sense to conceive social insurance as "getting out what one pays in." That particular model, with its accompanying administrative and financial mechanisms, has outlived its usefulness, rhetorically and practically. I reach this

**Correspondence to: Ben Chin, Deputy Director, Maine People's Alliance; Ben@mainepeoplesalliance.org*

conclusion by examining the context, policy choices, and consequences of five eras: the founding of the Social Security system; the dominance of public assistance in the 1940s; the dominance of social insurance in the 1950s and 1960s; the peak and retrenchment of social insurance of the 1970s and 1980s; and the popularity of alternatives to social insurance developed in the 1990s and early 2000s. In each era, the development of social insurance programs required *departure* from policies structured in that frame, even if policymakers suggested otherwise. That strategy worked in the postwar economy to expand programs. From the 1970s forward, however, that rhetoric actually undermined social insurance programs. Indeed, by creating racialized hierarchies between the deserving and undeserving, the paradigm threatens exactly the kinds of equality social insurance seeks to establish. I end by offering an alternative set of principles—public goods, progressive taxation, and a substantive commitment to equality—that I believe more closely reconcile the intention of social insurance reformers with contemporary political and economic realities.

Before diving into the history, it's worth connecting the popular phrase "getting out what one pays into the system" to a more precise set of terms used by scholars. Below, I rely on Jerry Cates's term, "conservative social insurance" to refer to the three policy principles to which "getting out what one pays in" typically refer: "risk selection, the contributory principle, and the wage-related principle."[1] First, "risk selection" means that one does not qualify for benefits based on need, but rather the experience of a "risk" in the market economy like unemployment, old age, or disability. Risk selection keeps eligibility structures narrow, focusing only on cases where markets truly cannot work. Second, the "contributory principle" means beneficiaries "pay into" the system, and do not receive benefits subsidized by general revenues. The contributory principle typically involves payroll taxes, trust funds, wage records, and complex benefit formulas. To symbolize the "contributions" of workers, the taxes apply only to "payroll" or its equivalent, i.e. salaries, wages, and tips—not income from capital (like stocks and bonds) that disproportionately flows to the wealthy. Third and finally, the "wage related principle" means wealthier people receive larger benefits, and poorer people get fewer, based on what people "paid in." In order to keep costs down, the wage related principle typically caps the maximum benefit a person can receive, ensuring the wealthy get proportionately more, but not so much as to financially drain the system. Consequently, tax caps (which make the taxes regressive) limit what the wealthy pay into the system, usually by establishing a 0% top bracket on the payroll tax, ensuring the wealthy

---

[1] Cates, *Insuring Inequality*, 14–15.

don't "pay more" for "the same benefits as everyone else." Moving forward, I use the term "conservative social insurance" and these three policy principles as the primary frame of reference for describing the evolution of social insurance throughout the five eras.

The 1930s: abandoning conservative social insurance from the start

Context

Passed in the middle of the Great Depression, the Social Security Act of 1935 created a family of social insurance programs, what I call the "Social Security system." To understand the choices made in the Act, and the revisions made just five years after its passage, we must understand the political dynamics of the Democratic Party, particularly of the social movements and elites who offered solutions for the economic woes the Social Security system eventually aimed to remedy.

Politically speaking, the Great Depression brought the Democratic Party to national power for the first time since the Civil War. Historically the party of the Confederacy, the Democratic Party won working class, immigrant whites in Northern industrial centers, primarily through appeal to social issues like the repeal of prohibition, not any kind of consistent economic ideology.[2] In order to deal with the depression, however, President Roosevelt's early agenda necessarily favored the government playing an active role in the economy. Yet the Supreme Court struck down most early New Deal legislation, like the National Industrial Recovery Act and the Agricultural Adjustment Act.[3] Thus, by the mid-1930s, Roosevelt needed an agenda that could rescue America from economic collapse, pass muster with the Supreme Court, maintain southern support, and continue to gain traction with urban workers. Eventually, the Fair Labor Standards Act, the National Labor Relations Act, and—of course—the Social Security Act created the policy and political solution Roosevelt needed, one still shaping America today.

Yet the Social Security Act was hardly the only policy model the nation was considering. Rowdy movements of social workers, populist politicians, and leftists all had their own ideas. Among social workers and first wave feminists, Mary Van Kleeck, for example, backed "a comprehensive income maintenance program financed by progressive taxation and—administered by workers."[4] In his gubernatorial bid, Upton Sinclair championed the End Poverty in California (EPIC) plan: progressive taxes, land reform, and a flat pension of $50 a month to everyone

---

[2] Schickler, *Racial Realignment*; McGirr, *The War on Alcohol*.

[3] Schlesinger, *The Coming of the New Deal, 1933-1935*; White, *Law in American History*.

[4] Gordon, *Pitied but Not Entitled*, 210.

over the age of sixty.[5] Southern populists swooned for Sen. Huey Long's Share Our Wealth (SOW) program: universal basic income and wealth, a flat pension to everyone over the age of sixty, and progressive taxes.[6] On the left, labor, socialist, and communist organizations backed Rep. Ernest Lundeen's vision for social insurance. A Farmer-Labor Party Congressman from Minnesota, he wanted unemployment assistance for all workers, deliberately including African Americans, paid for by progressive taxes.[7] Rep. Lundeen used the term "insurance" to denote the people achieving collectively what they could not individually. All of these movements and organizations garnered national attention; none of them fit within the framework ultimately adopted in the 1935 Act.

Nor were leftists the only ones creating alternatives program models. A more centrist mass movement, composed primarily of the professional class, actually had the most enduring influence. Physician Francis Townsend also opposed conservative social insurance. He sought a monthly $200 flat pension for all non-felons over the age of sixty, paid for by general revenues.[8] For two decades, even and especially after Social Security's passage, millions organized into "Townsend Clubs." Thus, throughout Social Security's founding decade, every major demographic of American society—urban workers, rural southern and western farmers, middle class professionals—built dynamic movements and organizations opposed to the vision of conservative social insurance.

Furthermore, among those supportive of social insurance, different schools of thought had begun to emerge among the elites. The Ohio school, for example, led by Abraham Epstien and Isaac Rubinow, did not conform to conservative social insurance principles. This school was the primary model employed by the Ohio and Pennsylvania unemployment insurance systems, which were constructed to prioritize adequate benefits (as opposed to a strict interpretation of the wage related principle), subsidized by general revenues. Overall, they opposed strict contributory systems that did not meet people's needs.[9]

On the other hand, however, the Wisconsin school, led by John Commons and John Andrews, favored the archetypal conservative social insurance model, on which the Wisconsin unemployment insurance system was built. As Mary Poole discusses, this approach sprung not just from a faith in capitalism, but racial eugenics as well. In their mind, social insurance should be based on (white) industrial wage earners, because

---

[5] Gordon, 226.

[6] Gordon, 229–30.

[7] Gordon, 237.

[8] Cates, *Insuring Inequality*, 50.

[9] Cates, 23.

they ultimately would triumph, economically and racially, over "Negro" and "immigrant" workers who were "unfit" and a "burden" on white workers because they accepted such low wages.[10] If white, industrial workers could pool their resources collectively through government, they could create their own salvation; Darwinian forces would eliminate the other problems of industrialization. Perhaps improbably, it was this very particular vision of the Wisconsin school that became the basis of the 1935 Social Security Act.

Policy Choices

To design the Act, the Roosevelt administration convened a panel of experts, the Committee on Economic Security (CES); the Wisconsin school dominated the proceedings.[11] Its vision, not the Ohio school or any of the alternatives backed by social movements, became the framework. Notably, however, even the CES still recommended that general funds be used to supplement payroll taxes, deliberately undermining the contributory principle.[12] President Roosevelt himself intervened, insisting on a contributory system, saying: "those [payroll] taxes were never a problem of economics. They are politics all the way through. We put those payroll contributions there so as to give the contributors a legal, moral, and political right to collect their pensions and their unemployment benefits. With those taxes in there, no damn politician can ever scrap my social security program."[13] We shall see later, however, that even Roosevelt changed his mind.

Further, the Act deliberately *avoided* creating programs that appeared to be "social insurance," for fear of the Supreme Court.[14] The CES went to great pains to separate the tax and benefit provisions of the Act into separate titles, avoiding any appearance that the legislation created a massive, government-run insurance agency, a power not clearly granted to Congress in the constitution. Immediately after the Supreme Court ruled the Act constitutional, however, Social Security administrators created pamphlets and films framing the Act in terms of conservative social insurance.[15] The divergence between the rhetoric and the reality of conservative social insurance had begun.

Just a few years later, President Roosevelt himself accelerated the departure from conservative social insurance policy. Facing pressure

---

[10] Poole, *The Segregated Origins of Social Security*, 76–77.

[11] Cates, *Insuring Inequality*, 25.

[12] Derthick, *Policymaking for Social Security*, 229.

[13] Schlesinger, *The Coming of the New Deal, 1933-1935*, 308.

[14] Derthick, *Policymaking for Social Security*, 1979, 199.

[15] Cates, *Insuring Inequality*, 29, 32.

from the Congress of Industrial Organizations along the same lines,[16] and a primary threat from Federal Security Administrator Paul McNutt (a proponent of a universal pension for the elderly financed by progressive taxes),[17] President Roosevelt kicked off his third campaign by announcing he supported a universal, flat pension. He and Social Security Commissioner Arthur Altmeyer drafted a "two-layered retirement system" consisting of a "universal pension of $20 a week…upon which the existing conservative social insurance system would be superimposed."[18] In one fell swoop, FDR was ready to create a system broad enough to violate the principle of risk selection, flat enough to violate the wage related principle, and probably would have necessitated general revenues in violation of the contributory principle to pay for it. The reality of insufficient benefits forced politicians to relax their policy preferences.

Other experts, even within Social Security, increasingly disagreed with conservative social insurance, for similar reasons. Edwin Clague, the Acting Director of Research and Statistics, opposed adopting the name of "Old Age Insurance" for the contributory program, fearing that it would lock in regressive tax contributions as the only funding source for the program, further exacerbating the challenging of meeting people's needs.[19] Economists within the Roosevelt administration, like Mariner Eccles, believed that the regressive taxes were a major contributor to the 1937-1938 recession, again exacerbating the economic hardships of regular people.[20] Thus, by the end of the decade, the conservative social insurance framework was hotly contested, not a settled consensus.

Most importantly, from a purely practical perspective, no Americans had received benefits from the contributory retirement system. By design, the trust fund had been taking in tax revenue as workers slowly "paid in;" no one had yet "earned" anything. In a classic dilemma, "earning" benefits necessitated years of paying taxes with nothing to show for it—a hard sell to any politician or working class person already struggling to make ends meet.

Thus, an idea championed by Republicans, took center stage in 1939, leading to the first major reform of the system after its enactment. They favored a "pay as you go" approach, deliberately departing from the contributory principle. Instead of functioning like so many individual savings accounts, the Social Security trust fund would merely cushion cash flow, enabling the working generation to directly pay benefits to the

---

[16] Cates, 58–59.

[17] Cates, 55.

[18] Cates, 60.

[19] Cates, 34.

[20] Cates, 43.

retired generation. Fiscal conservatives liked that it decreased the pool of capital government needed to accumulate. It also eliminated the need for scheduled payroll tax increases. Liberals liked getting more benefits out sooner. A political coalition began to form around a new paradigm that would push the system further from conservative social insurance—at least *in practice*.

In *rhetoric,* however, Congress doubled down on conservative social insurance. For the first time, the words "insurance" described the contributory programs, amended to also include survivors, now called Old Age and Survivors Insurance (OASI).[21] This divergence between rhetoric and reality only deepened over time.

Congressional debate over the welfare programs contained in the Social Security Act illustrates this dynamic. Southern, Western, as well as leftist members of Congress demanded more generous Old Age Assistance (OAA) benefits. This public assistance program, not OASI, was the focus of the most intense negotiations. The House and Senate disagreed over the "Connally amendment," which would establish a more generous reimbursement formula for state expenses in providing cash public assistance for low income seniors.[22] President Roosevelt and Social Security administrators supported the amendment, as well rural and low income states across the country who could not afford to provide those benefits without more generous federal support.[23] Importantly—and contrary to what many today assume—southerners backed OAA expansion *even though African Americans benefited from OAA*. Jim Crow southerners wanted more federal money for their communities, and far more of their white constituents would receive the benefit increases; these concerns outweighed fears of upsetting the racial order.

Northern, wealthy, urban representatives, on the House Ways and Means committee opposed these changes. Coming from industrialized states, they did not want to redistribute resources to poorer southern and western states. They won. The Connally amendment failed. Congress did increase the maximum OAA benefit level from $30 to $40 per month (and increased the reimbursement rate for ADC from one-third to one-half). But by structuring welfare liberalization around the maximum payment, not the reimbursement rate, wealthy, urban states could expand their public assistance programs, because they had a richer tax base from which to fund state programs. Rural and poor states, including Northern New England states like Maine, could not afford generous welfare programs, and therefore went into the 1940s far more reliant on federal

---

[21] Cates, 36.

[22] Sen Connally (TX), "Congressional Record--Senate," S8848-8912.

[23] Sen Connally (TX), S1135.

funds, unable to afford generous programs. Indeed, because communities of color were still overwhelmingly in the south, the urban, northern “liberals,” not Jim Crow southerners, actually denied communities of color more generous benefits.

Consequences

In other words, the US did not create a conservative social insurance system in the 1930s. Although the Wisconsin school imagined that conservative social insurance would elevate the (white) industrial worker, not a dollar of federal insurance benefits had moved to a single family by decade’s end. Instead, economic insecurity afflicted people from all walks of life, building a diverse coalition in support of public assistance. This alliance of southerners, westerners, populists, leftists, and middle class professionals became determined to pull the existing system closer to their vision.

Instead, proponents of conservative social insurance learned to separate the *rhetoric* of their policy principles from how the system actually worked. Payroll taxes, wage records, trust funds, and benefit formulas became important symbols, even if they signified a social vision more than a policy reality. Administrators certainly tried to communicate that social vision, one based on a society divided between workers who deserved government support and others who did not, through propaganda. But the policies touched so few people that they had little cultural resonance. They needed new strategies to advance that vision, and they would require even further departures from the actual policies of conservative social insurance.

Furthermore, whether they intended it or not, by refusing to invite social movement leaders to participate in CES or expand programs like OAA, hoping instead that (white) industrial workers could build an insurance system to solve their problems on their own, supporters of conservative social insurance suppressed one of the rare, multi-racial movements in American history where people from all different walks of life had aligned in support of a policy agenda from which all of them would benefit. Thankfully, however, the 1940s saw this coalition come into power, winning victories that most progressives cannot contemplate achieving today.

The 1940s

Context

Although it seems improbable, by the end of the 1940s, this coalition built a Social Security system that benefited millions of Americans, disproportionately women of color, primarily funded by progressive revenues, and primarily administered through state public assistance programs. The insurance programs, though they had begun to pay benefits, were dramatically overshadowed.

External conditions favored this emerging coalition. Spurred by World War II, the federal government directly regulated price, production, wage, and profit levels of major industries; it established confiscatory top income tax rates of over 90% that effectively set a maximum wage; enormous public expenditures catalyzed economic growth and narrowed inequality. Labor enjoyed its peak influence with the Democratic Party. Southern and Western states leaped forward in their economic development. African Americans in the south escaped sharecropping to enter industrial jobs for the first time; they moved north and flexed their political power, becoming essential components of the Democrats retaining national power.

With respect to social insurance, surpluses in the trust fund continued to be political *liabilities*, not benefits; working class people and conservatives alike disliked taxing regular people for narrow programs that had no immediate benefits. Seizing on these facts, this coalition gathered bipartisan support to pass reforms that enabled states to provide more generous benefits to more people, primarily through programs like Old Age Assistance (OAA,) Aid to Dependent Children (ADC), and Aid to the Blind (AB). This coalition was not anti-social insurance; most of them argued for bigger social insurance benefits and continued payroll tax increase. They were, however, clear-eyed in realizing that *conservative* social insurance did not meet people's needs.

Policy Choices

They struck first at the heart of the contributory principle. In 1944, continued trust fund surpluses reopened the possibility of again delaying scheduled payroll tax increases. Republicans naturally opposed them. President Roosevelt, however, wanted them to reduce the wartime deficit. Sen. Arthur Vandenberg (R-MI) proposed an amendment to the Social Security Act to prevent the payroll tax hike. At the encouragement of Social Security administrators,[24] however, Sen. James Murray (D-MT) amended the bill to ensure that general funds will be used to pay benefits, should the trust fund be exhausted—a possibility that seemed quite remote. The Vandenberg-Murray amendment passed without any serious debate.[25] In other words, given the choice, Social Security administrators and members of Congress easily prioritized benefit preservation over conservative social insurance ideology; social insurance meant more than the contributory principle.

---

[24] Derthick, *Policymaking for Social Security*, 238.

[25] Sen. Murray, "Congressional Record--House," 374.

Immediately after World War II, the coalition pushed Congress for benefit increases in the 1946 amendments. Battles lost in 1939 were won this year. Increasing reimbursement rates for state welfare programs, namely OAA, remained the primary focus. The House Ways and Means committee did its best to avoid a reimbursement rate formula that reimbursed lower income states for a greater portion of their costs, instead offering to again raise the Federal maximum reimbursed benefit (from $40 to $50 a month for OAA, and from $18 to $27 a month for the first child and $12 to $18 a month for subsequent children supported by AD-C).[26] Despite its powerful status and tradition of consensus, the Ways and Means report ran up against dissent that changed the course of the legislation. Not only did members of the House attempt to block the "closed rule" motion designed to shut down debate, the Senate—unlike in 1939—refused to back down. In the end, the House had to accept a more generous reimbursement rate structure for OAA and ADC: reimbursement of two-thirds of the first $15 and $9 a month for OAA and ADC respectively, followed by a 50% reimbursement up to the maximum benefit, raised to $45 for OAA and $18 for ADC.

In 1947 amendments, Republicans, leftists, westerners, and southerners again worked together to block the payroll tax increase, and renew the previous year's liberalizations (which had originally been set to expire). In 1948, the reimbursement rates were again enhanced. States subsequently received 75% of the first $20 a month for OAA, then 50% up to the new maximum benefit of $50; 75% of the first $12 for ADC, the 50% reimbursed up to the new maximum benefit of $27 for ADC (Ways and Means Report 1949).

In response to these changes, essentially all states—particularly the rural, low-income states that had been demanding these changes for the better part of a decade—immediately and dramatically increased the generosity of their programs,[27] suggesting that the previously low benefit levels were not due to anti-welfare ideology or racism. Grassroots movements, interested in alternatives to conservative social insurance, shaped state and local policy, where Social Security administrators had far less influence. Indeed, aggressive state action made federal administrators quite uncomfortable. For example, Texas attempted to run its OAA program without a means test, establishing a non-wage related, non-contributory, flat pension available to all its elderly; the SSB refused to reimburse for the program and it was shut down six months later.[28] Pennsylvania, Missouri, Washington, and California all created flat benefit plans that the

---

[26] Committee on Ways and Means, "Social Security Act Amendments of 1946," 10.

[27] Berman, "Legislative Changes in Public Assistance, 1947."

[28] Poole, *The Segregated Origins of Social Security*, 26.

Social Security Board fought to defund (on questionable legal grounds) because they feared these alternatives would undermine conservative social insurance in the long run.[29] In 1944, the Social Security Board realized, to its embarrassment, that lower level staff in the Bureau of Public Assistance, frustrated by low benefit levels[30] authorized overly generous plans for 32 states in violation of agency rules.[31]

Importantly, this coalition of southern and western states, along with northern leftists, also advocated for more generous benefits for agricultural and domestic workers within OASI—*even though in the south this invariably meant the inclusion of African Americans*. For example, Rep. Voorhis (D-CA) believed that "coverage of the act should be extended to those groups not now covered, farmers, agricultural workers, the self-employed and others."[32] Rep. Lane (D-MA) lamented the exclusion of "1,000,000 domestic servants, 4,000,000 farm workers, excluding farm owners; 9,000,000 self-employed persons; 1,000,000 employees of non-profit organizations; 3,000,000 State and local government employees; and 2,000,000 Federal employees."[33] Rep. Pace, the Democrat from Georgia and a leader on the Agriculture Committee, supported the inclusion of agricultural workers and expressed skepticism towards those who claimed that "administrative difficulties" prevented their inclusion.[34] He also complained that "All the millions who process farm commodities are covered by the law, but the people who work in the fields, who produce the commodities that provide the jobs and the security for the other fellow, are left out."[35] Clearly, the center of gravity against the inclusion of farm and agricultural workers was not Southern Democrats, but rather a bi-partisan coalition of Northern interests.

Thus, by the end of the 1940s, welfare programs like Old Age Assistance (OAA), the predecessor to Supplemental Security Income, covered twice as many seniors and had an average benefit 70 percent larger than its social insurance cousin, Old Age and Survivor Insurance (OASI).[36] This was true for other means-tested programs, like public housing; they were not just for the poorest of the poor, but for working- and

---

[29] Cates, *Insuring Inequality*, 115.

[30] Cates, 129–31.

[31] Cates, 129–31.

[32] Rep. Voorhis (D-CA), "Congressional Record--House," 9907.

[33] Rep. Lane (MA), "Congressional Record--House," 9925.

[34] Rep. Pace (GA), "Congressional Record--House," 9926.

[35] Rep. Pace (GA), "Congressional Record--House," H9926.

[36] Zelizer, *Taxing America*, 67.

middle-class families as well.[37] Looking at all the different programs that could be called "welfare," the federal government spent *three times more on welfare* than social insurance by 1949.[38]

These expansions had important implications for racial justice as well. Despite facing discrimination by local administrators, by the end of the 1940s, nonwhite families, African American women in particular, constituted thirty percent of ADC recipients (far more than their share of the US population), with the program's enrollment doubling between 1945 and 1950.[39] Women of color made up a disproportionate share of ADC recipients because they were disproportionately poor—a fact that previously had never led to this kind of federal investment in their well-being. Importantly, because women of color—and the other recipients of these general fund programs—did not carry the burden of regressive taxes to pay for these benefits, a powerfully redistributive fiscal tool had been created.

In other words, during the 1940s social insurance programs were simply not large enough to be considered a society-wide designator of worthiness or unworthiness; huge numbers of people, black and white, poor and working class, were all benefiting from the same, broad programs—in this case, funded by mostly progressive taxes, administered at the state level, and putting everyone in the same social boat.

Of course, not everyone was happy with this new arrangement. America had never provided such broad financial support to so many, particularly across lines of race. The Ways and Means Committee clearly had reason to fear that conservative social insurance might be swamped by grassroots pressure, particularly so long as a federated system gave states (and therefore even multiracial labor organizations like the Congress of Industrial Organizations [CIO]) significant power outside of their direct influence. They looked for a path to reassert control over the system, reincorporating the principles of conservative social insurance. And while they would certainly find ways to dramatically reduce the scale of Social Security's welfare programs, they were again forced to expand the insurance programs at the expense of the actual *practice* of conservative social insurance—even if they insisted the opposite *rhetorically*. Clearly, market forces would not automatically make social insurance and the (white) industrial worker dominant; politics was needed.

---

[37] Particularly for the increase in racial segregation caused by pushing middle income families out of public housing, see Rothstein, *The Color of Law*, 36.

[38] Zelizer, *Taxing America*, 67.

[39] Mittelstadt, *From Welfare to Workfare*, 44.

Consequences

The evolution of Social Security in the 1940s demonstrates that dramatic departures from conservative social insurance were not politically risky gestures towards redistribution. Rather, moving away from conservative social insurance became a political necessity. Social movement from nearly every major demographic of American society made progress towards implementing the alternative frameworks to fiscal policy that the architects of Social Security deliberately tried to avoid in the 1930s. White, industrial workers, as it turned out, simply could not pay their own way—even in a "pay as you go" system. Progressively financed public assistance programs became the central mechanism by which Americans could access cash assistance to deal with economic insecurity, dwarfing social insurance systems.

Further, these cash public assistance programs were not yet racially stigmatized; Jim Crow southerners actually championed them. Of course, this is not to say that racism is not an important factor in explaining the evolution of social insurance (and American fiscal policy in general). We shall see that it became the most important factor in shaping Social Security's evolution. Rather, it is to say that the racial contours of Social Security were shaped by a set of players who pursued their interests differently than they do today. It was not the case that enlightened, liberal northerners urged racial inclusion into more generous programs, only to be stymied by Jim Crow southern Democrats. Rather, urban centrists from both parties created a fiscal state to elevate the white, male, industrial worker, and were actively hostile towards efforts to make these programs benefit others. Another bipartisan coalition of populists--leftists, westerners, southerners, and fiscally conservative Republicans--also cared little about people of color, but their policy positions benefited communities of color, particularly in the south, far more than those advanced by northern centrists.

Moving forward, both coalitions would need to confront the consequences of the reforms won by the populists in the 1940s. Threats to the racial order would indeed become problems both coalitions eagerly sought to solve. But the changing economic and political context would force them to do so on terms that would—again—undermine conservative social insurance in practice, even though people trumpeted its rhetoric at the loudest volume in all five eras.

Rhetorical conservative social insurance peaks: the 1950s and 1960s

Context

At the opening of this era, conditions did not favor the coalition that reshaped the Social Security system in the 1940s, leading to a resurgence of conservative social insurance rhetoric. By the end of era, however, resurgent movements gave voice to a plethora of alternative visions, exceeding even the wide range of movement-backed frameworks of the 1930s.

At the beginning of the 1950s, Republicans captured the White House and Congress in the 1952 presidential elections, briefly interrupting Democratic dominance. Dissatisfaction over the Korean War and Cold War empowered more conservative voices in both parties, particularly as Sen. McCarthy and the House Committee on Un-American Activities stoked fears about communism. This panic gutted the labor movement, as the CIO fired many of its most talented organizers for fear of their ties to communism.[40] The strongest political anchor of a left vision for social justice in America was silenced. Remarkable progressive policies still received bipartisan support, but not for reasons of social justice. Republicans recodified steeply progressive income taxes, for example, in order to fund the military, not redistribute wealth.[41]

As the era wore on, however, the Civil Rights Movement resurrected the left. As the it gained force from the mid-1950s through the mid-1960s, many labor leaders rediscovered their voice—and many new voices entered the fray. By the end of the 1960s, labor would be back to criticizing conservative social insurance, backing progressive taxes and straightforwardly redistributive benefits;[42] welfare rights organizations, particularly led by Black women, upgraded the demands of reformers from the 1930s to include a more explicit focus on racial justice;[43] and feminist movements critiqued social insurance models that assumed a male breadwinner to be the only wage earner of a household.[44] At no time since the 1930s had advocates of conservative social insurance had to deal with so many competing policy paradigms.

Choices

In response to these pressures, advocates of social insurance chose to adhere more closely to the *rhetoric* of conservative social insurance, while abandoning its principles even more when it came to actual policy. They did this by making substantial changes to the internal working of the Social Security system, as well as creating new programs like Medicare.

In 1950, during the conservative turn in politics, Congress ex-

---

[40] Davis, *Prisoners of the American Dream*.

[41] Witte, *The Politics and Development of the Federal Income Tax*.

[42] Derthick, *Policymaking for Social Security*, 1979, 344.

[43] Piven and Cloward, *Poor People's Movements*, 264–362.

[44] Derthick, *Policymaking for Social Security*, 1979, 261–62.

panded OASDI coverage to 10 million workers, including increasing numbers of agricultural and domestic workers, and essentially doubled the generosity of benefits.[45] Although explicitly designed to shift people out of public assistance, these changes included the repeal of the Vandenberg-Murray amendment; cash social insurance no longer had a backstop to prevent benefit cuts when trust fund deficits arose. Yet to see the 1950 amendments as a move towards conservative social insurance *in practice* would be mistaken. Instead, the 1950 amendments should be seen as doubling down on the *rhetoric* of conservative social insurance, while departing *even further* from it in policy practice. Six examples illustrate this strategy.

First, the program continued on as a "pay as you go" system, just as Republicans had urged become established in 1939. The trust fund would merely be a cash flow cushion, ensuring that the payroll tax revenues of the working generation would be sufficient to pay the benefits of the currently retired generation. To pay for expanded benefits, workers did not "pay more" into the system, in order to "earn" greater benefits for themselves; rather, the present generation of workers simply paid more in payroll taxes to cover the costs of current and new beneficiaries. Millions of people gained coverage they had not "paid for"—a kind of welfare, but not funded by progressive taxes.

Second, Congress made technical changes to the benefit formula, abandoning the so-called "increment," which "added an additional 1 percent benefit increase for every year worked in covered employment."[46] The "increment" was one of the favorite symbols of conservative social insurance, particularly for Commissioner Arthur Altmeyer, because it implied that the longer one "contributed" to the system, the more one "earned a return on investment." Yet Social Security Chief Actuary Robert Myers, as well as others inside the OASI bureau, argued to remove it in order to pay for more generous benefits, particularly for low-income seniors. The Ways and Means Committee agreed, and the change became law.[47] This was another way that social insurance programs abandoned conservative principles in order to address benefit adequacy.

Third, Congress softened the "retirement" test. In the original 1935 Act, even a dollar of additional income rendered an individual ineligible for benefits. That was the whole point of the "risk selection" principle: social insurance would only be used in case the market was totally unable to provide income. In 1939, Congress softened that requirement, allowing recipients to earn an extra $15 a month. In 1950, $50 a month became

---

[45] Zelizer, *Taxing America*, 75.

[46] Cates, *Insuring Inequality*, 94.

[47] Cates, 95.

permissible. In 1960, Congress established a formula, where every two dollars of income from work would eliminate only one dollar of benefits.[48] To contemporary observers, this policy shift seems like common sense, because many assume that the goal of Social Security is to provide adequate income. But true believers in conservative social insurance, like Altmeyer, believed the market—not public programs—should set wage levels; benefits should only be available to those who could not make any money at all in the private sector. Basing policy on benefit adequacy opened questions about income redistribution—exactly what "risk selection" sought to avoid. Yet, these changes made the program more politically palatable and affordable, so Congress enacted them,

Fourth, Congress "blanketed in" individuals to OASI who never "paid into the system" at all. In 1966, Congress created a much-belated, mini-Townsend plan for three quarters of a million Americans who had worked their adult lives, not paid payroll taxes, and faced economic hardship in retirement. Under the new law, non-insured seniors aged seventy-two prior to 1968 qualified for $40 a month as an individual, and $60 as a couple.[49] Even more extraordinary, general revenues paid for this "blanketing in." Yet, as the Brookings Institute noted, the plan "arbitrarily" denied benefits to seniors currently on public assistance.[50] In other words, the purpose of the program was not to conform to the principles of conservative social insurance; rather, it was to use the rhetoric of conservative social insurance to legitimize cash benefits for middle income Americans.

Fifth, the magic of simultaneously increasing coverage and benefits *without raising taxes*, was made possible in this era by one actuarial device more than any other: the "level earnings assumption."[51] It projected payroll tax revenues assuming that wages (and therefore payroll tax receipts) would not grow over time. Yet this era saw the largest real wage gains for most working class people in American history. They generated the trust fund revenue surpluses that Congress needed to violate conservative social insurance in practice, while doubling down on its rhetoric.

Sixth, Medicare—by far the most important social insurance program created since the original 1935 Act—relied on general revenues from the very beginning; a version of the Vandenberg-Murray amendment was essential for Medicare Part B to exist. The original Democratic proposal for Medicare covered only hospital care, and relied exclusive-

---

[48] Cates, 96.

[49] Cates, 85.

[50] Cates, 85.

[51] Derthick, *Policymaking for Social Security*, 1979, 279.

ly on regressive social insurance payroll taxes.[52] Republicans (and the American Medical Association) proposed a broader set of benefits for low-income Americans, financed by progressive federal income taxes.[53] In the end, Mills, now the powerful chair of the Ways and Means Committee, became so worried about being outflanked on his left that he crafted his now-famous "three layer cake" approach to Medicare. Layer one was the original Democratic proposal, Medicare Part A, financed by regressive taxes. Layer two was Medicare Part B, the Republican plan, altered to have a more regressive structure,[54] though it still included some general revenues because the regressive taxes alone did not raise enough money. Layer three became Medicaid, always financed through general revenues.[55]

Thus, in combination, "pay as you go," the "increment," the "retirement test," "blanketing in" new beneficiaries, the "level earnings assumption," and Medicare all served to extend insurance programs to more people at bigger benefit levels, under the auspices of people "earning" their benefits, even though the financial math of these programs increasingly did not correspond to the rhetoric. Never before had so many Americans thought they "earned" their benefits; never before had so many Americans been mistaken.

This revision to the basic structure of the Social Security system

---

[52] President Johnson introduced his proposal to provided limited health coverage for seniors, HR 1 and S1, in 1965. From the beginning, the public "mistakenly thought the bill covered physicians services"(Marmor, *The Politics of Medicare*, 46).

[53] The American Medical Association introduced its bill, called "Eldercare," sponsored by Reps. Thomas Curtis and Sydney Herlong, HR 3737. The AMA noted, "Medicare would *not* cover physicians' services or surgical charges. Neither would it cover drugs outside the hospital or nursing home, or x-ray or other laboratory services not connected with hospitalization" (in Marmor, *The Politics of Medicare*, 47). Although it seems difficult to imagine Republicans today preferring a redistributive program financed by progressive taxes, this framework actually coheres more closely to a belief in market-based solutions to problems. Republicans wanted to let most seniors who could afford health care continue to purchase it on their own. But for those who could not afford, Republicans wanted them to be able to have all the services they needed.

[54] Originally, Byrnes proposed that Medicare beneficiaries have their contributions tied to their income, via their Social Security payroll taxes. Mills led the House Ways and Means Committee switch to a flat, more regressive $3 per member per month cost. Marmor, 49.

[55] An early version of Medicaid actually preceded the passage of Medicare. The Kerr-Mills Act of 1960 provided federal reimbursement for states to provide low-income seniors access to a wide range of health care services. By 1963, 32 of 50 states provided these benefits (Marmor, *The Politics of Medicare*, 2000, 29). Thus, Medicaid was essentially structured as an expansion of Kerr-Mills to non-seniors, while Medicare was built off a social insurance framework.

helped Democrats deliver real improvements in people's lives and retain political power for another generation. But not only did this occur under false pretenses, it generated a powerful new division in society that had never existed on such a scale: the division between those who "earned" their benefits, and those who did not. As Jennifer Mittlestadt demonstrates,[56] by the 1960s, after the reforms of the 1950s had taken hold, the first racialized welfare panics in America took place, with Louisiana and the mayor of Newburg, NY garnering headlines across the country for cracking down on Black women relying on Aid to Families with Dependent Children (AFDC, the similarly structured successor to ADC).

To get a sense of this shift in the terms by which public assistance was discussed, compare how none other than Ways and Means Chair Wilbur Mills discussed it on the House floor in the 1940s, versus the 1960s. In the 1940s, after speaking eloquently about the need for more generous benefits for low income seniors, children, and people who are blind, Rep. Mills argued that "Federal grants" should be "provided on a more generous basis for the recipients of public assistance."[57] By contrast, by the late 1960s, Mills descended into dignifying racial apocrypha more suitable for fake news sites: "Across town from my mother in Arkansas a negro woman has a baby every year. Every time I go home, my mother complains. The negro woman's now got eleven children. My proposal will stop this. Let the states pay for more than a small number of children if they want to."[58]

In the 1940s, that kind of rhetoric simply would not have been possible. With three times as many people on public assistance as social insurance in the 1940s,[59] it would not be tenable to categorize welfare recipients as undeserving of their benefits. Yes, Black women disproportionately benefited from those programs, but they were also the most important source of income support for working class white Americans as well. By the end of the 1960s, however, the situation had exactly reversed itself. Three times as many people enjoyed insurance benefits as welfare, allowing public assistance programs to easily become racially stigmatized, and the value of their benefits to markedly decline relative to social insurance. This was not because the actually policy of "insurance" programs operated that much differently than that of "welfare"; both relied on cash transfers that—in practice—were increasingly non-contributory. The rhetoric of conservative social insurance, however, allowed one set of beneficiaries to be deemed more morally worthy than another.

---

[56] Mittelstadt, *From Welfare to Workfare*.

[57] Rep. Wilbur Mills (AK), "Congressional Record--House," 10754.

[58] Zelizer, *Taxing America*, 153.

[59] Katz, *In the Shadow of the Poorhouse*, 276.

Consequences

This era illustrates, in both material and symbolic terms, how the continued abandonment of the practice of conservative social insurance became increasingly popular, even and especially in a conservative era. Democrats and Republicans worked together to create cash transfer systems to those who, in fact, did not "earn" their benefits.

Yet because these efforts doubled down on conservative social insurance *rhetoric*, these increasingly generous insurance programs undermined aspirations of social equality by creating an easily racialized distinction between the deserving and underserving. Notably, the energy for this distinction did not flow from the Jim Crow south. Again, it came from administrators and congressional champions of program expansion, who had spent three decades of their life committed defying mass movements backing more redistributive paradigms. In hindsight, addicted to the short term political advantages of conservative social insurance rhetoric, policy makers created long term problems from which the Social Security system has yet to recover.

Communities of color, of course, bore much of the brunt of inscribing these new social hierarchies. To be clear, the material consequences likely exceed that of simple social stigma. Frank Davis, for example, demonstrated by the mid-1970s that Social Security was *exacerbating,* not ameliorating racial inequality. Examining the system from 1957-1972, he showed how this shift to a regressively financed insurance system redistributed money *away* from Black Americans to white communities: African Americans contributed $21 billion in payroll taxes, but received only $11.5 billion in benefits, due primarily to segregation in low wage work, high unemployment rates, and lower life expectancies.[60] Recent work by the Urban Institute[61] has demonstrated that this trend has continued, not just for African American families, but for non-white American families in general. These findings, while initially shocking to many liberal supporters of the program, make perfectly good intuitive sense. Most Black men in the twentieth century, for example, died before they turned sixty-five,[62] meaning they would "pay into the system" their whole working lives, without "getting anything out." White people, particularly white women, born after the passage of the Social Security Act, however, have mostly had life expectancies that exceeded age 65.[63] While Americans are preoccupied with manufacturing outrage towards people who allegedly

---

[60] Poole, *The Segregated Origins of Social Security*, 179.

[61] Quakenbush, Smith, and Steuerle, "Has Social Security Redistributed to Whites from People of Color?"

[62] Bond and Herman, "Lagging Life Expectancy for Black Men."

[63] Bond and Herman.

did not “earn” their benefits, somehow there is no similar outrage for the millions of Black taxpayers who “pay into the system” their whole working lives, but never live to draw down a cent of their benefits.

Furthermore, as Social Security numbers became the main symbol of contributory citizenship, social insurance went backwards, not forwards, in its racialization of immigrants. Initially, Social Security was open to all workers (in eligible occupations), and did not even have a requirement of lawful entry to the US. In fact, as early as 1937, the Social Security Administration affirmatively issued press releases and administrative guidance clarifying that the information it collected would in no way be used for the purposes of immigration enforcement.[64] Yet, after the 1965 Immigration Act created the first mass population of undocumented immigrants in America,[65] Social Security numbers quickly became one of the principle administrative mechanisms distinguishing the documented from the undocumented. By 1976, Congress attached legal status requirements to every social insurance (and welfare) program—something that would have been unimaginable in the 1940s.

In short, payroll taxes and their administrative infrastructure fostered a shared national identity of moral superiority among whites—most of whom received enormous cash transfers that they did not “earn”; and they also constructed new forms of racial difference, enabling outright economic exploitation for people of color—just as the 1964 Civil Rights Act and 1965 Voting Rights Act dismantled Jim Crow. Yes, the Wisconsin school had been wrong in assuming that the construction of a *truly* contributory system would naturally lead to the (white) industrial worker dominating America’s *economy*. But Rep. Mills and a second generation of revisionist architects had discovered a related theory that did prove to be true: (white) workers could use the *fiction* of conservative social insurance to dominate American *politics*.

As scholars like Ian Haney Lopez have persuasively argued,[66] the coded racism in tropes like “welfare queens” became hugely important in the strategies of Republicans, desiring to convince white voters to elect candidates that supported economic policies counter to their material interests. Yet, while Republicans invented the phrase, Democrats like Rep. Wilbur Mills created the social position. Prior to the 1950s, that rhetoric would not have made sense, nor would Southern conservatives had reasons to defund public assistance. Now, these racially stigmatized programs have served to elect leaders hostile to the overall intent of the Social Security system in its entirety. The rhetoric of conservative social

---

[64] Fox, 261–62.

[65] Massey and Pren, “Unintended Consequences of US Immigration Policy.”

[66] Haney-López, *Dog Whistle Politics*.

insurance might have worked in the short turn; it backfired almost immediately. The 1970s accelerated that process.

The end of conservative social insurance: the 1970s and 1980s

Context

By the end of the sixties, a shadow of the old, populist coalition of the 1940s had begun to re-emerge. The American left, resurrected after McCarthyism by the Civil Rights movement, renewed its calls for progressive revenue to finance universal programs.[67] Contemplating the deteriorating economic and fiscal states of the country, President Johnson (again, a rural, Southern Democrat) advocated for progressive general revenues and more generous benefits for social insurance programs.[68] A genuine desire to deal with the inadequate benefits and other shortcomings of the Social Security system motivated these pleas. Unfortunately, the economic growth that fueled the trust fund surpluses essential for building the current system evaporated, thanks to tax cuts for the wealthy and the Vietnam War. Soon, supporters of Social Security of all stripes had to focus only on defending the status quo.

The income tax cuts began this downward spiral. In his 1963 *Economic Report of the President*, President Kennedy used language that we might mistake for Ronald Reagan: “the citizen serves his country’s interests by supporting income tax reductions….Tax reductions set off a process that can bring gains for everyone, gains won by marshaling resources that would otherwise stand idle…[T]he tax deterrents to private initiatives have too long held economic activity in check.”[69] In other words, Kennedy hoped that reducing taxes on the wealthy would induce the capital investment and modernization needed for US factories to compete with rapidly developing economies abroad, particularly in Western Europe—without significantly undermining the fiscal capacities to wage war or—crucially for our purposes—provide economic security for Americans via crucial programs like Social Security. Social insurance, after all, allegedly did not depend on general revenues.

Like George W. Bush, Kennedy (and then Johnson) then tried to finance the wars in South East Asia, while also cutting taxes. In combination with the capital flight already underway, America’s monetary position became so weak that it was eventually forced to go off the gold standard, and the Bretton Woods financial system that had guided the world since World War II collapsed.[70] The US famously entered a decade

---

[67] Derthick, *Policymaking for Social Security*, 1979, 344.

[68] Derthick, 342.

[69] Witte, *The Politics and Development of the Federal Income Tax*, 159.

[70] Block, *The Origins of International Economic Disorder*.

of economic stagnation and high inflation, “stagflation.” The revenue surpluses generated by a growing economy, providing the magic necessary to reconcile the conflict between the rhetoric of social insurance and the reality of how Social Security actually worked, dried up.

Choices

Thus, the story of social insurance in the 1970s and 1980s is primarily one of conservative social insurance ideology’s utter failure. Democrats and Republicans alike attempted to actually adhere closer to its principles in practice, not just rhetoric. For Democrats, that meant discarding the “level wage” assumption in order to finance more generous benefits—right before the economy collapsed. For Republicans, that meant taking advantage of the trust fund deficits created by the weakening economy to argue for cuts, and repealing the Medicare Catastrophic Coverage Act—the only example of a social welfare program’s total repeal since the mid 1930s. For anyone paying attention, even the rhetoric—never mind the actual policies—of social insurance had ceased to be economically or politically viable for those interested in expanding coverage. Meanwhile, general fund programs fared surprisingly well, exactly when conservative social insurance would predict them to do badly.

The story begins first with Social Security Administration officials urging Congress to abandon the level earnings assumption in order to finance a major benefit increase.[71] They were under major pressure from the New Left to ameliorate poverty. In the Social Security Amendments of 1972 and 1973, Congress and administrators abandoned the level wage assumption, financing a twenty percent benefit increase.[72] OASDI replaced 92 percent of the income for a married man making minimum wage, up from 67% previously.[73] These changes coincided with Rep. Mills contemplating a presidential run, the departure of Actuary Myers, and an overall generational shift of the leadership of the system.

Unfortunately, the timing could not have been worse. After the economic downturns of the early 1970s, trust fund expenditures were projected to exceed income in 1975 and 1976, with complete exhaustion sometime in the early 1980s.[74] Crucially, these changes were not based on a *departure* from accepted private sector actuarial principles; they occurred because Congress—led by arch-conservative social insurance advocate Wilbur Mills—insisted on more accurate wage projections. The “level wage assumption” had always been a fiction when wages were

---

[71] Derthick, *Policymaking for Social Security*, 1979, 357.

[72] Derthick, 366–67.

[73] Derthick, 363.

[74] Derthick, 382.

clearly rising; when they were stagnating, it actually would have been accurate.

Unsurprisingly, pragmatic, rural, southern, Democratic populists seeking to ally with the left were quick to depart from the principles of conservative social insurance. For example, President Carter made no qualms about essentially re-establishing the Vandenberg-Murray amendment, calling for general revenues to be used anytime unemployment rose over 6%, and called for the removal of the income cap on taxable wages paid by employers.[75] Also reminiscent of the 1930s and 1940, this approach had resonance within the Republican Party. House Republicans, for example, proposed to bring in general revenues to Social Security via the Medicare trust fund.[76] In the end, however, Congress stuck with the traditional approach developed by the Ways and Means Committee, the one most in line with the principles of conservative social insurance: massive increases in payroll taxes.

To be clear this shift to regressive taxes had real consequences for the lives and politics of regular people. Payment of these regressive taxes were not just an afterthought for working class Americans. As Josh Mound discusses, when Congressional investigators inquired into the major "pocket book squeezes," the increased cost of living expenses for the average American by 1970, the number one cause was not energy or housing—it was taxes.[77] Over two decades, Congress had steadily increased payroll taxes from 3 percent in 1951 to 12.26 percent (employee and employer contributions combined) by the end of the 1970s. Yet it was not just social insurance taxes that took money out of people's pockets. Because welfare programs were administered and jointly financed by state and local governments, and those governments almost universally have overall regressive tax systems (due to heavy reliance on sales and property taxes), the growth in anti-poverty programs—paradoxically—extracted a high price from the poor.

These burdens were not mere inconveniences. As Katherine Newman and Rourke O'Brien have found, for every $100 annual tax increase on the poor, mortality rates rise 6.6 per 100,000.[78] Such an increase in mor-

---

[75] Derthick, 408.

[76] Derthick, 410.

[77] Mound, Joshua, "Inflated Hopes, Taxing Times," 939. As Joshua Mound recounts in his dissertation, "the combination of cuts to the progressive income tax and increases in regressive taxes meant that, between the 1950s and the 1970s, the tax burden went up on average Americans, even as it fell for upper-income Americans" (Mound, Joshua, "Inflated Hopes, Taxing Times," 49). Black neighborhoods had far higher effective property tax neighborhoods than white areas (Mound, Joshua, 43).

[78] Newman and O'Brien, *Taxing the Poor*, 102–4.

tality is greater than any single year mortality rate increase caused by the opioid epidemic.[79] Thus, although it sounds obvious, it bears repeating: increasing taxes on poor people is not a good way to fight poverty; it kills poor people. Furthermore, taxing middle and low income people—particularly when those taxes are the biggest threat to their economic security—is not politically popular. Ronald Reagan so easily won on an anti-tax platform, in part because he was addressing a genuine threat to non-rich people.

This led to the next clear failure of conservative social insurance to protect the programs it allegedly justified; its rhetoric was used by President Reagan to justify its most significant cuts. As a percent of GDP, spending on OASDI declined once Reagan took office--a historic shift.[80] Relentlessly raising concerns over the trust fund "deficit," Reagan used the logic of social insurance to cut benefits and increase taxes in order to accrue a "surplus" that would cover the cost of the Boomers.[81] Reagan (with strong support from Congressional Democrats) also drastically slashed income taxes for the wealthy, deregulated most sectors of the economy, shrank the footprint of public spending in the economy even further, and initiated a long march towards economic inequality whose summit we have—apparently—not yet reached. In other words, the basic economic situation in which modern Social Security had been operating had completely reversed. Suddenly, the "pay as you go" trust fund was no longer a vehicle for creating surpluses to rationalize a more liberal program; it had become a vehicle for dramatic deficit projections that rationalized cuts. As the chief scholar of Medicare's history, Theodore Marmor, writes: "Perversely, the same social-insurance financing… through its artifact, the trust fund, [became] one of its greatest political vulnerabilities, and the nominal foundation to support the attacks of the program's harshest critics."[82]

Perhaps the best example of this dynamic, how the principles of conservative social insurance actually came to undermine the development of social insurance programs, came with the Medicare Catastrophic Coverage Act. As Richard Himmelfarb describes, another Southern Democrat, Rep. Claude Pepper, did his best to circumvent the normal Congressional procedures developed by Ways and Means, in order to bring directly to the floor his bill to pay for long term care for seniors by remov-

---

[79] Center for Disease Control, "Data Brief 356. Drug Overdose Deaths in the United States, 1999–2018."

[80] Department of the Treasury, "FY 2017 Financial Report of the United States Government," 177.

[81] Hacker, *The Divided Welfare State*, 158.

[82] Marmor, *The Politics of Medicare*, 137.

ing the tax cap on Medicare—a direct assault on conservative social insurance.[83] Just as powerful technocrats reacted to the Townsend movement by working to establish an insurance-based system, a network of Washington insiders, like Ways and Means Health subcommittee chair Rep. Fortney Stark and administrators like Otis Bowen, Secretary of Health and Human Services, worked together to draft an alternative more in conformity with conservative social insurance.[84] In this case, rather than support a "pay as you go" approach, these insiders wanted to ensure that the elderly really would pay for their own benefits. In the end, however, some amount of progressivity had to be introduced into the financing system of the program, charging more for high-income seniors to access the benefit, in order for people to actually afford it.[85] Consequently, a conservative backlash to the program, actually led by the National Committee to Preserve Social Security and Medicare, successfully organized a campaign to repeal the program just a year after its passage with bi-partisan support.[86] They relentlessly used the arguments of social insurance, particularly the contributory principle, to argue that one individual's taxes should never be used to pay for "someone else's" benefits. Thus, the MCCA, under the auspices of maintaining conservative social insurance principles, became the only major New Deal program to be repealed.

Meanwhile, conservative social insurance would predict that, in times of economic crisis, contributory systems would be safer than those financed by general revenues, because people feel they have "earned" their benefits. Just as the policy choices above demonstrate the surprising vulnerability of programs justified by the rhetoric of conservative social insurance, so do the general fund programs demonstrate the surprising viability of a non-contributory model of financing. From the 1980s through the early 2000s, general fund programs faired remarkably well, and to understand the emergence of public good social insurance, it's important to see how policy makers found their way to these strategies.

Of course, many cash benefit welfare programs suffered enormous cuts (and were highly racially stigmatized). Programs like Food stamps and AFDC suffered greatly under Reagan. Yet over the next twenty years, other cash benefit programs targeted for the poor increased substantially, like the Earned Income Tax Credit (EITC). Subsequently, as a percent of GDP, cash welfare programs maintained a roughly similar portion of GDP in America in the early 21st century as they were in 1980.[87]

[83] Himelfarb, *Catastrophic Politics*, 25.

[84] Himelfarb, 17,27.

[85] Himelfarb, 38,39.

[86] Himelfarb, 73–93.

[87] Organization for Economic Cooperation and Development, "Family Benefits

More to the point, health care programs for the poor dramatically expanded.[88] This was not mere health care inflation; rather it represents a deliberate expansion of coverage and benefits. When Reagan took office, Medicaid was still a fragile, new program, with Arizona becoming the last state to adopt the program in 1982.[89] Overall, Medicaid spending grew from about $25 billion in 1980 (less than one percent of GDP) to over $600 billion (over three percent of GDP),[90] as its coverage began to include pregnant women, parents, and even childless adults. The mid-1990s saw a major increase in health care spending on the poor with the passage of the State Children's Health Insurance Program (SCHIP). Of course, Medicaid (not Medicare, which still lacks a long term care benefit) became the largest payer of long term care services as well.

Consequences

Thus, while it certainly appears that there are real dangers in narrow, means-tested public assistance programs being politically vulnerable to cuts, particularly in times of increasing inequality, their financing mechanism (progressive taxes) does not seem to be the main source of their vulnerability. In fact, programs directly connected to the income tax code, like the EITC, actually seemed to fair quite well. They seem to be another example of how the left can actually find common ground with Republicans looking to lower taxes, even when creating straightforwardly redistributionist policies, just as payroll taxes were delayed in the 1940s, in conjunction with the expansion of public assistance benefits. Furthermore, when general revenues finance programs that are not cash benefits, but instead pay for a public good like health care, as in the case of Medicaid, it appears that there are strong political forces—not just protecting it against austerity—but actually favoring their development.

In part, this is because that progressive taxes actually still function in times of rising inequality the way regressive payroll taxes previously created trust fund surpluses to finance program expansions. Then, working class wage growth, combined with the "level wage assumption", enabled trust fund surpluses that fueled coverage expansions and increasingly generous benefits. In the neoliberal era, however, progressive

---

Public Spending."

[88] Many object to referring to Medicaid and other means-tested programs as "welfare." Its use here is for simplicity and accuracy, not as advice for how to best describe these programs to a public that undoubtedly has negative connotations with the word. Still, it seems worth noting that the public appetite for straightforwardly redistributive programs has clearly been underestimated.

[89] Oberg and Polich, "Medicaid," 85.

[90] MACPAC, "Medicaid Enrollment and Spending, FYs 1968-2016."

income taxes grew with the economy (more than regressive taxes)[91] because they captured revenue from where incomes were growing—at the top. Throughout the 1980s and 1990s, just like in the 1940s, organizers at a state level could take advantage of periodic revenue surpluses to argue that Medicaid programs should be expanded. And in an improvement from the 1940s, states receive Medicaid reimbursement via the kind of formula for which Southern Democrats advocated, where lower per-capita income states receive more money.

Indeed, when economists evaluate the overall effects of fiscal programs on mitigating inequality, only Medicare and Medicaid have made any substantial impact since the 1980s.[92] To be clear, my argument is not for means-testing; I do not believe universal programs should be reduced to merely providing benefits to the poorest of the poor. I do, however, believe it is essential to realize progressively raised general revenues *were an important political asset, not a liability*, for expansionary fiscal policy in the last two decades of the twentieth century. And in that respect, it appears that a growing chorus of policy developers from the 1990s onwards have increasingly seen the wisdom of abandoning the principles of conservative social insurance.

Thus, the 1970s and 1980s demonstrated that in an era of low economic growth and rising inequality, the rhetoric of conservative social insurance does not serve the interests of those looking to build social insurance programs. Stagnant wages do not generate trust fund surpluses; trust fund deficits become reasons to cut benefits, not protect beneficiaries. While many means tested programs certainly suffered from the racial stigmatization wrought by the changes to the system made in the 1950s and 1960s, programs funded by progressive taxes actually fared remarkably well. Many of them continued to grow in an era where social insurance programs did not. Policy makers today would be foolish to employ even the rhetoric of conservative social insurance, let alone implement its actual policy principles. This fact has been understood since at least the early nineties, when a panoply of new approaches to problems that had traditionally been solved under the rhetoric of conservative social insurance began to be framed differently.

From the 1990s forward: the rise of public good social insurance

Context

From the 1990s forward, policymakers have increasingly aban-

---

[91] For an analysis of state revenues see Elizabeth McNichol, "Strategies to Address the State Tax Volatility Problem."

[92] Piketty, Saez, and Zucman, "Distributional National Accounts: Methods and Estimates for the United States*

doned the rhetoric and policies of conservative social insurance. Growing inequality meant that the benefits of economic growth flowed to the wealthy, through income streams out of the reach of contributory payroll taxes. Further, the major gaps in America's Social Security system primarily concerned in-kind health care benefits—whether for health care coverage for children, or prescription drugs for seniors. In general, these matters are awkward for the wage-related principle. (Do low income seniors deserve to have fewer drugs covered, simply because they "paid less into the system"?) If anything, the dramatic rise of inequality created the opposite perception: in a world where the rich could become so phenomenally wealthy,[93] and standards of living and mortality rates were actually *declining* for others,[94] lower income people deserved *more* assistance, not less. Furthermore, with the Democratic Party enacting progressive taxes to reduce the general fund budget deficit, and the Republican Party consistently ignoring the deficit when it came time to govern, there was far less pressure to balance revenues and expenditures for general fund programs than those attached to special trust funds. Below, I trace how policymakers of both parties began to abandon both the rhetoric and the policy prescriptions of conservative social insurance in this era—although some still cling to the ideology. I close by summarizing what I take to be the three policy principles that ought to guide the development of a non-conservative philosophy of social insurance moving forward: public goods, progressive taxation, and a substantive commitment to equality.

Choices

Immediately after taking office, President Bill Clinton removed the Medicare payroll tax cap—exactly what Rep. Pepper had asked for in his original alternative to the MCCA—in the Omnibus Budget Reconciliation Act of 1993.[95] The State Children's Health Insurance Program, the most major health care expansion of the 1990s, was also financed by general revenues, and received bi-partisan support. In 2003, President George W. Bush continued the bi-partisan tradition of relying on bi-partisan revenues, this time passing Medicare Part D, which receives substantial general fund subsidy. But the biggest departure—indeed *inversion*—of conservative social insurance is the Affordable Care Act (ACA).

The ACA defies every principle of conservative social insurance. Instead of aiming at mitigating "risks" only in the cracks and crevices of the market, it straightforwardly aims for universal coverage, and seeks

---

[93] Piketty and Goldhammer, *Capital in the Twenty-First Century*; Piketty, Saez, and Zucman, "Distributional National Accounts: Methods and Estimates for the United States*."

[94] Case and Deaton, Angus, "Mortality and Morbidity in the 21st Century."

[95] "H.R.2264 - 103rd Congress (1993-1994)."

to restructure the basics of the whole health care sector—even directly limiting the profits of insurers. To the extent that the ACA conforms to a principle of wage-relatedness, it actually gives *more generous benefits to lower-income people*, exactly the opposite of the Social Security. Rather than a "contributory" system of dedicated regressive taxes flowing to a trust fund, it is mostly financed by general revenues: a "Net Investment Income Tax"[96] and the "Additional Medicare Tax"[97] that tax income from wealth (not just salaries and wages), and ensure the wealthy pay higher rates than everyone else. Furthermore, although the rate structure mirrors Medicare's Hospital Insurance payroll tax, these new taxes are actually administered through the income tax code, drawing attention to the arbitrary distinctions made between income and payroll taxes. As John McDonough, senior advisor on National Health Reform to the U.S. Senate Committee on Health Education, Labor, and Pensions remarked about this dramatically progressive departure in the ACA, "For progressives, this is an enormous and positive breakthrough in tax policy heretofore considered untouchable."[98] Yet despite the obvious drawbacks, many policy developers still cling to the paradigm of conservative social insurance.

Unfortunately, the policy landscape is littered with MCCA-like failures, of those who naively cling to the principles of conservative social insurance, primarily for political protection, when those principles have consistently been shown to undermine the short and long term viability of policies. In fact, after all the sound and fury, the first piece of the Affordable Care Act to be repealed was not the employer mandate or any of the taxes; it was the only policy based on conservative social insurance: the Community Living Services and Supports Act (CLASS), designed to provide a universal long term care benefit under a contributory system. It simply didn't work, and was shut down in 2011.

Similarly, after Vermont passed its single payer health care law, Green Mountain Care, it failed because conservative social insurance ideologues insisted on actually applying those principles, not just using them as rhetorical devices. Under ACA requirements, Vermont could not force low income people to pay more for their healthcare in the new system—including payment of new or higher taxes. Unfortunately, the implementing committee decided to pair this progressive approach to taxes on the bottom end of the income scale, with the most regressive ideas of social insurance at the upper end: caps on how much the wealthy had to pay. This necessitated middle-income people paying higher rates.

---

[96] Internal Revenue Service, "Net Investment Income Tax."

[97] Internal Revenue Service, "What Is the Additional Medicare Tax and Who Pays It?"

[98] McDonough, *Inside National Health Reform*, 258–59.

The tax burden, consequently, took the worst political shape possible, an inverted-U: low taxes for the poor and the rich, high taxes on the middle class. Further, because the tax base was so narrow, the overall rate had be increased, giving Governor Shumlin such sticker shock that he abandoned the program.[99]

Conservative social insurance principles have, of course, had a few successes; similarly, progressive taxation does not automatically guarantee success. Washington state's universal long term care system is based on conservative social insurance, as are all state-level paid family and medical leave systems. Conversely, the campaign for universal home care in Maine, led by Maine People's Alliance, the organization for which I work, did not succeed, despite relying on progressive taxes. But the history above certainly demonstrates that conservative social insurance systems are likely to face a much harder road financing their benefits in an economy of increasing inequality. Further, the universal home care ballot measure was attacked because the tax was *not progressive enough*, not that it failed to conform to the principles of conservative social insurance. It is also worth noting that, at the federal level, when Congress needed to move quickly to implement a national paid family and medical leave system, bipartisan support coalesced behind a structure that far more closely resembled the ACA, rather than Social Security: a non-contributory program, funded by general revenues, administered through the tax code, not a separate trust fund. Furthermore, in my conversations with advocates working to establish other universal benefits for paid family leave, child care, elder care, and health care at both the state and national level, it seems quite clear that many people are increasingly interested in approaches that favor general revenues and progressive taxation.

Consequences

To close, I offer a synthesis of what might be an alternative framework, from which to approach social insurance in the twenty-first century, seeking to learn both the policy and political lessons of the first near-century of large-scale American experiments in this realm. The framework I offer, as opposed to "conservative social insurance" is "public good social insurance." Below, I outline the three principles on which it is based.

First, public good social insurance focuses on ensuring universal access to that which is "essential for a society's well-being and success," borrowing Sabeel Rahman's definition.[100] Clearly, some basic amounts of education, health care, income, and other forms of transportation and

---

[99] Shumlin, "Green Mountain Care: A Comprehensive Model for Building Vermont's Universal Health Care System."

[100] Rahman, "Losing and Gaining Public Goods."

communications infrastructure are necessary for society—including private markets—to function. Unlike conservative social insurance that views public programs as only needing to focus on the "risks" at the periphery of market activity, public good social insurance recognizes that these foundational investments in people's basic well-being actually precede market activity. They are "insurance," not in a narrow, transactional way. Rather, the insurance metaphor simply describes the need to accomplish collectively that which cannot be accomplished individually.

Second, public good social insurance necessitates progressive taxation. It is essential that we contribute to the provision of public goods, but not create hierarchies between those who deserve benefits and those who do not; everyone deserves basic public goods. We all contribute differently to the provision of public goods, not because we deserve them more (or less), but because we have benefited more (or less) from the existing structure of public goods. Those with more contribute more because they have benefited more, not because their moral character makes them more deserving of basic necessities.

Third, public good social insurance aims to create a more equal—and therefore democratic—society. It does not view enormous inequalities—like those between economically developed and impoverished regions of the country, or those between white industrial workers and Black sharecroppers, or those between minimum wage care workers and millionaire hospital CEOs—as good for society; it actively seeks their remedy. Those who need more generous benefits to access equal opportunities should receive more generous benefits.

This commitment to equality also has an important administrative aspect as well. Administrators of public goods must deliberately cultivate mechanisms to ensure that those with less power in society are deliberately given *more* influence in program design and administration—contrary to the strategies of conservative social insurance administrators. A genuine commitment to equality means that administrators must help people understand how and why programs actually function the way they do, seeking disproportionately greater input from those disproportionately in need of the equalizing effects of public good provision. This is based on both an ethical imperative to provide adequate goods to those who would otherwise lack them, and a politically pragmatic necessity, as a system based on public misperceptions cannot be sustained in the long run.

Looking back, it seems that the best intentioned advocates of conservative social insurance clearly desired at least the *outcomes* associated with public good social insurance. But they took market-driven economies (and a eugenic teleology) as their foundation. That future never came. In hindsight, it seems much better to form political coalitions with those willing to commit to a more robust vision of equality, willing to challenge inequality, than create programs that appeal to the public on misleading terms, increasingly operating in ways that are not defensible in new contexts. In another world, policy developers would have viewed grassroots social movements as important partners in a democratic society, and could have built a system that sustained their aspirations. Perhaps that world is one we can build together over the next ninety years. A universal long-term care system, built on the principles of public goods, would be a great place to start.

References

Berman, Jules H. "Legislative Changes in Public Assistance, 1947," n.d., 9.

Block, Fred L. *The Origins of International Economic Disorder: A Study of United States International Monetary Policy from World War II to the Present*. Berkeley: University of California Press, 1977.

Cates, Jerry R. *Insuring Inequality: Administrative Leadership in Social Security, 1935-54*. Ann Arbor: University of Michigan Press, 1983.

Center for Disease Control. "Data Brief 356. Drug Overdose Deaths in the United States, 1999–2018." Accessed August 17, 2020. https://www.cdc.gov/nchs/data/databriefs/db356_tables-508.pdf#page=1.

Congressional Budget Office. "Baseline Budget Projections as of March 6, 2020." Accessed August 11, 2020. https://www.cbo.gov/publication/56268.

Covert, Bryce. "Washington State Has Created the Nation's First Social-Insurance Program for Long-Term Care | The Nation." Accessed August 17, 2020. https://www.thenation.com/article/archive/long-term-care-insurance-washington-elderly/.

Davis, Mike. *Prisoners of the American Dream: Politics and Economy in the History of the US Working Class*. London New York: Verso Books, 2018.

Department of the Treasury. "FY 2017 Financial Report of the United States Government," February 15, 2018. https://www.fiscal.treasury.gov/files/reports-statements/financial-report/02142018-FR(Final).pdf.

Derthick, Martha. *Policymaking for Social Security*. Washington: Brookings Institution, 1979.

Fauntroy, Michael K. *Home Rule or House Rule: Congress and the Erosion of Local Governance in the District of Columbia*. Lanham, Md: University Press of America, 2003.

Fox, Cybelle. *Three Worlds of Relief: Race, Immigration, and the American Welfare State from the Progressive Era to the New Deal*. Princeton Studies in American Politics: Historical, International, and Comparative

Perspectives. Princeton [N.J.]: Princeton University Press, 2012.

Gordon, Linda. *Pitied but Not Entitled: Single Mothers and the History of Welfare, 1890 - 1935*. 1. Harvard Univ. Press paperback ed., 4. print. Cambridge, Mass: Harvard Univ. Press, 1999.

Goss, Stephen, Wade, Alice, Skirvin, J. Patrick, Morris, Michael, Bye, K. Mark, and Huston, Danielle. "Effects of Unauthorized Immigration on the Actuarial Status of the Social Security Trust Funds." Social Security Administration, April 2013. https://www.ssa.gov/oact/NOTES/pdf_notes/note151.pdf.

Hacker, Jacob S. *The Divided Welfare State: The Battle over Public and Private Social Benefits in the United States*. New York: Cambridge University Press, 2002.

Haney-López, Ian. *Dog Whistle Politics: How Coded Racial Appeals Have Reinvented Racism and Wrecked the Middle Class*. Oxford: Oxford Univ. Press, 2014.

Himelfarb, Richard. *Catastrophic Politics: The Rise and Fall of the Medicare Catastrophic Coverage Act of 1988*. University Park, Pa: Pennsylvania State University Press, 1995.

H.R.2264 - 103rd Congress (1993-1994): Omnibus Budget Reconciliation Act of 1993. Webpage, August 10, 1993. 1993/1994. https://www.congress.gov/bill/103rd-congress/house-bill/2264.

Internal Revenue Service. "Net Investment Income Tax." Accessed August 17, 2020. https://www.irs.gov/individuals/net-investment-income-tax.

Internal Revenue Service. "What Is the Additional Medicare Tax and Who Pays It?" Accessed August 17, 2020. https://www.irs.gov/newsroom/what-is-the-additional-medicare-tax-and-who-pays-it.

Kaiser Family Foundation. "Understanding How States Access the ACA Enhanced Medicaid Match Rates." KFF, September 29, 2014. https://www.kff.org/medicaid/issue-brief/understanding-how-states-access-the-aca-enhanced-medicaid-match-rates/.

Katz, Michael B. *In the Shadow of the Poorhouse: A Social History of Welfare in America*. 10th anniversary ed., rev.Updated. New York: BasicBooks, 1996.

Massey, Douglas S, and Karen A. Pren. "Unintended Consequences of US Immigration Policy: Explaining the Post-1965 Surge from Latin America." *Population and Development Review* 38, no. 1 (2012): 1–29.

MACPAC. "Medicaid Enrollment and Spending, FYs 1968-2016." Accessed August 17, 2020. https://www.macpac.gov/wp-content/uploads/2015/01/EXHIBIT-8.-Medicaid-Enrollment-and-Spending-FYs-1968%E2%80%932018.pdf.

Marmor, Theodore R. *The Politics of Medicare*. 2nd ed. Social Institutions and Social Change. New York: A. de Gruyter, 2000.

McDonough, John E. *Inside National Health Reform*. California/Milbank Books on Health and the Public 22. Berkeley : New York: University of California Press; Milbank Memorial Fund, 2011.

McGirr, Lisa. *The War on Alcohol: Prohibition and the Rise of the American State*. First Edition. New York: W. W. Norton & Company, 2016.

McNichol, Elizabeth. "Strategies to Address the State Tax Volatility Problem." Center on Budget and Policy Priorities, April 18, 2013. https://www.cbpp.org/research/strategies-to-address-the-state-tax-volatility-problem.

Mittelstadt, Jennifer. *From Welfare to Workfare: The Unintended Consequences of Liberal Reform, 1945-1965*. Gender and American Culture. Chapel Hill: University of North Carolina Press, 2005.

Molina, Natalia. *How Race Is Made in America: Immigration, Citizenship, and the Historical Power of Racial Scripts*. Berkeley: University of California Press, 2014.

Mound, Joshua. "Inflated Hopes, Taxing Times," 2015. https://deepblue.lib.umich.edu/bitstream/handle/2027.42/116785/mound_1.pdf?sequence=1&isAllowed=y.

National Academy of Social Insurance. "A Pledge to Create a Stronger Society, a Fairer Future." Accessed August 18, 2020. https://www.nasi.org/press/releases/2020/06/pledge-create-stronger-society-fairer-future.

National Academy of Social Insurance. "Designing Universal Family Care." Accessed October 24, 2020. https://universalfamilycare.org/wp-content/uploads/2019/06/Designing-Universal-Family-Care_Digital-Version_FINAL.pdf.

National Academy of Social Insurance. "Learn." Accessed August 18, 2020. https://www.nasi.org/learn.

National Immigration Law Center. "Basic Facts About SSNVS." National Immigration Law Center. Accessed August 24, 2020. https://www.nilc.org/issues/workersrights/basic-facts-about-ssnvs/.

Newman, Katherine S., and Rourke L. O'Brien. *Taxing the Poor: Doing Damage to the Truly Disadvantaged*. Wildavsky Forum Series 7. Berkeley: University of California Press, 2011.

Oberg, Charles N., and Cynthia Longseth Polich. "Medicaid: Entering the Third Decade." *Health Affairs* 7, no. 4 (January 1988): 83–96. https://doi.org/10.1377/hlthaff.7.4.83.

Organization for Economic Cooperation and Development. "Family Benefits Public Spending." Accessed August 17, 2020. https://data.oecd.org/socialexp/family-benefits-public-spending.htm#indicator-chart.

Piketty, Thomas, and Emmanuel Saez. “How Progressive Is the U.S. Federal Tax System? A Historical and International Perspective,” n.d., 22.

Piketty, Thomas, Emmanuel Saez, and Gabriel Zucman. “Distributional National Accounts: Methods and Estimates for the United States*.” *The Quarterly Journal of Economics* 133, no. 2 (May 1, 2018): 553–609. https://doi.org/10.1093/qje/qjx043.

Piven, Frances Fox, and Richard A. Cloward. *Poor People’s Movements: Why They Succeed, How They Fail*. New York: Vintage Books, 1979.

Poole, Mary. *The Segregated Origins of Social Security: African Americans and the Welfare State*. Chapel Hill: University of North Carolina Press, 2006.

Pres. Roosevelt. “Congressional Record--House,” February 24, 1944. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201939-46%20Vol%201.pdf.

Rep. Allen (Louisiana). “Congressional Record--House,” June 9, 1939. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201939.pdf.

Rep. Collins. “Congressional Record--House,” June 9, 1939. https://www.ssa.gov/history/pdf/Downey PDFs/Social Security Amendments of 1939.pdf.

Rep. Cooley (NC). “Congressional Record--House,” June 9, 1939. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201939.pdf.

Rep. Hobbs (AL). “Congressional Record--House,” June 6, 1939. https://www.ssa.gov/history/pdf/Downey PDFs/Social Security Amendments of 1939.pdf.

Rep. Pace (GA). “Congressional Record--House,” July 24, 1946. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201946-48.pdf.

Rep. Rankin (Mississippi). “Congressional Record--House,” June 9, 2020. https://www.ssa.gov/history/pdf/Downey PDFs/Social Security Amendments of 1939.pdf.

Rep. Wilbur Mills (AK). “Congressional Record--House,” August 2, 1946. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201946-48.pdf.

Rep. Marcantonio (NY). “Congressional Record--House,” October 5, 1949. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201950%20Vol%201.pdf.

Quakenbush, Caleb, Karen E Smith, and C Eugene Steuerle. “Has Social Security Redistributed to Whites from People of Color?” . . *Social Security*, 2006, 8.

Rahman, K. Sabeel. "Losing and Gaining Public Goods." Text. Boston Review, September 5, 2017. http://bostonreview.net/forum/k-sabeel-rahman-losing-and-gaining-public-goods.

Rep. Wilbur Mills (AK). "Congressional Record--House," August 2, 1946. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201946-48.pdf.

Rothstein, Richard. *The Color of Law: A Forgotten History of How Our Government Segregated America*. First edition. New York London: Liveright Publishing Corporation, a division of W. W. Norton & Company, 2017.

Schickler, Eric. *Racial Realignment: The Transformation of American Liberalism, 1932-1965*. Princeton Studies in American Politics: Historical, International, and Comparative Perspectives. Princeton, New Jersey: Princeton University Press, 2016.

Schlesinger, Arthur M. *The Coming of the New Deal, 1933-1935*. 1st Mariner Books ed. The Age of Roosevelt, v. 2. Boston: Houghton Mifflin, 2003.

Sen Connally (TX). "Congressional Record--Senate." Accessed November 21, 2020. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201939.pdf.

Sen Lee (OK). "Congressional Record--Senate," July 12, 1939. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201939.pdf.

Sen McFarland (AZ). "Congressional Record--Senate," July 30, 1946. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201946-48.pdf.

Sen McFarland (AZ). "Congressional Record--Senate," August 2, 1946. https://www.ssa.gov/history/pdf/Downey%20PDFs/Social%20Security%20Amendments%20of%201946-48.pdf.

Shumlin, Peter. "Green Mountain Care: A Comprehensive Model for Building Vermont's Universal Health Care System." Office of the Governor, State of Vermont, December 30, 2014. https://ljfo.vermont.gov/assets/docs/healthcare/e50f43fa39/GMC-FINAL-REPORT-123014.pdf. White, G. Edward. *Law in American History*. Oxford ; New York: Oxford University Press, 2012.

West, Rachel, and Rebecca Vallas. "Rising Earnings Inequality Is Taking a Mounting Toll on Social Security." Center for American Progress, February 16, 2017. https://www.americanprogress.org/issues/poverty/news/2017/02/16/415260/rising-earnings-inequality-is-taking-a-mounting-toll-on-social-security/.

White, G. Edward. *Law in American History*. Oxford ; New York: Oxford University Press, 2012.

Witte, John F. *The Politics and Development of the Federal Income Tax*. Madison, Wis.: University of Wisconsin Press, 1985. http://books.google.com/books?id=pN-zAAAAIAAJ.

Yen Li, Yvonne. "Vermont Breaks Ground in Health Coverage for Migrant Workers," June 10, 2011. https://www.colorlines.com/articles/vermont-breaks-ground-health-coverage-migrant-workers.

Zelizer, Julian E. *Taxing America: Wilbur D. Mills, Congress, and the State, 1945-1975*. Cambridge: Cambridge University Press, 2000.

Chapter 14

Kevin P. Lyness
Antioch University New England

Reflections on Family Caregiving

In the summer of 2018, we held the Groves Conference on Marriage and Family in Portland, Maine on the topic of family caregiving. Ellie Macklin (this volume) defines *caregiving* "as 'a commitment to providing care to the extent needed and for as long as needed.' *Family caregiving* is when such caregiving is extended to family members, whether related or adopted family. It refers to a serious commitment of intent, effort, and resources on behalf of kin and loved ones, as needed" (p. 88-89), italics added). At that conference we explored many different aspects of caregiving and what follows is a summary of what we learned and some additional reflections.

Family caregiving tends to be informal and unpaid but intersects with the world of formal and paid caregiving (Chin, this volume; Le Roux, this volume; Settles, this volume). As was noted at the outset, family caregiving occurs throughout the family life cycle (Scott, 2018). Parents care for children and different types of caregiving are required at different points in children's lives (Blanchard, 2018). At times, parents are not able to care for their children, either through illness or incarceration or addiction, and others must take over. Foster families provide some of this care (Mallette & Almond, 2018) and often grandparents provide this care (Bailey, 2018; Bailey & Letiecq, this volume; Frazier, 2018; Mazurik, 2018). Fictive kin and non-family networks also are key sources of caregiving for families and children (Settles & Donaker, 2018; Settles, this volume).

In families, family members care for each other within generations as well (caring for siblings, spouses and partners, and others), and this

**Correspondence to: Kevin Lyness, Antioch University New England; klyness@antioch.edu*

care can range from mild and normative care to care needed in the case of acute or chronic illness or injury or disability (le Roux, this volume; Readdick, this volume). Other causes of non-normative family caregiving are incarceration (which disproportionately affects families of color) (Harcourt & Baugh, 2018) and war (both through injury and death but also through military deployments) (Lucier-Greer et al., 2018; Quichocho et al., 2018). At the other end of the life cycle, family elders often need extended care and often require high levels of specialized care (e.g., to deal with dementia) (Easom, this volume; Shulz, 2018).

We learned about many current (pre-pandemic) pressures on family caregiving: an aging population with fewer caregivers available, dispersing families reducing the availability of family caregivers, caregiving needs lasting longer (in part due to advances in medical care), reduced or inaccessible resources, and increased stresses on family relationships (both caregiving relationships and other relationships) (Easom, 2018). These pressures make family caregiving more challenging and more stressful.

Caregiving is most often provided by family members (parents, adult children, spouses and partners, or others), and as noted above is informal and unpaid. More formal caregiving may be provided by those in the medical community, by case managers and care workers, by social workers and mental health professions, and by chaplains and those in the religious community (Scott et al., 2018; Scott, this volume). Settles summarizes this well (this volume, p. 67): “Fundamentally, it [caregiving] is a rather informal set of mutual linkages among family members and fictive kin as defined by themselves and the relative recognition that is given by family networks, other close or local people who may be rallied and recruited, and professional or paraprofessionals who have been secured to help with the situation.”

These perspectives on caregiving can clearly fit into a stress and coping model (as described by Fischer, this volume) that takes into account stressors, appraisal of stressors, supports and resources, and coping strategies. Next is a brief description of interventions designed to increase resources and effect positive coping.

There are many current interventions designed to support family caregiving. Many of these revolve around self-care and building additional resources. Some that we learned about include the use of life review as a way to engage elders, care consultation groups (see Easom, 2019) including those for dealing with dementia and Operation Caregiver for those dealing with war injuries (Easom, 2018). The Rosalyn Carter Institute for Caregiving (https://www.rosalynncarter.org/) has many resources in these areas and for caregivers in general. We also learned about Rural Outright (Burns, 2018) for helping those working with LGBTQIA+ individuals, including family members, as well as *Together We Can,* a relationship education program implemented with low-SES families (Almond et al., 2018).

Caregiving also involves care-receiving (Macklin, 2018; Macklin, this volume), and much depends on the nature of the relationship between caregiver and receiver (Fischer, this volume; Macklin et al., 2018; Macklin, this volume). Macklin provides a nice summary:

> The caregiver/care-receiver relationship will depend largely on the ability of the two persons to empathize with one another and to talk easily about their realities. Both will benefit from having others in whom they can confide, to whom they can vent their distress, and with whom they can reaffirm their hopes. Having an outside source of comfort can go a long way toward ensuring that the caregiving is done with respect and understanding and gentle kindness. Moreover, having an external network to supplement caregiving will do much to alleviate stress and burn-out. (Macklin, this volume, p. 90)

Finally, we have learned a lot about what can help with the burdens of caregiving. The Groves Statement on Family Caregiving states that "caring is a fundamental family function" and that "the demands and responsibilities of caring and receiving care ebb and flow over the lifespan and across generations. … Further, we believe that caring in families is best sustained within care communities, grounded in an ethic of social justice for all families" (this volume, p. 256). As le Roux (this volume, p. 60) noted: "A social justice focus on caregivers should attend to racism, classism, religious oppression, sexism, heterosexism, transgender oppression, ableism, and ageism." Solutions to the challenges of caregiving must attend to the intersections of oppression and privilege. Chin (this volume) explores this from a policy perspective.

In discussing the politics of caregiving, le Roux (this volume, p. 49) is clear: "we have to be very deliberate in countering the marginalization of human relationships across generations, where caregiving is belittled as private (and women's) stuff." le Roux goes on to argue for a move to what Tronto (2013) calls a *Caring Democracy*. In talking about Tronto, le Roux stated "What it means to be a citizen is to be someone who takes up the challenge: how should we best allocate care responsibilities in society? She [Tronto] makes a compelling argument for the need to make care, not economics, the central concern of democratic political life."

As I write this in the summer of 2020, the world is in the midst of a global pandemic—COVID-19—that is testing the limits of and irrevocably altering family caregiving. At this point six months into the pandemic, millions of people in the United States have tested positive and over 150,000 have died, stay-at-home orders have been placed and lifted, some places have required masks while others have not, and a debate rages about opening schools in the fall, and opening the economy. The effects on families have been widespread, and I'm sure I will not be able to capture every consequence here. One of the biggest challenges for family caregiving has been that due to the highly transmissible nature of the illness, those who are the sickest require hospitalization and families cannot even visit, and many families have had multiple members get sick. I heard a first responder on a radio program the other day say that COVID-19 uses our humanity against us by using our desire to care for each other to spread.

Of those of who have died, most have died without their families present and caring for them and families unable to grieve together. This disruption in normal family caregiving and grief processes will have ongoing consequences in ways we don't yet understand. We learned about caring as part of the family life cycle in Portland (Scott, 2018), and this pandemic is one of the biggest challenges to this normative process we've seen. We've also learned that COVID-19 has disproportionate effects on those who are poor and on ethnic minorities in the US (especially Black and Brown communities). These individuals are at greater risk of contracting the illness due to work conditions, living conditions, differential levels of pre-existing conditions and the effects of systemic racism across our country.

Another consequence of COVID-19 is that it has exposed both the best and worst in people. There are many examples of healthcare workers traveling to hot spots to treat those who are ill, often at grave risk to themselves (many healthcare workers have been infected and many have died). Communities have also come together to care for each other in countless ways—many people have taken quarantine very seriously and have isolated themselves to help others. Sadly, COVID-19 has also revealed, at times, a profound lack of caring and community in the United States. Wearing a mask in public has become highly politicized, but public health experts all agree that one of the keys to containing the pandemic will be consistent mask use. Wearing a mask is seen by some as an act of caring—a way to prevent neighbors and community members from getting sick, yet it is seen by others as an act of oppression and government overreach. The United States has also seen highly partisan mixed messaging and a lack of coordinated federal response. One consequence is that, as of the end of July 2020, 25% of the world fatalities due to COVID-19 are in the United States, which has just 5% of the world's population, and the US leads the world in infections and fatalities.

COVID-19 has placed other burdens on family caregiving as well. It has disproportionately affected those in long-term care facilities; places whose residents by definition are in need of care. Families have been unable to visit these facilities, seriously challenging the ability of families to care for their members. At the other end of the spectrum, schools across the country have been closed or moved to online and remote learning, placing a heavy burden of caregiving on families (and especially women who disproportionately care for children). The economic burdens are also immense. Millions of workers in the US have been unemployed, and government responses have mostly benefited larger corporations over individual workers. Resources needed for caregiving are unavailable, and we don't yet have a grasp on what all of the consequences will be. There is an untold amount of stress and anxiety and the physical and mental health consequences will be seen for many years. In this post-COVID-19 world, this move to "claim dignity as care" (le Roux, this volume, p. 60) could not be more relevant.

There are many scholars who are addressing these challenges by focusing on caregiving needs and challenges in university settings. For example, Montpare and le Roux (2018) described the Age-Friendly University Initiative, which aims to increase intergenerational programming in higher education settings, and O'Rourke (2018) described programs to increase quality in online gerontology/aging degree programs. Settles and Donaker (2018) also provided information about improving aging studies programs with a focus on caregiving, while Hamon and Berke (2018) described an intergenerational story listening intervention focused on caring where Intergenerational pedagogical strategies encourage college students to respectfully listen to life stories of older adults. There are also many community initiatives that are helping build a focus on caring and caregiving across generations (Ballard et al., this volume; Chin & Simowitz, 2018; Pomelow, 2018; Viti, 2018).

We know that there are many other things that can help: self-care and mindfulness and other stress reduction techniques help caregivers take care of themselves so that they can take care of others (Almond & Resor, 2018; Malia et al., 2018; this volume); storytelling and story listening help build empathy skills (Hamon & Berke, 2018), poetry (Brown, this volume), music (Corson, 2018), and art (Viti, 2018) provide means of connecting across generations and also can build empathy; building external and social supports and having access to adequate resources ease caregiver burden and are vital in reducing stress (Easom, this volume; le Roux, this volume); skill building provides necessary skills for enacting caregiving (Easom, this volume); improving family functioning leads to improved caregiving efficacy and reduced stresses (Blanchard, 2018;

Mallette & Rodriguez, 2018); religion and spirituality give caregivers a sense of meaning and a belief structure to rely on (Scott et al., 2018); and planning (e.g. eldercare planning—Malia, 2018; Vincenti et al., 2018) can help reduce future caregiving needs and stressors.

As was noted at the outset, caregiving involves investment of intent, effort, and resources to care for others. We are at a moment in time when this investment is being tested and we have many resources in place (professional and academic as well as personal) that can help us to build our caregiving capacity. From this volume and our conference comes a commitment to claim dignity as care.

References

Almond, L., & Resor, J. (2018, June). *Basics of daily mindfulness*. Workshop presentation, Groves Conference on Marriage and Family, Portland, ME.

Almond, L., Baugh, E., Mallette, J., & Harcourt, K. T. (2018, June). *Together We Can: Increase couple functioning for low-SES families*. Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Bailey, S. J. (2018, June). *Rural grandparents raising grandchildren: Family caregiving from crisis to advocacy.* Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Bailey, S. J., & Letiecq, B. L. (2022). Rural Grandparents Raising Grandchildren: Family Caregiving Through Crisis, Adaptation, and Advocacy. In S. M. Ballard & C. A. Readdick (Eds). *Caring for each other: Family caregiving across the generations* (pp. 99-115). Groves Monographs on Marriage and Family. MPublishing.

Ballard, S. M., Iglesias, A., Pomelow, M. & Viti, N. (2022). Cultivating a Culture of Care Through Intergenerational Programming. In C. A. Readdick & S. M. Ballard (Eds). *Caring for each other: Family caregiving across the generations* (pp. 117-128). Groves Monographs on Marriage and Family. MPublishing.

Blanchard, S., (2018, June). *African American parents of toddler sons: Understanding daily life.* Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Blanchard, S., Johnson, S., & Seay, K. (2018, June). *The impact of family folkway and religious traditions on caregiver's early literacy beliefs and practices*. Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Burns, C. (2018, June). *Rural Outright logic model: Application to support group for those caring for LBGTQIA+ individuals*. Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Brown, M. F. (2022). Labors of devotion: Poetry, the family & caregiving.

In S. M. Ballard & C. A. Readdick (Eds). *Caring for each other: Family caregiving across the generations* (pp. 39-48). Groves Monographs on Marriage and Family. MPublishing.

Chin, B. (2022). Charting a Political Path for Social Justice for Maine Families Who Care. In S. M. Ballard & C. A. Readdick (Eds). *Caring for each other: Family caregiving across the generations* (pp. 204-240). Groves Monographs on Marriage and Family. MPublishing.

Chin, B., & Simowitz, K. (2018, June). *Universal Family Care: A plan for Maine.* Panel presentation, Groves Conference on Marriage and Family, Portland, ME.

Corson, K. (2018, June). *Old songs, new opportunities: The impact of a community music and early childhood training program on families and schools of New Americans and refugees.* Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Easom, L. (2018, June). *Establishing best practices in family caregiving: RCI initiatives.* Plenary presentation, Groves Conference on Marriage and Family, Portland, ME.

Easom, L. R. (2019). New—and Needed—Care Manager Education supports aging and disabled populations. *Aging Today, xl*(2), 1-3.

Fischer, J. L. (2022). Theoretical considerations and personal reflections on reciprocity in care giving/care receiving. In S. M. Ballard & C. A. Readdick (Eds). *Caring for each other: Family caregiving across the generations* (pp. 91-97). Groves Monographs on Marriage and Family. MPublishing.

Frazier, C. (2018, June). *Custodial grandparenting in the post-millennial era: Toward a new understanding of culturally appropriate intergenerational caregiving.* Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Hamon, R. R., & Berke, D. L. (2018, June). *Intergenerational storytelling and caring.* Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Harcourt, K. T., Baugh, E., & Adler-Bader, F. (2018, June). *Co-parenting and incarceration*. Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Le Roux, T. (2022). Dignity, duty, and dependence: Feminist perspectives on caregiving in a neoliberal climate. In S. M. Ballard & C. A. Readdick (Eds). *Caring for each other: Family caregiving across the generations* (pp. 49-63). Groves Monographs on Marriage and Family. MPublishing.

Lucier-Greer, M., O'Neal, C. W., Burke, B., Quichocho, D., & Mancini, J. A. (2018, June). *Military caregiving supports and utilization of military-sponsored youth programming*. Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Macklin, E. (2018, June). *Receiving care: The other side of care-giving.* Workshop presentation, Groves Conference on Marriage and Family, Portland, ME.

Macklin, E., Sibbison, G., Fischer, J., Steele, C., Readdick, C., & Settles, B. (2018, June). *A Groves Perspective on Caring.* Panel presentation, Groves Conference on Marriage and Family, Portland, ME.

Malia, J., Malia, J., & Malia, S. (2018, June). *Tai Chi & Qigong: A lifelong self-care strategy.* Workshop presentation, Groves Conference on Marriage and Family, Portland, ME.

Malia, J. A., Malia, J. E., & Malia, S. E. (2022). Tai Chi and Qigong: Slow Dances of Self-Care for Family Caregivers and Care-receivers. In S. M. Ballard & C. A. Readdick (Eds). *Caring for each other: Family caregiving across the generations* (pp. 188-203). Groves Monographs on Marriage and Family. MPublishing.

Malia, S. (2018, June). *Legal tools for managing family transitions in giving and receiving care: Navigating murky waters.* Plenary presentation, Groves Conference on Marriage and Family, Portland, ME.

Mallette, J., & Almond, L., (2018, June). *Fostering healthy relationships in foster families.* Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Mallette, J., & Rodriguez, Y. (2018, June). *Co-parenting support and child outcomes: A longitudinal examination of Latinx families*. Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Mazurik, K. (2018, June). *Principles and practices of care according to Canadian young adults living with their parent(s).* Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Montpare, J. M., & le Roux, T. (2018, June). *The Age-Friendly University (AFU) Initiative: Broadening Intergenerational Programming in Higher Education.* Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

O'Rourke, K. (2018, June). *From classroom to online: Providing high quality interdisciplinary gerontology/aging studies degree programs.* Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Pomelo, M. (2018, June). *Gorham House Preschool-Intergenerational Program.* Panel presentation, Groves Conference on Marriage and Family, Portland, ME.

Quichocho, D., Lucier-Greer, M., O'Neal, C. W., Burke, B., & Ching, D. (2018, June). *Understanding the experiences of family caregivers of adults with traumatic brain injury: An empirical and theoretical review*. Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Scott, J. P. (2018, June). *Giving and receiving care in the circle of family life*. President's welcome presentation, Groves Conference on Marriage and Family, Portland, ME.

Scott, J. P., LaRiveire, M., Wahl, R., Vaughn, M. (2018, June). *A conversation about religion, spirituality, and caring.* Panel presentation, Groves Conference on Marriage and Family, Portland, ME.

Settles, B. (2022). Intergenerational caring and sharing: A personal and professional exploration. In S. M. Ballard & C. A. Readdick (Eds). *Caring for each other: Family caregiving across the generations* (pp. 65-78). Groves Monographs on Marriage and Family. MPublishing.

Settles, B., & Donaker, K. (2018, June). *Aging studies: Today's caring families.* Paper presentation, Groves Conference on Marriage and Family, Portland, ME.

Shulz, R. (2018, June). *Families caring for older adults: From research to policy*. Plenary presentation, Groves Conference on Marriage and Family, Portland, ME.

Vincenti, V., Teaster, P., & Malia, S., (2018, June). *Elder family financial exploitation: Minimizing risk, maximizing resilience*. Panel presentation, Groves Conference on Marriage and Family, Portland, ME.

Viti, N. (2018, June). *Opening minds through art at The Cedars.* Panel presentation, Groves Conference on Marriage and Family, Portland, ME.

Appendix A

Caring for Each Other: Family Caregiving Across the Generations

Program Chairs: Sharon M. Ballard and Coco Readdick
Portland, Maine
June 10th - June 13th, 2018

List of Presentations in order of Presentation at the Conference

*Names and affiliations are listed as they were at the time of the conference.

Poetry Reading -Marcia F. Brown (Poet Laureate for the City of Portland, ME, 2013-2015)

A Groves Perspective on Caring
Ellie Macklin, (Syracuse University); Ginny Sibbison, (Welfare Research Institute); Judy Fischer, (Texas Tech University); Connie Steele, (University of Tennessee); Coco Readdick, (Florida State University); Barbara Settles, (University of Delaware)

Tai Chi & Qigong: A Lifelong Self-Care Strategy
Julia Malia, Jim Malia, & Sarah Malia (University of Tennessee)

Giving and Receiving Care in the Circle of Family Life
Jean Pearson Scott (Texas Tech University)

Dignity, Duty, and Dependence: Feminist Perspectives on Caregiving in a Neoliberal Climate
Tessa le Roux (Lasell College)

Rural Outright Logic Model: Application to Support Group for Those Caring for LBGTQIA+ Individuals
Caitlyn Burns (Antioch University)

Military Caregiving Supports and Utilization of Military-Sponsored Youth Programming
Mallory Lucier-Greer (Auburn University), Catherine Walker O'Neal (The University of Georgia), Ben Burke (Auburn University), Davina Quichocho (Auburn University), & Jay A. Mancini (The University of Georgia)

Understanding the Experiences of Family Caregivers of Adults with Traumatic Brain Injury: An Empirical and Theoretical Review

Davina Quichocho (Auburn University), Mallory Lucier-Greer (Auburn University), Catherine Walker O'Neal (The University of Georgia), Ben Burke (Auburn University), & Deveney Ching (University of South Florida)

The Impact of Family Folkway and Religious Traditions on Caregiver's Early Literacy Beliefs and Practices

Sheresa Blanchard, Shawnice Johnson, & Kaitlyn Seay (East Carolina University)

Together We Can: Increase Couple Functioning for Low-SES families

Lindsey Almond, Eboni Baugh, Jacquelyn Mallette, & Kate Taylor Harcourt (East Carolina University)

Invited Address and Feldman Award Winner - *Families Caring for Older Adults: From Research to Policy*

Richard Schulz (University of Pittsburgh)

Basics of Daily Mindfulness

Lindsey Almond & Jessica Resor (East Carolina University)

Receiving Care: The Other Side of Care-Giving

Ellie Macklin (Syracuse University)

A Conversation about Religion, Spirituality, and Caring

Jean Pearson Scott (Texas Tech University), Marie LaRiviere (Antioch University), Rosie Wahl (Communal Jewish Chaplain, Southern Maine Community), Michael Vaughn (Catholic Chaplain, Maine Medical Center)

Community Environments for Caring

Sharon Ballard (East Carolina University), Meghan Pomelow – "Gorham House Preschool-Intergenerational Program", Nick Viti – "Opening Minds through Art at The Cedars", Ben Chin, Maine People's Alliance & Kevin Simowitz, Caring Across Generations – "Universal Family Care: A Plan for Maine"

The Age-Friendly University (AFU) Initiative: Broadening Intergenerational Programming in Higher Education
Joann M. Montepare & Tessa le Roux (Lasell College)

Intergenerational Storylistening and Caring
Raeann R. Hamon (Messiah College) & Debra L. Berke (Wilmington University)

From Classroom to Online: Providing High Quality Interdisciplinary Gerontology/Aging Studies Degree Programs
Kathleen O'Rourke (Eastern Illinois University)

Aging Studies: Today's Caring Families
Barbara Settles (University of Delaware) & Karen Doneker (Towson University)

Establishing Best Practices in Family Caregiving: RCI Initiatives
Leisa Easom (Rosalyn Carter Institute of Family Caregiving, Georgia Southwestern University)

Family Caring via Family Financial Socialization: The Intergenerational Financial Effects of Parent Teaching and Practice
Clinton G. Gudmunson (Iowa State University), Elizabeth M. Dolan (University of New Hampshire), & Sara K. Ray (Iowa State University)

Old Songs, New Opportunities: The Impact of a Community Music and Early Childhood Training Program on Families and Schools of New Americans and Refugees
Kimberly Corson (Pennsylvania State University, Behren)

African American Parents of Toddler Sons: Understanding Daily Life, Caregiving, and Parenting
Sheresa B. Blanchard (East Carolina University)

Principles and Practices of Care According to Canadian Young Adults Living with their Parent(s)
Kathrina Mazurik (University of Saskatchewan)

Rural Grandparents Raising Grandchildren: Family Caregiving from Crisis to Advocacy
Sandra J. Bailey (Montana State University)

Custodial Grandparenting in the Post-Millennial Era: Toward a New Understanding of Culturally Appropriate Intergenerational Caregiving
Charlotte Frazier (Lasell College)

Legal Tools for Managing Family Transitions in Giving and Receiving Care: Navigating Murky Waters
Sarah Malia, Attorney at Law, Tennessee

Fostering Healthy Relationships in Foster Families
Jacquelyn Mallette & Lindsey Almond (East Carolina University)

Co-parenting and Incarceration
Kate Taylor Harcourt, Eboni Baugh (East Carolina University), & Francesca Adler-Baeder (Auburn University)

Co-parenting Support and Child Outcomes: A Longitudinal Examination of Latinx Families
Jacquelyn Mallette & Yuliana Rodriguez (East Carolina University)

Elder Family Financial Exploitation: Minimizing Risk, Maximizing Resilience
Virginia Vincenti (University of Wyoming), Pam Teaster (Virginia Tech), Sarah Malia (Attorney at Law, Tennessee)

Conference Summary & Wrap-Up Discussion
Kevin Lyness (Antioch University)

Appendix B

Groves Statement on Family Caregiving

We know that caring is a fundamental family function. We know that the demands and responsibilities of caring and receiving care ebb and flow over the lifespan and across generations. Back and forth throughout our lives we elicit and extend care:

- singing a lullaby to the baby falling asleep on our chest
- wheeling our aging mother into a sunbeam in her garden
- accepting a parent's instruction about first-day-of-school deportment
- welcoming the steadying hand of a partner as we cross a busy street

Further, we believe that caring in families is best sustained within care communities, grounded in an ethic of social justice for all families.

As members of Groves Conference on Marriage and Family, who give and receive care within our own families and serve as professionals who conduct research, teach, and derive best practices in service, we will continue to study how as human beings we can ever better care for each other across time and space and under widely varying circumstances. With others we will strive to support caring families and communities in all that we do.

Approved by the Groves Board of Directors on November 8, 2018.

SOCIOLOGY / Social Science / Marriage & Family

Groves Monographs on Marriage and Family is an edited book series based on the annual meetings of the Groves Conference on Marriage and Family, an interdisciplinary, interprofessional organization of limited invited membership founded in 1934. The Groves Monographs publishes work on the leading edges of theory development and empirical research in the field of family studies. Individual volumes are edited by the chairs of the annual Groves Conferences and include peer-reviewed chapters by the conference presenters and invited authors. Topics are timely and provoca-tive with diverse themes.

Volume 8: Caring for Each Other: Family Caregiving Across the Generations In Maine, 2018, Groves Conference gathered voices from family science and other social sciences, the arts, and history to address the giving and receiving of care within the circle of family life. In this volume, contributors highlight individual, family, and social influences that afford or deter successful family caregiving. Implications from this body of work and thought are derived and offered to lay person, teacher, program developer, researcher, and public policy maker alike.

Christine A. (Coco) Readdick is Professor Emerita of Child Development at Florida State University.

Sharon M. Ballard is Professor and Chair for the Department of Human Development and Family Science at East Carolina University. She is a Certified Family Life Educator through the National Council on Family Relations.

ISBN 978-1-60785-831-7
90000
9 781607 858317