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Using Nursing Research to Shape Health Policy

Patricia A. Grady, PhD, RN, FAAN
Ada Sue Hinshaw, PhD, RN, FAAN
Editors
To nurse scientists worldwide for their valued and productive contributions to patient care and health policy! Such efforts are providing the building blocks for a healthier nation and globe. Your successes in these endeavors enrich the quality of the lives you touch, and we are glad to be a part of that journey with you.
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The public policy/political process may seem but a far-off dream for the next generation of nursing leaders—yet those who have gone before have established an impressive foundation on which to build. Nursing continues to mature into our nation’s premier health care profession, and nurses into international visionaries. Public policy possesses its own history, culture, and language, yet the majority of those involved have only a rudimentary appreciation for the intricacies of health care delivery or practice. Accordingly, it is incumbent upon nursing’s best and brightest to become personally involved in shaping our nation’s priorities. Who else has long championed patient-centered care, the importance of prevention and wellness, as well as a population-based focus—which are the hallmarks of President Obama’s landmark Patient Protection and Affordable Care Act? Today’s call for interprofessional collaboration has always been nursing’s forte. Study after study consistently affirms that advanced practice registered nurses (APRNs) provide the highest quality of care, second to none. Yet, historical barriers enacted by legislative bodies and professional licensing boards still prevent those citizens most in need from having ready access to nursing care. The leaders of nursing’s next generation must become intimately involved in the public policy process and thereby bring about meaningful change.

Passion alone is not sufficient. History has shown that to truly make a difference in the lives of those most in need, practitioners must have access to, and be actively engaged in, cutting-edge science. With advancing knowledge and unprecedented technological breakthroughs, many of today’s “clinical truths” will soon become “tomorrow’s myths.” Clinicians and researchers must continuously inform each other for the greater good. There is a similar reality within the public policy arena. Only by nursing science actively engaging in the critical public policy deliberations will society ultimately benefit.

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Preface

This book, *Using Nursing Research to Shape Health Policy*, examines the crucial interrelationship between nursing research and health policy. It presents examples of specific health care policies that have been influenced, implemented, or changed as a result of nursing research, as well as a number of examples that have the potential to change policy as they move forward in their translation. This text builds on the discussion that began in an earlier book, *Shaping Health Policy Through Nursing Research* (Springer Publishing, 2011). The current book updates earlier information with new examples of nursing research by esteemed scholars. In addition, it encompasses research related to major policy statements of the decade, including the Institute of Medicine’s (IOM) *Future of Nursing* report, the Affordable Care Act, and the genomic nursing science blueprint, and highlights how they have influenced, and will continue to influence, health policy.

Written for multiple audiences, including undergraduate and graduate students, faculty, and nursing professionals, the book presents information on how science shapes health policy in general, models and strategies for linking research and health policy, and multiple examples of how major nursing research has influenced health policy. The text provides both a conceptual orientation and an operational approach to strategies linking research to policy and influencing policy makers at the organizational, community, state, national, and international levels.

This text is particularly timely, as advances are being made in the efforts to translate research into health policy. The editors found a higher level of engagement and activity in this area when setting out to write this book. There are many more researchers and clinicians focusing on the importance of shaping policy than there were 5 years ago.

In addition, the complexity of the health care system continues to increase incrementally, and spawns new questions and issues over which policy has not yet been formulated. The redesign of the health care system necessitates implementation of a thoughtful approach to policy, and it is best shaped by using an evidence base related to patient satisfaction and safety. Put another way, the redesign of the health care system provides opportunity for change, and that change is best informed by the research that nurses are doing. This book provides guidance and examples.

The three major health policy directives addressed in this book—the IOM *Future of Nursing* report, the Affordable Care Act, and the genomic nursing science
blueprint—are landmark documents and will continue to shape health policy for decades to come. Each of these is considered for its implications and impact.

**ORGANIZATION**

*Using Nursing Research to Shape Health Policy* is organized into three sections. The first is an introductory section composed of six chapters that deal with major concepts related to research shaping policy. In the second section, a series of research programs and models, successful strategies for implementation, and lessons learned are described. The third section consists of an analysis and summary of trends and patterns used by the contributors, which helped to guide efforts in shaping health policy.

Chapter 1, “Policy Directives, Scientific Challenges, and Patterns,” sets the stage by addressing major scientific challenges, innovative clinical patterns related to those challenges, and three major policy directives that help to shape policy change. Recommendations from each of those directives are explored.

Chapter 2, “Expanding Areas of Clinical and Basic Sciences,” and Chapter 4, “Integration of Genomics in Nursing Research,” address how the relatively new areas of genomics are beginning to shape science and policy as we move further into the 21st century. Cashion and Austin discuss some of the new advances in Chapter 2 and describe how those advances are beginning to shape our nursing agendas, while Williams in Chapter 4 provides a historical context for and identifies ways in which genomics has become integrated into our nursing research. In Chapter 3, “Implementation Science,” Titler and Shuman provide a detailed description of translational science, including definitions, and deftly identify some of the roadblocks and strategies to overcome those roadblocks.

In Chapter 5, “Team Science: Challenges and Opportunities in the 21st Century,” Naylor, with co-author Vega, describes the aspects of team science that are so necessary in building a research base, identifies how to build teams, and describes ways in which her team has operationalized the concept of “interdisciplinary” in the process of carrying out their studies.

Data collection, data analysis using new and emerging strategies, and data sharing emerge as increasingly important tasks as we move further into the 21st century. Understanding both new data technologies and when and how to use them has become increasingly important for discovery. Section I concludes with Chapter 6, “Data Science.” In it, Bakken describes this emerging field and, using several examples, explores how this technology promises to be instrumental in helping nursing science. The chapter describes how this particular set of approaches can facilitate the manner in which data may be obtained more quickly and more robustly, which, in turn, will facilitate its use in shaping policy.

Section II offers examples of programs and strategies that have been successful in shaping health policy. Several of these examples contain elements for future use in shaping policy. All of these are described by the senior investigators and their teams involved in carrying out the research.
As our population ages and remains relatively healthy compared to previous generations, continues to be active, and is better informed, people are increasingly prepared to take a more active role in their health and wellness. This demographic change underscores the role of self-management, a hallmark of nursing science. Chapters 7 and 8 deal with this increasingly important area. Chapter 7, “Self-Management of Illness in Teens,” describes a successful program in helping teens manage their diabetes, and explicates successful strategies for translation, while Chapter 8, “Self-Management of Illness in Adults,” addresses some of the pioneering work with an adult population experiencing heart failure.

Chapter 9, “Integration of Genomics in Nursing Research: An Example,” provides an example of planning ahead in a rapidly developing area. A specific plan is described, starting with targeting a clinical problem (neuropathic pain), studying it from a basic science perspective, and setting the stage for a successful intervention to be translated into policy. This is a good example of going from bedside to bench to bedside, a strategy that is often discussed but difficult to achieve.

Chapter 10, “Gastrointestinal Symptom Science and Assessment,” provides an example of a program of research in symptom science, a cornerstone of nursing research. This chapter begins at the inception of a program to address symptoms of gastrointestinal distress, continues through paths of discovery, and ends with testing in clinical trials.

With the aging of our population, changing requirements for care and caregiving challenge us as a society to develop new approaches. Chapter 11, “Caring for Caregivers in an Aging Society: Contributions of Nursing Research to Practice and Policy,” and Chapters 12 and 13, “Aging in Place: Adapting the Environment” and “Aging in Place: Innovative Teams,” describe creative ways to address these changing demographics by redefining caregiving teams and altering environmental barriers. All three researchers and their teams have used equally creative strategies to solve demographic challenges and to help shape policy.

As people live longer—with one or more chronic health problems, on average—strategies to address these issues assume a greater importance. The next three chapters deal specifically with issues related to chronic illness. Chapter 14, “Chronic Illness: Addressing Hypertension and Health Disparities in Communities,” describes an early community-based program of hypertension control in an adult inner-city population of African American males. Chapter 15, “Chronic Illness: Promoting Cardiovascular Health in Socioeconomically Austere Rural Areas,” describes a program designed to address cardiovascular health problems in a rural community and the challenges encountered in rural settings. Both chapters address an aspect of the health disparities that remain a challenge. Chapter 16, “Chronic Illness: Telehealth Approaches to Wellness,” provides several examples of the power and potential of telehealth to revolutionize our health care system. Roadblocks and strategies are identified.

Additionally, as our population ages, end-of-life issues are becoming more urgent. Three chapters deal with palliative care and the end of life from the perspective of adult and pediatric populations, and describe the intricacies of policy implications.
These chapters describe the efforts and successes in dealing with numerous policy issues that have been influenced so far. Chapter 17, “Palliative and End-of-Life Care Issues in Adults: The Physician Orders for Life-Sustaining Treatment (POLST) Program,” describes the experience of a team of investigators to develop a tool to facilitate wishes of adult patients and families at the end of life. Chapter 18, “Nursing Research and Health Policy Through the Lens of Pediatric Palliative, Hospice, and End-of-Life Care,” describes innovative approaches with pediatric populations and their families. Finally, Chapter 19, “Palliative and End-of-Life Care Issues: Policy Perspective,” elucidates many of the policy considerations that are currently being dealt with or that will emerge as our health care system begins to address this important phase of the life span.

Section III consists of a single chapter that summarizes and analyzes the strategies and models used throughout the text, noting the unique characteristics and similarities in the approaches and strategies used by the researchers in both setting the stage for and actually shaping policy. Various levels of change have been effected, and several researchers have broken new ground that anticipates potential policy change as they and the next generation of researchers and policy experts move forward.

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FEATURES

As evidenced by the titles and descriptions of the chapters, a number of distinguishing features characterize this book.

- It offers examples of cutting-edge nursing research that provide a foundation for practice and policy.
- It incorporates major policy directives of this decade and highlights how nursing research has influenced health policy.
- It demonstrates to undergraduate and graduate students, faculty, and nursing professionals how nursing research can shape health policy decisions.
- It includes perspectives, models, and strategies for using nursing research to influence health policy.
- Last but not least, it addresses how nursing research shapes policy at organizational, community, state, national, and international levels.

Patricia A. Grady
Ada Sue Hinshaw
The authors are enormously grateful to the many senior colleagues and their mentees who have been committed to producing a volume to update the accomplishments in tying nursing research to health policy. This forward-thinking cadre is pioneering innovative approaches to shaping health policy. Their span of expertise is broad, and provides a state-of-the art summary of major accomplishments and their implications. We express a special, heartfelt appreciation for their outstanding contributions to this book!

Leaders in the nursing profession are actively engaged in this important process and are instilling the inspiration for continuing it in the next generation of nurses. This important mentoring will help to ensure that the profession will be an integral part of future changes as our health care system evolves to meet the changing demands of our society.

In the 5 years that intervened between our earlier book, *Shaping Health Policy Through Nursing Research*, and this book, *Using Nursing Research to Shape Health Policy*, the authors were pleased to observe the extent to which the nursing profession has moved forward incrementally in its awareness of the importance of tying research to health policy by the actions to accomplish it.

The authors are grateful to Pat DeLeon for writing the inspiring Foreword to this text, and also for his unflagging support to the nursing community—support that has continued for more than 30 years. His strong advocacy has been an integral part of the success of the National Institute of Nursing Research from the time of its inception. We value his continued contributions.

The authors want to thank Margaret Zuccarini, Publisher, Nursing, at Springer Publishing, and her staff, particularly Amanda Devine, for their help. We are especially grateful to Margaret for her expertise, sage advice, support, and encouragement during the writing of this book. We would also like to thank Amanda for keeping us on schedule with timely, helpful reminders.
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Using Nursing Research to Shape Health Policy
Aging in Place: Adapting the Environment

Marilyn J. Rantz, Kari R. Lane, Lori L. Popejoy, Colleen Galambos, Lorraine J. Phillips, Lanis Hicks, Greg Alexander, Laurel Despins, Richelle Koopman, Marjorie Skubic, Mihail Popescu, and James Keller

It was clear to any young nurse, in the 1970s and 1980s, that the looming problem facing our society was the coming “explosion” of the aging population. Predictions in every data source about the U.S. population repeated the impending “crisis” in which increased numbers of older people would simply overload and “implode” the long-term care system. At the same time, health care advances were amazing; many people who previously would have been identified as having “terminal” diagnoses suddenly had a better prognosis both for survival and for a good quality of life for more years than had ever been experienced before.

The predictions were not lost on the federal Health Care Financing Administration (HCFA), now the Centers for Medicare and Medicaid Services (CMS). Concerned about the predictions, they launched several HCFA-sponsored large demonstration pilot projects to test potential approaches for modifying long-term care services in an effort to find potential solutions (Hughes, 1985; Kemper, 1990). These demonstrations preceded state and federal public policy decisions to encourage the development of home- and community-based services and the HCFA-sponsored demonstrations of community nursing organizations of the 1990s (Abt Associates Inc., 2000; Collins, Butler, Gueldner, & Palmer, 1997; Elkan et al., 2001).

Nurses were at the forefront, not only providing direct services to older adults in the community and long-term care settings, but also working to influence the development of new models of care, and encouraging older adults to maintain independence and function, and receive health promotion services where they lived. For instance, the Minnesota Block Nurse Program was started more than 30 years ago. The program combined public health and home care ideas and used the skills of nurses to keep people independent and manage chronic illness; that program is still active today (Living at Home Network of Block Nurse Programs, 2016; Martinson, Jamieson, O’Grady, & Sime, 1985; Metropolitan Council of the Twin Cities Area, 1980).
1990). Nurse-run clinics, which are often affiliated with schools of nursing and funded by small grants and demonstrations, have been operating in public housing, nursing homes, rehabilitation centers, and community sites since the early 1980s (Matherlee, 1999).

Local efforts in the 1980s attempted to work through county agencies in some states, not only to build affordable elder housing, but also to offer nursing services within the housing. Stated goals of these efforts were to help people stay healthier, and (it was hoped) avoid nursing home care. In the mid-1990s, the potential solutions to the projected explosion of aging people seemed to be directed at modifying traditional approaches to long-term care, with none of the real revolutionary change that the problem was demanding. Environments were clearly ripe for change—both actual living environments for people to age well and the public policies and political environment that influenced neighborhoods and communities. In this chapter, we present one such example of a program of research and university faculty effort to revolutionize traditional models of long-term care for older adults and influence public policy to disseminate a new model of care delivery promoting independence and function through the end of life.

THE AGING IN PLACE PROJECT AT THE SINCLAIR SCHOOL OF NURSING

In 1996, at the American Academy of Nursing (AAN) meeting, participants were challenged to create a new vision for care and services for the looming surge of elders in the United States. Several faculty and administrators from the school were attending and gathered informally just after the session. We began brainstorming about what we could do at our school of nursing to launch a visionary new approach for serving elders. We realized we had a group of faculty with strengths and expertise in gerontological nursing to provide the critical mass and skills that could launch such a new vision to better meet the needs of elders in the future. The question was, what would that new vision be?

We came home from the academy meeting with some preliminary ideas and convened a large group of interdisciplinary faculty from across the campus. With sage advice and creative ideas, we decided to “blow up” the traditional long-term care system, talk to elders and their families about what they wanted, and start anew (Marek & Rantz, 2000; Rantz et al., 2008). We conducted a series of focus groups, and the message from older people was consistent throughout the process. Seniors wanted to remain independent as long as possible and in the home of their choice, if at all possible, through the end of life. Families, on the other hand, wanted their mom (or dad or other relative) to be safe, above all else. Interesting verbal exchanges among participants ensued during the group discussions, and the seemingly conflicting values emerged during the sessions. Our interdisciplinary team was challenged and continued to meet to create a new vision—Aging in Place (AIP). This AIP vision continues now, 20 years later. Highlights include:
A dramatic change to the way long-term care is provided in this country through a new approach to care and service delivery

- The foundation of care is RN care coordination/community case management supported by an interdisciplinary team of social workers, activity personnel, rehabilitation specialists, physicians, and aides managed by the RN care coordinator
- Providing seniors with the right services at the right time and early illness detection and intervention to maximize regaining or maintaining health and independence
- Provide research and education opportunities for students and faculty to support and train the next generation of health care workers

To achieve this AIP vision, two complementary parts were designed: an innovative home care agency (Sinclair Home Care) and an innovative independent living environment, TigerPlace, named after the University of Missouri (MU) mascot, the tiger. For the AIP Project to be fully realized in Missouri, legislation was required; the necessary legislation was successfully passed in 1999 and 2001 (Rantz et al., 2008). These two pieces of legislation made the AIP Project an official Missouri demonstration (without any state funds); this was our first public policy change. The next large policy change was to work with state regulators to be able to construct and operate TigerPlace under the new visionary approach, which did not match current regulatory requirements; this second change took 3 years. TigerPlace was envisioned to be an ideal AIP independent living environment where people could live through the end of life, with care and services from Sinclair Home Care brought to them in their private homes as needed. It opened and rapidly filled to capacity in 2004.

**SINCLAIR HOME CARE**

In 1999, prior to the development of TigerPlace and after 3 years of business planning on the AIP vision, the project team successfully applied for a CMS grant to test the concept of AIP for home- and community-based services delivered through a home health and home care agency. A new agency, Sinclair Home Care (initially named Senior Care), was started as a department within the Sinclair School of Nursing. The new agency specialized in services for older adults, was certified for both Medicare and Medicaid clients, and also served those people funded by private insurers and private pay.

With grant funding (1999–2003), we were able to develop a critical research foundation for the AIP work. Our goals were to test the effectiveness and cost-effectiveness of RN care coordination. The project to facilitate AIP in community living sites was funded by the grant, as these nursing services were not reimbursable at the time. Some decisions that were critical to success were:

- Use an electronic health record (EHR) for medical records and charting of services.
- Use a carefully selected set of standardized measures of health with known validity and reliability to use in the care of clients, and also use for assessment
of outcomes and quality of care. These standardized measures enabled comparisons with other groups and state and national databases.

- Collect cost, staffing, and quality outcomes data to monitor the agency operations, as well as the AIP evaluation.

For 10 years, Sinclair Home Care provided Medicare and Medicaid home health services to the older residents in six counties in the mid-Missouri region using RN nursing care coordination, which enabled an excellent evaluation of that AIP service approach for older adults (Marek et al., 2005, 2010; Marek, Popejoy, Petroski, & Rantz, 2006; Marek, Stetzer, Adams, Popejoy, & Rantz, 2012). The team wanted to be able to potentially influence legislators and other public policy makers about the value of RN care coordination to not only older adults and their families, but also to pose possible solutions to the growing demand for traditional long-term care services and the rapid escalation of older adult health care costs. Importantly, we carefully examined outcomes of care and costs using Medicare and Medicaid files, recognizing that both were essential to influencing public policy.

For outcomes, the CMS evaluation (1999–2003) demonstrated that clients who received care from Sinclair Home Care with RN care coordination had improved clinical outcomes (cognition, depression, activities of daily living [ADLs], and incontinence) compared with individuals of similar case mix in nursing homes (Marek et al., 2005). Outcomes (pain, shortness of breath, and ADLs) were also significantly better for clients with RN care coordination than without RN care coordination in a community-based waiver program called Missouri Care Options (MCO; Marek et al., 2006). A later study comparing AIP to traditional home care found that even though AIP clients were significantly older, more likely to be on Medicaid, be cognitively impaired, and be depressed, they had significantly lower rates of decline in ADLs and instrumental activities of daily living (IADLs; Popejoy et al., 2015). Additionally, they experienced significantly fewer rehospitalizations and emergency department visits, but all-cause hospitalization rates were not different (Popejoy et al., 2015).

For costs to Medicare, monthly costs were significantly lower ($686) for MCO clients with RN care coordination compared to those without care coordination (Marek et al., 2010). Finally, total costs to Medicare and Medicaid were $1,592 lower per month in the AIP group than a nursing home comparison group over a 12-month period (Marek et al., 2012). The measurement of significant cost savings and better clinical outcomes has been essential to our efforts, the efforts of other nurses, and the efforts of organizations to change public policy for funding of RN care coordination services. Importantly, Medicare regulations were changed so that limited funding is now available for some of these services (AMA, 2013). This is evidence that yes, indeed, research and practice demonstrations with continuous evaluation and publication of measurable results can influence and change public policy.
TIGERPLACE, IDEAL HOUSING FOR AIP, STATE DEMONSTRATION

As explained previously, legislation was required and successfully passed in 1999 and 2001 with the assistance of a group of interdisciplinary stakeholders, including a state legislator, that grew from our original interdisciplinary group initiated in 1996 (Rantz et al., 2008; Rantz, Popejoy, Musterman, & Miller, 2014). The legislation enabled the construction of TigerPlace as the state’s first AIP site and officially recognized the Sinclair School of Nursing AIP Project as a Missouri demonstration. The legislation did not fund the evaluation or construction, as no funds were associated with its passage, but regulators were directed to work with the AIP site and develop an approach that would enable the construction, operation, and regulation of the demonstration.

Recognizing that additional capital would be needed to fund the project, the school, through a publicly announced Request for Proposals process, sought a partner for the initiative. Americare Systems, Inc., of Sikeston, Missouri, a well-respected long-term care owner/operator of numerous assisted living and nursing homes in several states in the Midwest, stepped forward. The plan was for the school to provide the RN care coordination, as well as health promotion and care services through Sinclair Home Care; Americare would build, own, and operate the building and services related to housing, dining, and hospitality. Key staff of Americare and faculty of the school worked on detailed plans for day-to-day operations, planned with regulators, created architectural plans, and developed detailed operational agreements between the entities. We created a private–public partnership dedicated to the success of TigerPlace as a business, incorporating the AIP research/state demonstration evaluation, and including educational experiences for students of all disciplines at the university.

The foundation for the care delivery system at TigerPlace is RN care coordination, and there is a commitment from all staff to maximize independence and function through the end of life. Just as in the community-based evaluation of AIP, funded by CMS (explained earlier), we made the same three decisions that were critical to success:

1. The continued use of an EHR for all health records
2. Collection of routine health assessment information on admission and every 6 months using standardized health measures (these assessments are used in everyday clinical decision making as well as for continued research about the effectiveness of AIP, and can be used in other related studies)
3. Continuously collecting cost, quality, and staffing data for longitudinal evaluation of AIP for publication of results in order to potentially influence public policy

We also made an important fourth decision:

4. To create a research infrastructure for ongoing development and testing of technology to help older people age well, remaining as independent as possible as long as possible.
Infrastructure for Interdisciplinary Research

All older persons who move into TigerPlace understand and agree that they are participating in a state evaluation of AIP and that their de-identified health information will be used in research. Faculty from the College of Engineering were solicited to join the planning team to design the building’s electronic networking infrastructure that would support technology research. The joint team helped plan for appropriate network cabling, a server room, and easy access to each apartment via an attic with walkway and lighting for future retrofitting as needed.

TigerPlace opened in 2004 with 31 well-designed apartments, each with screened porches and easy access via sunlit interior corridors and exterior exits via the screened porch. It was expanded in 2008 to a total of 54 apartments due to demand. Then, in 2011 as planned, Americare built an 85-bed Medicare skilled nursing facility, the Neighborhoods of TigerPlace, with five distinct “neighborhoods” in the facility, on property adjacent to TigerPlace. The rehabilitation focus of this facility has served the general community demand for these services; also, some residents of TigerPlace have used the services episodically for rehabilitation following joint replacement or other health events and then they return to their home at TigerPlace.

All residents who move into TigerPlace agree upon admission (via written informed consent) to actively participate in ongoing wellness activities and complete biannual health assessments. These assessments are used as clinical information by the health care staff and are also considered outcome measures to evaluate the effectiveness of the AIP Project. Assessment measures include: Minimum Data Set, Geriatric Depression Scale (GDS), Mini-Mental State Examination (MMSE), SF12® Health Survey, ADLs, and IADLs, and fall risk assessments. Other functional and health data collected include gait speed, Timed Up and Go (TUG), length of stay, hospitalizations, chronic illnesses, and medications. As in the earlier AIP CMS evaluation, we found that, in addition to these regular assessments, the RN care coordinators were able to make some early illness connections related to subtle changes in a resident’s condition (Marek et al., 2005, 2006; Rantz et al., 2005). It was our vision that in addition to testing a new model of care in the AIP Project, there could also be new technological discoveries for early illness detection that could enhance care coordination with ongoing assessments and observation.

Technology Research to Enhance AIP

In 2005, the Center for Eldercare and Rehabilitation Technology (CERT) in the College of Engineering at the MU installed the first version of an environmentally embedded sensor system to potentially measure functional status (Rantz et al., 2005, 2008). Early focus groups of older people revealed that they did not want to do anything with the technology, that they did not want to wear anything, and they wanted it to work seamlessly (Courtney, Demiris, Rantz, & Skubic, 2008; Demiris, Hensel, Skubic, & Rantz, 2008; Demiris, Parker-Oliver, Dickey, Skubic, & Rantz, 2008). Years of ongoing research and development have resulted in a sensor system
that continuously (24×7) collects data; automated algorithms analyze the data and send care coordinators health alerts days and even weeks before health status changes are apparent to residents or care coordinators (Rantz et al., 2012, 2013; Rantz, Skubic et al., 2015; Skubic, Guevara, & Rantz, 2015).

Residents kept asking for reliable fall detection from a sensor that they did not have to wear, and the research team developed new methods for privacy-protecting depth image processing for not only fall detection (Figure 12.1), but also automated fall risk assessment (Stone & Skubic, 2013, 2014; Stone, Skubic, Rantz, Abbott, & Miller, 2015). Recent analyses revealed that using automated analysis of in-home gait speed can predict falls 3–4 weeks before they occur. In these analyses, the odds of a resident falling within 3 weeks after a cumulative in-home gait speed change of 2.54 cm/sec is 4.22 times the odds of a resident falling within 3 weeks after no change (Phillips et al., 2017). The sensor system can send fall risk alerts, just as it does health alerts, weeks before events, providing adequate time for older people, their family members, and care coordinators to pursue ways to intervene with fall prevention strategies to prevent a fall from occurring (Stone, Skubic, & Back, 2014).

Research results from the Eldertech team have added to the success of the AIP model at TigerPlace. Since 2005, sensor systems have included various sensors: passive infrared motion sensors; a bed sensor that captures pulse, respiration, and restlessness; and gait analysis/fall detection systems using vision, radar, acoustic arrays, and the Microsoft Kinect depth camera (Skubic et al., 2013; Skubic, Alexander, Popescu, Rantz, & Keller, 2009). Sensor systems are installed in the apartments of those residents who elect to participate in the technology research. The current version includes: (a) bed sensor (monitors heart rate, restlessness, and respirations; Rosales, Su, Skubic, & Ho, in press); (b) motion sensors to monitor activity in rooms (Wang, Skubic, & Zhu, 2012); and (c) Kinect depth images to monitor walking, gait parameters, report falls in real time, and automatically assess fall risk (Stone et al., 2015; Stone & Skubic, 2013). The sensors send health, increasing fall risk, and fall alerts in real time to direct care staff (Rantz, Skubic, et al., 2015). Figure 12.2 is an

**FIGURE 12.1** Images of a fall. A sequence of depth images showing a fall that was captured in a TigerPlace apartment. The depth image captures a distance measure for each pixel. The fall detection and gait analysis systems extract a 3D silhouette of a person moving about in the scene. These are colored in the depth images shown. Blue shows the detected ground plane. The grayscale readings show depth; darker gray is closer and lighter gray is farther away. The black regions are noise, often from glass or metal surfaces (see the color version of this image on the inside back cover).
illustration of the health sensor system developed by the Eldertech team and used by the care coordinators at TigerPlace.

Since 2010, health alerts have been automatically triggered by computer algorithms designed to detect changes in trends in each resident’s sensor data that may indicate a change in health status. The technology with health, fall risk, and fall alerts enhances care coordination effectiveness (Rantz, Skubic, et al., 2010, 2012). Recently, we compared length of stay in TigerPlace between residents \( (n = 52) \) with environmentally embedded alert-generating sensor systems and residents \( (n = 81) \) without such sensor systems, all of whom received care coordination services (Rantz, Lane, et al., 2015). Care coordinators receive health alerts for the group living with the sensor system, assess and intervene to determine if the health alert was clinically significant. Strikingly, the group living with sensors had an average length of stay of 4.3 years, whereas length of stay for the comparison group without sensors was 2.6 years. It appears that the embedded sensor technology increases length of stay even further at TigerPlace by another 1.7 years. That being said, the RN care coordination model at TigerPlace appears to have increased the average length of stay by about a year, even for those living without sensors, compared to the national median residential senior housing length of stay of 22 months (i.e., 1.8 years; Caffrey et al., 2012). Cost to residents was analyzed and compared to skilled nursing home costs, which demonstrated a projected cost savings of $29,920 per person (Rantz, Lane, et al., 2015).

Advancements in early illness recognition using environmentally embedded sensors are pushing the envelope to help not only older people living at TigerPlace, but also those individuals living in senior housing and long-term care settings, and at home. Fourteen research projects have been funded by the National Science
Foundation, National Institutes of Health, the Agency for Healthcare Research and Quality, the U.S. Administration on Aging, the RAND/Hartford Foundation, and the Alzheimer’s Association, for a total over $10 million. The research infrastructure at TigerPlace, with two groups of residents, with and without the sensor system, living there through the end of life has facilitated research projects and enabled evaluation of the effectiveness of the technology in a real-world setting. Efforts are now under way to commercialize the sensor-based health alert system. This will allow deployment in other types of senior housing and target user groups for scaled-up studies, as well as making the technology available to a wide range of older adults who can benefit.

Policy makers are interested in the results of our technology research. Our research team is committed to dissemination of results and also has assistance from the MU News Bureau to prepare national press releases with new findings in major publications. Keeping the public informed about the work is important, so news articles and film coverage are actively planned. We maintain two websites about the work to share with other researchers, health care providers, students, and the public (www.eldertech.missouri.edu and www.agingmo.com).

In July 2015, Dr. Skubic, the engineering lead for the Eldertech Research team, testified to the federal Senate Committee on Aging about the advancements that could enable elders to remain at home as independent as possible and as long as possible. She was challenged to analyze the cost implications of using the technology to reduce the burden on long-term care services. This analysis led to the cost savings mentioned previously ($29,920 per person). In addition, an analysis was done using a reimbursement model, comparing the average annual cost of long-term care paid by Medicaid (in Missouri) to the cost of reimbursing expenses for the in-home sensor-based health alert system and the nursing care coordination. The cost savings was estimated at $87,000 per person. This finding was of interest to policy makers, and we are hopeful that they will seriously consider technology in the home as an alternative to facility care for elders in the future. Our team will continue working toward additional cost-effective technological advancements in the home, publicizing these results, informing policy makers, and influencing their decisions.

**Results of the Missouri Demonstration of AIP at TigerPlace**

The AIP results from the state demonstration have been consistent (Rantz, Phillips, et al., 2011; Rantz, Popejoy, Galambos, et al., 2014) and consistent with the Sinclair Home Care CMS evaluation (1999–2003) explained earlier (Marek et al., 2005, 2006, 2010, 2012). Using the health data routinely collected for all residents who have lived at TigerPlace, 2-year evaluations have been conducted. The first 4 years (2005–2008) at TigerPlace (n = 66) revealed that the program was effective in restoring health and maintaining independence while being cost-effective (Rantz, Phillips, et al., 2011). Similar results were found for the subsequent 4 years (2009–2012) of the program (n = 128) (Rantz, Popejoy, Galambos, et al., 2014). Positive health outcomes (fall risk,
gait velocity, functional ambulation profile [FAP], handgrips, SF-12 PH, SF-12 MH, GDS), slightly negative ADLs, IADLs, and MMSE, and positive cost-effectiveness results were found. Combined care and housing costs for any resident who was receiving additional care services and qualified for nursing home care ($n = 44$) were about $20,000 less per year per person than nursing home care. As discussed previously in the section “Technology Research to Enhance AIP,” in a follow-up analysis of length of stay, residents living at TigerPlace without sensors had a length of stay of 2.6 years (Rantz, Lane, et al., 2015). This is nearly a year more than that of the national median of people living in residential senior housing (1.8 years), and may be attributable to the RN care coordination model at TigerPlace. These evaluation results are of interest to public policy makers in our state and other states, as they search for options for their state to address the growing demand for elder housing, assisted living, and other long-term care options.

Notice in the evaluations that outcome data as well as cost data are key elements. They must be planned and measured repeatedly to be able to attract and influence policy decisions. Using these data to publish findings is important; also, disseminating results so that the public knows the potential impact that could benefit them is essential. In 2008, the AAN recognized the AIP Project at the Sinclair School of Nursing as an Edge Runner. As explained on the AAN website,

Raise the Voice: Edge Runners are the practical innovators who have led the way in bringing new thinking and new methods to a wide range of health care challenges. Edge Runners have developed care models and interventions that demonstrate significant, sustained clinical and financial outcomes.

The AAN promotes the Edge Runner programs as potential “answers to the many problems that plague our health system.” Our team has maintained our Edge Runner status through the continued evaluation and publication of those results that demonstrate program effectiveness and cost-effectiveness.

There is interest in duplicating TigerPlace and the care coordination delivery model in other states. Our team has developed collaborative relationships with other universities, particularly the University of Arkansas. The technology is generating national and international interest. Visitors from around the world are common at TigerPlace, interacting with residents, families, staff, students, and faculty to learn about the project.

**Importance of Interdisciplinary Team for Planning, Operations, and Research**

The importance of an interdisciplinary team to get the work done and to engage in thoughtful planning cannot be overemphasized. The use of such an interdisciplinary team ensures that the program is exposed to a diversity of ideas and that a variety of perspectives are represented. With diversity of ideas, better decisions are made for the program and the people it serves. From its inception, interdisciplinary
team work has been a foundation for the work in the AIP Project and at TigerPlace—from the conceptualization of our unique model to the development of our approach to the implementation of our health care and research initiatives. In terms of AIP operations, the nursing component is supported by qualified social workers who address psychosocial issues, work with families, garner community resources, and liaise with agencies and the larger community. Throughout the history of our project, social work services have been provided on both a part-time and a full-time basis. In the original community-based operations of Sinclair Home Care, a full-time social worker was essential to serve the then Medicare- and Medicaid-certified agency. When the agency downsized to accommodate just TigerPlace (as explained earlier), the operations could not fund a full-time position.

However, over the years as TigerPlace expanded, we discovered that a full-time social worker was most beneficial and essential to support the work and activities of the nursing and all staff of TigerPlace. The social worker’s focus is on meeting the psychosocial needs of the client and family members, which allows the nursing staff to focus on the physical aspects of care, care planning, and care coordination. With the support of social work staff, all needs of the patient are more fully met (Galambos, Starr, Musterman, & Rantz, 2015).

Sinclair Home Care has also benefited from the presence of social work intern students, which helps to provide new perspectives and approaches to health care operations. These students infuse extra energy, knowledge, and expertise to existing AIP services. Student supervision is carried out by the full-time social worker, which is an important responsibility of this position (Galambos et al., 2015). TigerPlace serves as a learning laboratory for not just social work students, but students from many disciplines, such as nursing, engineering, health information and management, medicine, rehabilitation, and veterinary medicine. Students learn the importance of interdisciplinary problem solving through these experiences.

The interdisciplinary focus of the research team has been essential to that success as well. Conducting complex aging studies requires such a team. With the commitment from faculty in engineering, nursing, social work, health management and informatics, physical therapy, medicine, and other schools and colleges at MU, our productivity as a research team is still growing today. Nearly every Friday afternoon for almost 15 years, members of the team come together to guide studies in progress, plan new ones, and mentor students as well as other faculty. Since the construction of TigerPlace, these meetings are held there, in a classroom. Students and faculty interact with the people who live there each week. Such interactions inform and challenge our next research ideas.

**REASONS FOR SUCCESS OF AIP PROJECT**

From the beginning, AIP was inspired by nurses with a vision to change the care for older adults. We built an interdisciplinary team that included not only health care professionals, but also consumers, architects, veterinarians, engineers, and information technologists. We partnered with Americare, a high-quality, visionary
nursing home corporation, which has supported a radically different vision of care for older adults. We work tirelessly to build relationships with legislators in order to facilitate the changes in public policy needed for the vision to happen. We have stayed closely connected with the regulatory community so that we can continue to achieve high-quality outcomes, while giving care in a different way.

Perhaps our biggest success has been our willingness to be pushed to seek unique solutions to age-old problems. As people age, they often become more frail, and staying in the same environment becomes an increasing challenge. The older adults and their families who are partners with us in this enterprise asked us to think differently about early illness, falls, frailty, and infections. They asked to find ways to monitor changes in their condition but not to tie them down to their rooms, or to a sick role. We have stepped up to that challenge: nurses, social workers, engineers, health information technology professionals, physical therapists, and many others discover new ways to identify early illness through changes in activity and passive vital sign measurement, risk for falls through measurement of stride length, and remediation of future fall risk by using depth image sensors.

Our health care team, including RN care coordinators, social workers, nurses, and aides, works closely with families to develop interdisciplinary plans of care based on the resident/family’s needs and wishes. We put services in place judiciously and thoughtfully, to avoid inducing dependence on others. The system of care delivery, including the use of EHRs, allows for quality improvement and early recognition of system problems. We have found that it is essential to the system of care delivery that everyone from the housekeepers to administrators is empowered to think about how to improve care and residents’ experiences. We have also found that EHRs are essential elements for program effectiveness, so that health outcomes can be measured, cost of care and services evaluated, and quality of care and services assessed. *Always* measure cost, quality, outcomes, and describe the staffing and services so that others can replicate and learn from what we have done in the AIP Project.

**CONCLUSION**

Our experience with AIP supports the benefits that can be achieved when physical environments and care models are re-envisioned to more successfully meet the needs of older adults. We have demonstrated that through adapting environments to be more responsive and more relevant to older adults, effectiveness and efficiency can be achieved. A public policy approach that capitalizes on the successes of our project would simultaneously add to the quality of life of older adults while realizing fiscal savings. It is time for our nation to adopt such an approach.

**REFERENCES**


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This book explores the process of using nursing research to shape health policy. There is no single best approach to accomplish this, but there are a number of ties that bind research to health policy. Some of these are actual, some are implied, and others have the potential to be realized in the future. This text focuses on all three of these in the overview, the contexts that are provided, and the examples that are given. In this chapter, several areas are highlighted: the concepts used by the researchers, innovative clinical patterns that have emerged, lessons learned from the illustrative examples provided in the chapters, and finally the policy directives shaped by the examples provided.

INNOVATIVE CLINICAL PATTERNS

The first section of this text deals with innovative clinical patterns that are influencing nursing science and health policy, including expanding areas of clinical and basic science, team science, data science, and implementation science.

Expanding Areas of Clinical and Basic Science

Over time, there has been a shift in the type of research nurse scientists are engaging in, although the focus remains primarily clinical. As pointed out by Cashion and Austin, nurses are incorporating more biological measures and themes into their research. With the expansion of genetics into genomics and the surge of other areas of “omics,” additional knowledge is required to conduct cutting-edge research that will improve patient care. Symptom science, the core of nursing, has evolved over time. Still focusing on the patient, it now incorporates the explosion of new information, adapting it in ways that support the nursing research agenda. A good example of this
approach is the National Institutes of Health Symptom Science Model (NIH-SSM; Cashion & Grady, 2015). This model integrates biological, psychological, and socio-logical components. It identifies a symptom, develops the related phenotype, and uses omics methodologies to identify biomarkers that will lead to development of clinical interventions for individuals. A good example of the clinical and basic science interface, examined by Williams in Chapter 4, is the work of Starkweather et al. (2016) in phenotyping and management of low back pain. This study was designed in a manner that would facilitate translation into policy.

This confluence of clinical and basic science that is emerging is particularly relevant to nursing science, as nurses have a strong clinical focus and are better able to recognize appropriate opportunities and tie them to the basic science knowledge in ways that may be more challenging for other disciplines.

**Team Science**

Team science, once considered a new idea, is now becoming essential as the level of complexity of science continues to grow. There are numerous examples of team science in the chapters contained in this book. Naylor, in Chapter 5, makes the point that team science is necessary because the concept of health itself is very complex. She identifies key points related to team science in the area of health that are necessary for successful knowledge development and translation. She characterizes the successes of the Transitional Care Model (TCM) developed and implemented by her team, and describes activity based on that success. Her chapter also identifies the important contributions that nurses make to interdisciplinary teams: nurses contribute unique knowledge and skills to share with other disciplines, and their collaboration with other disciplines is essential for safe and effective health care; nurse leadership of interdisciplinary teams is associated with improved safety and higher quality outcomes; and nurse team leadership is associated with greater team interdependence, fosters greater respect among members, and positively contributes to organizational culture of interprofessional learning.

Interdisciplinary team approaches are key in most of the examples contained in this text. Team science is most often understood in terms of clinical studies, but due to the growing complexity of science, it is increasingly seen in the basic sciences as well. Dorsey’s work is a good example to illustrate this. Although her work is framed in the clinical health problem of neuropathic pain, she is currently carrying out primarily basic science studies. Within that context, to help her carry out those studies, she has created an interdisciplinary team of experts that include geneticists, clinicians, pain experts, and neuroscientists, to name a few.

The expertise of members who constitute an effective team can cover a broad span, as demonstrated by the chapters in this book. Increasingly, patients and community members are becoming a formal part of teams. Hill has shown the important role of the community in achieving successful outcomes working with African American males with hypertension; Hickman, using the Physician Orders for Life-Sustaining Treatment (POLST) tool, has formally incorporated the patient in ways that are
essential in facilitating the achievement of their health care preferences toward the end of life; Hinds has developed strategies to include families in a more practical and essential way to improve outcomes for their dying children. Her approach has positive outcomes that span the period of bereavement of surviving parents.

Szanton’s work with homebound older adults helps to redefine the potential range of expertise that can constitute a successful team, including handymen, social workers, and occupational therapists. Hickman’s team has included the clergy, lawyers, and legislators in order to create and implement the POLST method of incorporating patient care wishes. Rantz has included engineers, architects, university administrators, and city planners on the team she created to develop TigerPlace, Missouri’s first Aging in Place site.

Data Science

The area of data science is considered one of the most rapidly expanding areas of science. Clinical nurses and nurse scientists have long been generating enormous amounts of data, through patient histories, health records, and observations. The challenge moving forward is how to collect such large amounts of data in meaningful ways and how best to store, analyze, and share it so that the most can be extracted from all the information that is collected. This is also an area primed for and in need of health policy formation, given the issues related to privacy, data sharing, and resource allocation and utilization. The National Consortium on Data Science has released a relevant white paper covering these issues (Ahalt et al., 2014); the NIH has formulated a Big Data to Knowledge (BD2K) Initiative, which will provide an NIH Data Commons and a toolkit for research (NIH, 2016); and the International Committee of Journal Editors (ICJME) has developed a framework for data sharing to be used by journals (Warren, 2016). It is important that nursing engages in these discussions in order to capture opportunities and to make the significant contributions for which it has the potential.

Bakken makes a very compelling case for the importance of, advantages of, and the necessity of becoming familiar with these new data science approaches, either singly or, more aptly, as part of a team in order to capitalize on the opportunities emerging. She stresses the importance of getting the major nursing organizations involved and helping to underscore the importance of emerging opportunities.

Implementation Science

The importance of implementation of science is underscored by Titler and Shuman in Chapter 3. Despite additional resources developed over the past few decades to help in translating research to policy making and decision making, limited progress has been made. She also points out that despite the availability of evidence-based recommendations for health policy and practice, evidence-based care is delivered only about 70% of the time, according to a 2014 National Healthcare Quality and Disparities
Report (Agency for Healthcare Research and Quality [AHRQ], 2015). Implementation can be facilitated when tied to national programs such as the Centers for Medicare and Medicaid Services (CMS) value-based programs, which reward systems with incentive payments for quality of care; or credentialing bodies such as the Joint Commission for Accreditation of Healthcare Organizations (The Joint Commission), which sets standards of care for accreditation. Titler and Shuman also give examples of how local and state governments can facilitate progress in areas such as childhood obesity by implementing sound nutritional policies for school lunch programs. Barriers to implementation are identified and strategies to overcome them are elucidated as well. Titler underscores the facts that it is difficult to change attitudes and that change does not happen quickly, even in the face of new knowledge. Relationship building and trust are required to get individuals or groups to endorse change, and that trust must be maintained in order for change to be sustained.

FACTORS THAT INFLUENCE CLINICAL PATTERNS AND PROVIDE TIES THAT BIND RESEARCH

In progressing forward, changes are made over a range of parameters. Important factors that influence clinical patterns and provide ties to bind research to policy include: identified gaps, timing, changes in technology, health disparities, new knowledge and emerging scientific areas, and adaptation of existing models and tools. A number of innovative clinical patterns, as developed and described by senior researchers, are highlighted within the chapters of this text.

The first of these, identifying gaps, is an important factor in setting the stage for change. The absence of satisfactory health care options for our older populations is noted by both Rantz and Szanton in Chapters 12 and 13. Each has addressed the issues, while keeping the patient central to the equation. Szanton focused her work on enabling individuals to remain in their homes through adaptation of those environments. Unique to her approach was the idea of creating innovative, nurse-led teams that could help to modify the environment. She included a handyman as well as others who could help to bring a more external environment to modify the one in which her patients were living. Examples included occupational therapists and social workers. Rantz developed a creative approach to extended care at TigerPlace, a facilitated living environment for those who were not able to remain at home. This approach involved the use of wearable and environmentally placed sensors that could serve as activity monitors. Thus, those living at TigerPlace could safely and freely move around, with the sensors noting and reporting any changes in activity patterns that might indicate a need for assistance.

Several examples illustrate the importance of timing. Innovative clinical approaches are often required in order to make change, and those changes often lead to changes in policy. However, change can be greatly facilitated or impeded by timing. Readiness of the health care system, health team members, our communities,
and legislative groups are all examples of how timing can play a role. Some innovations described were created to make more immediate changes, such as the examples of Rantz, and Szanton, in responding to changing demographic imperatives; or Grey, in her work, addressing the near-epidemic increase of diabetes in teenagers. Other examples set the stage for change, such as the work of Cashion, Williams, and Dorsey in the area of genomics and Finkelstein in the use of technology. It is worth noting that gaps and timing are often closely tied together.

Changes in technology also influence clinical patterns. The ability to use emerging technologies to better deliver care, monitor health or response to therapy, or provide improved access are all potential advantages. As the population ages, but still remains relatively active, new ways of maintaining health become important. Finkelstein and his colleagues have pioneered the use of technology in their telehealth studies as a way of meeting these new and emerging needs for more accessible ways to obtain care and maintain good health. This is a creative way to approach the changing health care landscape and has the added advantage of increasing access to health care for many populations, both rural and urban.

Health disparities continue to plague society. An added advantage of approaches using emerging technologies is that they may help to address the health disparities currently present in our society, by reaching hard-to-reach populations. Other creative clinical approaches highlighted that address health disparities include those of Moser and her team in addressing the needs of rural populations with cardiovascular issues, and the pioneering work of Martha Hill and her team in addressing health disparities in inner-city populations using community-based approaches.

New knowledge in emerging scientific areas is another important tie. One of the unique aspects of nursing research is that nurses engage in both basic and clinical research and thus have a collective expertise with a wide span of influence. This is a particular advantage for using nursing research to shape health policy. Emerging scientific areas addressed in this text include genetics, end-of-life and palliative care, and caregiving for the aging population. The latter two areas, although they have not just emerged, are emerging in new ways and with additional urgency due to the increased numbers and new care circumstances.

An interesting example of the confluence of basic science and clinical expertise is in the area of genomics. The NIH Symptom Science Model, described by Cashion and Austin in Chapter 2, demonstrates this dynamic and provides a unique approach to collect data in a comprehensive fashion, providing the ability to synergize both basic and clinical knowledge acquired.

In terms of clinical models, the approach of addressing symptoms rather than disease has long been a hallmark of nursing and nursing research. Heitkemper’s program of research on the symptoms of gastrointestinal distress is a good example. This approach can be a powerful tool in the health policy arena, as it is symptoms that typically get the attention of patients and the general public. Addressing symptoms can be an important catalyst for change related to issues surrounding chronic illness and in circumstances in which self-management is an important driver.
Within the emerging area of end-of-life and palliative care, there are several good examples in this text. The research of Hinds with children experiencing life-limiting illnesses, and their families, is breaking new ground. Her programs are producing an evidence base for clinical care and informing the national conversation at a time when policies are being developed in this important area of health. Hinds’s work is novel in the extent to which she is incorporating the family as integral members of the team for children with life-limiting illness. This is a good example of being at the beginning of policy formation or even slightly ahead of the curve, although it is not ahead of national need.

Creative clinical approaches are often developed out of necessity, just as policy is often developed for the same reason. This necessity is usually preceded by changing demographics or circumstances. Gitlin describes this well when she talks about the need for improved models to address caregiver needs. Because the changing demographics of age and medical advances led to shorter hospital stays, caregiving shifted from hospitals and medical centers to home or residences for older adults. Historically, health care systems have been based on acute care paradigms, and the changing structure of families, decreased number of caregivers available, and increased women in the workforce have created a need for patterns of caregiving that differ from the previous norm. Her studies address this need in new and creative ways, and form the basis for policy change.

The forces shaping Gitlin’s work differ markedly from those prevailing at the time Riegel began to develop her self-care model in the 1990s, and serve as an interesting example of change over time. Early in her career, Riegel noticed that patients appeared to improve in the hospital, but experienced frequent readmissions following discharge. Her observations and determination to do something to change the situation were met with resistance and what she refers to as a “fill the beds mindset.” However, her research showed positive outcomes and led to her development and the acceptance of the self-care model used today.

Clinical innovation through adaptation of existing models is demonstrated by several examples in this text. This approach may be met with less resistance, since the change is less extensive and the benefit more obvious. Another example provided in this text is the POLST strategy of Hickman and her team in end-of-life or acute life-limiting illness. Much of the important work in this area has been done by nurses, showing that advance directives (ADs) successfully determine that a patient’s wishes are followed more often if an AD is in place, and periods of bereavement are often shortened for survivors. However, an AD is a minimal approach to supportive care, so Hickman and team have developed a more comprehensive approach to supportive care called POLST, which helps the patient and caregiver mutually determine what the patient wishes.

Another example of adaptation of a previously existing model that was successful in adults, but not teens, is the work of Grey. Knowing your audience is important when attempting to make change. One creative innovation exemplifying both of these concepts is shown in Chapter 7 by Grey and Rechenberg, which describes the work of Grey and her team in developing the Coping Skills
Training (CST) model for teens to better manage their diabetes. Teens, even when they know what they should do, do not always do it, and the protocol, as originally developed, placed serious limitations on a teen lifestyle. What the team did was to take the successful model from the Diabetes Complications and Control Trial (DCCT), which worked well in adults, and add a CST module for teens that helped them maintain good blood sugar control while still being allowed to act like teenagers. This is also a good example of adapting a successful model to fit specific circumstances. A further innovation the team added was to scale up the programs and test them using Internet approaches. Finding out which programs lend themselves to this approach, and which do not, helps to set the stage for new approaches in telehealth, or precision telehealth, using the most current terminology. This is an example of a scientist further adapting his or her own successful model to a different set of circumstances, and in doing so, becoming able to reach the target audience effectively.

LESSONS LEARNED

Throughout this text, a number of threads emerge, which when tied together create a tapestry of lessons learned to serve as a guide to shaping health policy. Among these include: selection of a pressing need or public health issue; timing; barriers; constituency or stakeholders; sustainability; evaluation and refinement; and translation. The examples in this text demonstrate most, several, or all of these approaches in successfully using nursing research to shape health policy.

Pressing Need or Issue

Major public health problems, disorders affecting large segments of our population, acceleration of a previously dormant issue, or an emerging public health issue all garner more attention and provide a greater potential for active change. Szanton advises to fit your interests in with what society needs. Making change in these areas is generally facilitated by the urgency of the problem and the higher number of invested stakeholders. Any of these factors can lead to a greater demand for action. As our population ages, the issues surrounding end of life are a good example of increasing attention and demand for change. With an emerging public health problem, there are often unexpected opportunities. As the technology in the area of genomics has become more available, genetic screening is increasing. Williams cites an example of a study of the problems experienced by parents while awaiting the results of newborn screening. Results showed that a major hardship was the anxiety created during the extensive waiting period between testing and results; a rapid change in policy was made to considerably shorten the time, thereby creating a rapid improvement for parents. This also led to a better understanding of the importance of genetic counseling.
Timing

Timing is an important factor in successful efforts to shape health policy. Identifying a pressing issue or need can facilitate change because the urgency provides momentum. Altered circumstances may cause an issue to emerge suddenly or over time. Examples are provided in this text in which timing is facilitated, such as with Gitlin’s work, where the need for caregiving is increasing due to changes in population demographics of aging and earlier discharge changes in the health care system. Examples are provided in which the push is uphill at first, followed by increasing demand, such as in the research areas of self-management described by Riegel and the efforts in telehealth pioneered by Finkelstein. A recent review highlights the importance of timing for the use of telehealth (E. R. Dorsey & Topol, 2016). Telehealth use is being facilitated now because it is not only providing better access to care, but also convenience and economy; it is expanding from acute care applications to episodic and chronic conditions; and it is migrating from hospitals and satellite clinics to the home and mobile devices.

Other researchers are in the position of being ahead of the curve, and able to anticipate what might be needed. They potentially have the advantage of being able to plan ahead and even be proactive, such as in the areas of genomics as described by Cashion and Austin, Williams, Dorsey, and Miller, Hickman, and Hinds in end of life. In another example, Bakken and colleagues are literally helping to forge an emerging field of data science, not widely discussed even 10 years ago.

Societal issues may often push a policy agenda, so that there is increased receptivity for research to inform emerging policies. Hickman, Hinds, and Miller, working in the area of end of life, provide examples of this. As the societal push for more autonomy during this phase of life grows, there is a demand for information about the best way to deliver care, rules governing patient autonomy, and regulations governing access to facilities over the period of this trajectory.

Windows of opportunity do occur, and should be captured, but they do not always occur at convenient times. Lack of data, incomplete data, and other factors may challenge one’s skills to provide timely advice based on best professional judgment informed by available data. Lessons learned from interdisciplinary teams and data science may help to mitigate these challenges.

Barriers

Inevitably, barriers will be present when making change. Barriers to the use of research evidence in health policy, well described by Titler and Shuman in Chapter 3, include beliefs and attitudes, knowledge and skills, relevance, and organizational context. It is important to develop successful strategies to address these barriers in order to promote the use of research for evidence-based policies. Such strategies include capacity building, provision of research findings for use by policy makers, relationship building, and models for knowledge translation to the public and
policy makers. The section on how best to provide research information to policy makers clearly addresses this challenge.

In some cases, barriers may not be related to information as much as emotional overtones surrounding an issue. Research involving children, genomics, and end-of-life issues is a good example of this. Miller talks in Chapter 19 about addressing the emotional component and the intellectual component of issues before being able to move forward. These considerations can be seen in the work of both Hinds and Hickman. Framing a context becomes key in such instances to help facilitate understanding and provide a basis for change.

Constituency or Stakeholders

Constituents are those concerned about an issue, and their specific interests around an issue can vary widely. Before moving forward, assessment of who has a vested interest and the nature of that interest is key to success. Constituents can provide history, expertise, context, and even economic resources. They can also provide opposition. Some intriguing partnerships over a wide range of constituencies and participants are described in the chapters within this text.

Community members, health care team members, congressional representatives, professional associations, and legal representatives, as well as a variety of other groups, can constitute one’s constituency. It is essential to engage the commitment and imagination of these groups to pave the way for success. An interesting example of creating engagement is that of Rantz and her team when naming their health care facility. Because the facility was developed under the auspices of the University of Missouri, whose mascot is the tiger, using the name TigerPlace immediately provided a sense of investment of the university campus and its associates. Another example of strategic engagement of constituency is that of Hickman. Knowing that end-of-life issues are very sensitive to religious communities, Hickman and her team engaged in discussions with the Indiana Catholic Bishops to help get a passable bill drafted in the Indiana legislature for the use of the POLST instrument in situations of life-limiting illness. Also sensitive to the myriad legal issues, the team started discussions early with the American Bar Association to help with any subsequent legislation.

Sustainability

Planning for sustainability to the extent possible is an important factor. Ideally, the information gained from successful research studies will provide compelling rationale for policy or regulation change, but that is not always the case. Finkelstein and Cady in Chapter 16 provide several examples of successful telehealth interventions that were not sustained due to lack of reimbursement. His chapter also provides a good example of how timing can work favorably. There is now a greater impetus for incorporating telehealth approaches into the health care system, and the persistence
in this area appears to be paying off. Incorporating constituents also helps to build sustainability. Naylor involved third-party payers in piloting her transitional care work, thus paving the way for eventual reimbursement and sustainability. Building upon what is already in place or adapting something already in use may be a positive factor. Examples of this include Hickman refining the concept of ADs in developing the POLST and Grey in adding CST to an accepted DCCT protocol.

**Evaluation and Refinement**

Once changes in policy have been made, it is also important to evaluate whether the changes have been successful and to be sensitive to changes over time. This helps to maintain the relevance of changes made and to maintain currency and sustainability. This is described well by Titler and Shuman in Chapter 3.

**Translation**

Despite the availability of evidence-based practice recommendations for health policy and practice, evidence-based care is delivered only about 70% of the time, as discussed by Titler. She points out that this demonstrates a gap between availability of evidence-based recommendations and their application to improve population health. Translating research into practice and policy is a necessary step to realize the benefits of new knowledge, and many of the factors that can facilitate that translation are discussed in this text. Communication of new knowledge as widely as possible with specific attention to target audiences and tailoring the message so that it is best received by intended audiences are key ingredients to translation.

Being a member of a professional, civic, or advocacy organization can also help in the quest to implement and affect national policy. Grey, with her expertise as a pediatric nurse practitioner, networked with practitioners and practices across the country to implement her CST program for teens with diabetes.

Incorporating key constituents in the design and implementation of research and policy activities can be helpful in translation, as these individuals have a vested interest in seeing or experiencing the benefit from results. This strategy was described in several chapters in the text. A strategy used by Szanton was that of obtaining funding from the CMS Innovations Laboratory, which was designed to facilitate translation by streamlining reimbursement provision for research studies with successful outcomes.

Context is also an important factor in translation of research to policy. Finkelstein gave several examples of successful outcomes, but at the time was addressing future needs in a system geared to traditional methods. This poses a challenge for adoption of new and innovative ways.

As it may be difficult to translate research to policy change, it is important to note that persistence pays off. As mentioned by many contributors, sometimes with innovation, it is a waiting game. The system may not be ready and has to be primed.
or updated. In this spirit, it is worth noting that several authors spoke implicitly or explicitly about what fueled the determination that inspired them. It was noted specifically by Riegel, Rantz, and Szanton, in that early clinical experiences inspired them to attack a challenging issue and make change. So, when considering the next generation, it is noteworthy that early experiences often spark an interest that is sustained over time, resulting in the passion to make a difference. Regardless of the special circumstances, it is clear from the examples in this text that perseverance is a key ingredient required to shape health policy.

HEALTH POLICY DIRECTIVES: RECIPROCAL RELATIONSHIP WITH NURSING RESEARCH

A reciprocal relationship between nursing research and health policy is evident in many of the nursing research examples provided by the senior scientists writing for this text. Just as such a relationship is understood with professional practice, the same dynamic, cyclical relationship exists with health policy. Research, as one of the many factors that shapes health policy, is, in turn, influenced by such policy. Three national health policy statements have been examined in terms of their being shaped by nursing research and having also informed the research: the Affordable Care Act (ACA), the Institute of Medicine (IOM)/National Academy of Medicine (NAM) Future of Nursing report, and the genomic nursing science blueprint. For example, the reciprocal relationship is evident with Hickman’s development of the POLST as a research team endeavor. The POLST facilitates an individual’s end-of-life ADs being honored by having them signed by a qualified health provider, such as a physician or a nurse practitioner and clearly recorded. The POLST has shaped national and state policy of ADs. In turn, as the POLST has been adopted in a number of states, research has been conducted to refine and protect the ethics of the program.

As with the practice–research relationship, the policy–research relationship may be more or less direct. The POLST example provides understanding of a direct relationship, but often the research may be removed several steps from immediate shaping of health policy. The condition of the directness of the relationship varies by many factors, including the type of research such as laboratory or intervention level and the length of time in the research program. For example, Dorsey’s study, using genomics in her nursing research quest for a new intervention for neuropathic pain in patients with spinal cord injury (SCI), has yet to progress through the development and testing of an intervention. She is laying the genetic foundation for the possible intervention, as is appropriate. Dorsey’s work provides an excellent example of nursing research with strong potential for influencing clinical guidelines for SCI patients in the future.

This section examines the reciprocal relationship between nursing research and health policy within the context of the three national health policy directives cited earlier. The numerous strategies employed by the nurse scientists in their endeavors to shape health policy are addressed.
The Affordable Care Act

Nursing research has informed, as one of many factors, two of the major directives of the ACA: that is, the development of new models of care that provide high-quality care at lower or reasonable costs and the shift to community health care with an emphasis on health promotion and disease prevention, especially for chronic health conditions. In turn, the Innovative Care Center at the CMS has funded several of the nursing studies that are developing new models of care, particularly those situated in the community with chronic illnesses.

Rantz and her co-investigators (Rantz, Popejoy, Musterman, & Miller, 2014) have created and tested a new model of care for older adults under the concept of Aging in Place. Through 20 years of research, studying clinical and cost outcomes when individuals are able to age in place with the facilitation of nurse care coordination and home care (Sinclair Home Care) and ultimately in an independent living facility (TigerPlace), the evidence was clear. Stronger clinical outcomes, such as cognition, activities of daily living (ADLs), and less depression, were achieved in conjunction with lower costs for the care. Forming a public/private partnership with Americare, the TigerPlace facility was sustained. This research program is an excellent example of the nursing research/health policy relationship. In order to start the Sinclair Home Care and TigerPlace program for aging in place, legislation was required at the state level and in turn, a new model for long-term care of the older adult has been demonstrated with stronger clinical outcomes and lower costs. Medicare regulations have been changed to reimburse some nurse care coordination services. This team of investigators, including nurses, physicians, social workers, engineers, and management/informatics, wranglers, has provided a new model of care; the research was funded partly by the National Institute of Nursing Research (NINR) and partly by the CMS, to address the “explosion” of older adults needing long-term care, allowing them to remain in their homes as long as possible.

Riegel, Dickson, and Faulkner (2015) are known for their development and study of the concept of self-care and self-management with adults who experience heart failure. As one of the early pioneers in this area, Riegel has generated a middle range theory of self-care that incorporates the processes of maintenance and management of the chronic illness. As she and the team conducted a series of studies, the evidence showed stronger health outcomes, such as with clinical congestion concurrent with fewer rehospitalizations among patients with heart failure who practiced self-care maintenance and management. One of the ways Riegel has influenced health policy is through professional organizations, such as the International Self-Care organization, and marketing awareness programs, such as a Self-Care Day, acknowledged by the U.S. Senate. This program of research provides information for shaping the health management of individuals with heart failure, a prevalent chronic illness in our society.

While the three examples provided earlier illustrate how nursing research shapes health policy, several of the investigators and their teams also address the issue of community care for individuals and families. Hill and her team of researchers
developed a community-based intervention to facilitate the health of African American men with hypertension.

Nursing research, because it focuses on problems of concern to the American people, often provides important insight for health policy makers. Not only does the research target critical health problems, but it is almost always conducted by multidisciplinary teams of scientists. This brings many diverse expert opinions to focus on the identified health problems, which are quite complex. These are the characteristics of research, in general, that garner the attention of policy makers (Hinshaw, 2011).

The Future of Nursing: Leading Change, Advancing Health

The IOM/NAM report on the future of nursing outlined a number of recommendations. The research programs addressed in this text strongly illustrate two of the major recommendations: the need for nursing to provide leadership in (a) redesigning the health care system, as called for in the ACA; and in (b) building interprofessional teams to generate and conduct those endeavors. The nurse investigators in this text, reporting their research programs and how they have shaped health policy, are exemplary in how they have met the criteria for providing leadership in redesigning the health care system with new models, as well as having built strong multidisciplinary or interprofessional teams. Several examples are considered.

Grey, Knafl, Schulman-Green, and Reynolds (2015) are studying how to assist teens with type 1 diabetes in coping with and engaging in self-management. Both the chronic condition and the self-management process are challenging for teens to relate to, comply with, and value. A CST program has been developed and tested to provide a community-based intervention. The research program has shown that clinical outcomes are improved in teens who participate in the CST; for example, increased glycemic control, self-efficacy, and quality of life. The CST program has also involved families of the teens and teens at risk for type 2 diabetes. Being innovative, the researchers chose to put the CST program into an online intervention (i.e., TEEN COPE). This delivery of the intervention greatly appealed to teens and was as effective as any other. Grey and her team’s studies have informed the American Diabetes Association (ADA) recommendations for screening teens with type 1 diabetes for depressive symptoms yearly. The CST program is being used in more than 150 clinics with teens with chronic illnesses and stands as an example of practice shaping policy.

Szanton et al. (2011) investigated a new community-based intervention program for older adults living in their homes (CAPABLE, or Community Aging in Place, Advancing Better Living for Elders). Building on Gitlin and Rose’s studies (2016) focusing on older adults, Szanton especially targeted the person–environment fit for elders. She cited an example of an older woman in a wheelchair who could not enter her kitchen because of the door size and had to crawl around the room to get food. With this tragic example in mind, Szanton formed a research team of nurses, occupational therapists, and handymen to build and test an intervention.
that focused on functional ability and making the environment fit the older adults (e.g., repairing doors and stabilizing banisters). Randomized clinical trials indicated that stronger outcomes were achieved with the CAPABLE program; for example, less difficulty with ADLs, lower pain levels, and improved handling of falls. These studies have been funded by NINR and the CMS Innovations Center. They have major potential for influencing Medicare reimbursement for services beyond the usual in health care. Data now exist to suggest that reimbursement for handyman repairs would be to the patients’ long-term benefit. As Dr. Szanton suggests: How can you control or manage your diabetes if you cannot move about your kitchen with reasonable ease? The other “lesson” to be learned is how to be creative with research and practice teams; including a handyperson on these teams is unusual. This type of leadership is an excellent example of what The Future of Nursing report called for: creative leadership in redesigning the health care system with innovative practice and research multidisciplinary teams.

Two studies mentioned earlier are excellent examples focused on redesigning the health system through new models and the use of multidisciplinary, interprofessional teams to address complex issues and problems. Rantz’s and others’ research with the aging in place program of home care and independent living facility has the potential to change the face of long-term care for older adults. A strong multidisciplinary team contributed to the generation and testing of this community-based program. Hickman’s studies with the POLST have had extensive state and national influence on the use of ADs for older adults and their families. Again, a multidisciplinary team representing several disciplines brought diverse, needed expertise to the research program.

Blueprint for Genomic Nursing Science

The genomic nursing science blueprint (Calzone et al., 2013) was generated by the Advisory Panel for Genomic Nursing Science. The goal was to identify the priority areas for research through a comprehensive review of the current science and expert evaluations of that scientific base. The priorities were aligned with the strategic plan of the NINR. Williams’s chapter in this text, addressing the blueprint, acknowledges its contribution to the discipline in providing guidelines for needed areas of genomic nursing science. As a pioneer in genomic nursing research, Williams addresses the interrelationship of such research with health policy.

S. G. Dorsey et al. (2006) are laying the genetic foundation for understanding neuropathic pain with SCI patients. This is a type of pain that is unusual and often does not appear until months after the injury. Understanding the genetic difference in such pain and especially the genetic underpinnings for a viable intervention is critical. Dorsey’s research program is an excellent example of the integration of genetics into nursing research. Its potential for shaping health policy is excellent because the studies underlie a major research field for nursing: symptom assessment and management. Symptom assessment and management is an integral area for research in the nursing discipline. Beginning to integrate genomics in this field will greatly add
to our ability to understand and intervene with symptoms that are experienced by patients.

A number of examples have been provided of the reciprocal relationship between nursing research and health policy. The relationship is a dynamic, cyclical one with mutual ability to shape both health policy and the discipline’s research.

**Strategies Used by Nurse Researchers to Shape Health Policy**

In 2011, Hinshaw outlined the multiple strategies that senior nurse researchers reported using to inform policy makers about the information gleaned from their studies. Those strategies included:

- Informing local practices in acute care organizations (e.g., hospitals) and communities
- Shaping state health policies
- Informing national health guidelines and standards
- Informing national health policies through federal testimony, NAM report recommendations
- Shaping health science policy (Hinshaw, 2011, p. 11)

The authors in this text utilized the strategies identified in the 2011 study and added several others. The strategies show sophistication and goal-driven productivity. It is evident that nurse researchers understand that their research should shape health policy, so they engage in actions to make their information available to policy makers at the local, state, national, and international levels.

A number of the nurse investigators reporting their research programs in this text informed organizational practice policies in their local acute care or community agencies. Grey and her colleagues implemented the CST program for teens with chronic illnesses in more than 150 clinics across the country. Rantz and her team have established a demonstration program for home care and independent living for older adults who wish to age in place.

State health policies have been influenced by Hickman and her colleagues’ series of studies refining and implementing the POLST program for facilitating ADs for older adults and their families. This program is implemented in a number of states, and the NAM recommends that it be part of the policies for all states. Gitlin’s research with the caregivers of older adults is being tested in an additional state (Connecticut).

Several national/international guidelines have been informed by these nursing research programs. Grey and her team have contributed to the guidelines and standards for the ADA regarding the annual screening of teens with chronic illnesses for depression. In the 2011 text *Shaping Health Policy Through Nursing Research* (Hinshaw, 2011), this was also one of the major strategies cited for nursing studies to influence health policy.

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In this text, a number of additional strategies were cited in terms of informing health policies. Riegel, collaborating with an international organization on self-care of which she is the leader, has promoted a “Self-Care Day” to enhance client and professional awareness. A U.S. Senate resolution was sought to highlight this concept and type of care. Hickman and her team shaped a recommendation for the NAM that POLST be implemented in every state in the country. Finkelstein and his colleagues’ research program is shaping new federal policies about the reimbursement of telehealth. The strategies being used by nurse investigators to shape health policy are expanding and becoming more sophisticated in nature.

Shaping science policy for health is another critical area in which nursing has been quite effective. The NINR is the lead institute for the NIH for research on palliative care and end-of-life issues. Miller’s chapter outlines an infrastructure that has been implemented to compile the research funded across the institutes in this field of study. The Office of End-of-Life and Palliative Care Research provides such compiled information to multiple sources, at their request; for example, for congressional testimony and NAM study committees and reports. In addition, the information is used by the nursing scientific community and other disciplines to examine the state of the science and identify future areas for study.

Nurse investigators are actively seeking ways of shaping health policy. Awareness days, congressional testimony, and NAM recommendations are examples of effective ways of garnering the attention of policy makers. A number of strategies are evident for informing health policy at the local, state, national, and international levels.

CONCLUSION

There are burgeoning opportunities for using nursing research to shape health policy as we move forward into the future. The health care system is changing in ways that focus more on wellness, self-management of chronic illness, and using new and emerging technologies. Additional emphases on shared infrastructure, interdisciplinary and team science, as well as community involvement are increasing. All of these aspects are a part of the fabric of nursing science and tie us to health policy for the future. The impetus is for us to provide the data that will drive safe, progressive evidence-based polices. This volume provides some outstanding examples of what has been done, and provides a snapshot of what can and should be done in order to meet these challenges. It is imperative for nursing science to play an essential role in the policy changes that will help to determine the future health of individuals and of the nation. It is up to nurse researchers, from both current and future generations, to tie nursing science to that healthy future.

REFERENCES


