

A low-angle, upward-looking photograph of several tree trunks reaching towards a dense canopy of bright yellow autumn leaves. The perspective creates a sense of height and growth. The leaves are vibrant yellow, suggesting a late autumn setting. The tree trunks are dark and textured, contrasting with the bright foliage.

Sofia Widén & William A. Haseltine

Aging with Dignity

Innovation and Challenge
in Sweden – the Voice of
Care Professionals

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Preface

Demographic change is a defining issue of our time. As the worldwide population ages, the healthcare systems of every country will meet challenges of scale in providing for their populations. *Aging with Dignity: Innovation and Challenge in Sweden – the Voice of Care Professionals* is a study of the future of long-term care through the lens of the Swedish healthcare system. The Swedish long-term and social care systems have remarkable strengths, including well-trained nurses, innovative dementia services, and passionate leaders who make a difference in their own organizations and beyond.

Over the past years, the think tank ACCESS Health International has conducted in-depth interviews with more than thirty care professionals in Sweden. *Aging with Dignity* summarizes the interviews and provides a broader analysis. The full-text interviews can be found at the ACCESS Health website, accessh.org/agingwithdignity.

If a small, wealthy nation such as Sweden, with well-developed healthcare and social welfare systems, encounters difficulties adapting to demographic change, so will other nations. By examining Sweden's healthcare coordination, homecare technology, dementia services, and eHealth initiatives, *Aging with Dignity* makes the case for best practice. It is our hope that readers will recognize as universal both the challenges and the innovative solutions presented here.

Foreword

Aging with Dignity by Sofia Widén and William A. Haseltine is a learning experience based on the stories of healthcare professionals in Sweden. The book offers practical approaches that societies can use as their national demographic profiles shift in pace with aging populations. For a collective, peaceful future, we must implement sustainable models and practical approaches to care for the health of all individuals. Step by step over the decades, the government of Sweden has developed a collaborative healthcare system that embraces all the country's municipalities, counties, and regions. The Swedish system is designed to support its aging population.

Every nation needs to find its own unique model to care for the elderly, based on local cultures, traditions, economic resources, and political priorities. *Aging with Dignity* is a constructive voice in the deliberations of these nations as they develop their own models of care for aging societies. More and more countries are searching for high-quality, long-term care models to create societies where aging with dignity is possible. In the course of these reforms, governments and the private sector alike need to explore policies that balance quality of care and quality of life with the costs.

Deliberate and deliberative reform benefits from the input of individuals and organizations that can provide examples of best practice from across the world, and that can implement experience, economic insights, and creative strategies to help countries develop sustainable long-term care models. Ideally, any such reform process will be structured like a triple helix, with three equally important and interlinked strands: one strand representing action; one, the holistic strategy or big picture; and the third, a questioning, reflective, learning journey that is open to change. *Aging with Dignity* is one strand in this triple helix.

If reform processes are successful, more and more individuals across the world will have the opportunity to age with dignity. It is incumbent

upon all of us to ensure that every society is able to sustain the welfare and wellbeing of their aging populations.

Nils Bohlin
Global Practice Leader—Health Care
and Life Sciences at Arthur D. Little

Acknowledgements

We are deeply grateful to all those who gave the interviews that form the core of this book. Not only did they take the time to describe their work, but they carefully reviewed and edited the final transcripts.

Specifically, we wish to thank Eva Nilsson-Bågenholm, former national coordinator for the government project “De mest sjuka äldre”, the Most Fragile Elderly Project, and Maj Rom, program manager for the Most Fragile Elderly Project, for sharing their valuable experiences of Swedish healthcare. Ms. Nilsson-Bågenholm and Ms. Rom also recommended several follow-up interviews and case studies that allowed us to broaden the scope of this book.

We were inspired by the work of Forum för Valfärd (Forum for Welfare) and their project on integrated care. Representatives from Forum för Valfärd, including Oscar Boldt-Christmas, senior partner and managing director of McKinsey & Co., and Oscar Stege-Unger, director of the Wallenberg Foundations, generously spoke about their pilot projects on technology, care integration, and outreach. We owe Oscar Boldt-Christmas a debt of thanks for providing information about the work of Forum för Valfärd in Sweden. These insights guided our choice of case studies.

While working on this book, we spent time interviewing representatives from TioHundra, a care company based in Stockholm County. Dr. Peter Graf effected the necessary introductions to help us gauge the importance of care coordination and integration in a larger care organization. He also worked with us on several occasions when assessing TioHundra’s values and their unique position in Swedish healthcare. We wish to thank various members of TioHundra’s staff: Ulrika Karlsson, department manager for care and homecare; Merja Manninen, temporary homecare manager, and Britt-Marie Bylin, district nurse, for their efforts in describing the opportunities and challenges of home health and integrated care; Lena Kallin-Persson, quality coordinator, and Lena Eriksson, quality coordinator, for dis-

cussing the strategic and continuous work of the company in improving care services; and Jan Blomkvist, department manager of long-term care housing, Marielle Nilsson, vice unit manager of the Sjöglinten Short-Term Care Home, and Ann-Sophie Holgersson, manager of the Grind Care Home. All TioHundra's interviewees were very generous with their time and added greatly to our understanding of care coordination in Sweden.

We wish to thank Jeanna Thorslund, lawyer in the Department of Digitization at the Swedish Association of Local Authorities and Regions, for explaining the legal considerations of welfare technologies, and Dr. Åke Dahlberg, advisor to the Swedish government on questions relating to the economics of welfare technologies, who described the costs and benefits of implementing welfare technology.

In the course of our research, we met with users of care services. We owe special thanks to Inga Brehmer for her efforts in hosting focus groups, and to our most frequent focus group participants, Gudrun Bergström, Guje Boström, and Ingrid Svahn. They and all the focus group participants gave us valuable insights into changing consumer needs in assistive technologies.

We also met with public sector policymakers, program managers, and the private sector. We are grateful to Magdalena Marklund, program manager for Technology for the Elderly; to Raymond Dahlberg, senior advisor at the Agency for Participation, who described the innovative programs for seniors living in Sweden; and to Markus Merne, chief executive officer of Everon, who provided invaluable insights into the use of assisted devices and global positioning technologies in care.

We are grateful to Henrik Ahlen, digital strategist at the consulting firm Alfa Bravo, for sharing his thoughts on the future of eHealth; Patrik Sundström, program manager for eHealth at the Swedish Association of Local Authorities and Regions, who went through the national effort to standardize eHealth requirements and technical specifications; and Erik Weiman, former chairman of Uppsala County Council and Moderate Party politician, for describing the political priorities in the area of long-term care. Our study touches on Estonia's eGovernance and eHealth systems. In particular, we would like to thank Dr. Ain Aaviksoo, deputy secretary general of eServices and innovation at the Estonian Ministry of Social Affairs; Artur Novek, implementation

manager and architect of the Estonian eHealth Foundation; Taavi Kotka, government chief information officer and deputy secretary at the Estonian Ministry of Economic Affairs and Communications; and Stein Samsom, who explained the distributed architecture of the eGovernance system.

This book includes several interviews conducted in the county of Uppsala, home to numerous innovative programs. We wish to thank Magnus Gyllenspetz, senior physician, Christina Mörk, senior physician, Angela Edman, nurse, and Pia Ekeröth, nurse, for describing their work with the Mobile Emergency Team for the Elderly in Uppsala, a leading example of integrated care in Sweden; Carina Kumlin, manager, and Pia Lagerström, care coordinator, who discussed their work to improve the coordination of long-term care in Uppsala; Christianne Simson, program manager of Support for Relatives, for describing her tireless efforts to improve discharge processes in Uppsala; and Annika Brehmer for recommending suitable case studies and for her valuable comments.

We appreciate the generosity of a number of municipalities in Sweden. In particular, we would like to thank Åsa Löwing, former eHomecare manager of Västerås Municipality, for explaining the eHomecare model. We also studied the close-care system and mobile teams in Lidköping, in the southwest of Sweden. We are thankful to Marianne Alärd, care coordinator of the Mobile Operational Team, and Dr. Jesper Poucette of the Lidköping Mobile Doctor Service for explaining the Mobile Operational Team and the Mobile Doctor Service, and to the members of the Mobile Operational Team, Ulla Andin, senior physician, Anna Karlsson, resident physician, Siv Jonsen, district nurse, and Christina Pettersson, nurse, for their time.

We wish to thank Lotta Roupe, assistant nurse, Silvia Sister, and manager of the Stiftelsen Silviahemmet's day-care center. Ms. Roupe explained Stiftelsen Silviahemmet's history and its palliative care philosophy; and Linda Martinson, Regional Manager of Aleris care come, for sharing her long experience of care methods.

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Introduction

Aging with Dignity is a close look at the future of long-term care through the lens of the Swedish healthcare system. The book provides context and analysis for the full range of in-depth interviews available on the ACCESS Health International website, accessh.org/agingwithdignity.

We believe Sweden to be a useful model for two reasons: the high level of care Sweden has achieved for its people, particularly individuals who live with multiple chronic illnesses, provides an excellent template for any nation interested in reforming its healthcare system; and the problems encountered in Sweden anticipate what most countries, whether rich or poor, can expect to face in an era of demographic change.

Over the past year, ACCESS Health has conducted interviews with long-term care professionals across Sweden. We have spoken with users of long-term care services, doctors, nurses, administrators, and government officials. Each professional we spoke with has dedicated their career to making sure their fellow citizens receive the best care possible. Each confronts a complex set of social, health, financial, and regulatory issues; each struggles to find more effective ways to improve care. The complete set of interviews on which this book is based is available at the ACCESS Health website, accessh.org—it is in the interviews you will hear their voices, understand their perspectives, and learn about their plans and aspirations.

The interviews highlight the pressure that aging populations are placing on healthcare systems, long-term care infrastructure, and pension funds. We are living longer than ever before. We are also accumulating a greater number of chronic diseases as we age. Our healthcare systems are not designed to care for aging populations; indeed, they are often specifically designed to care for younger people with short-term health issues such as broken legs or appendicitis. Healthcare professionals in Sweden have known about this system failure for a long time, and they realize that healthcare costs are increasing rapidly because of it.

Sweden has now taken the lead in building a society and a health system that is truly age-friendly. The system places high value on a few important aspects of age-friendly living. It focuses on active living, where people of all ages are encouraged to stay active and break through the cycle of loneliness and isolation that is far too common. It tries to integrate healthcare and social services at the local, regional, and national levels. The best practices in Sweden focus on individual needs, and provide patient-centered solutions such as home-based care and eHomecare. The system also recognizes that care must be provided quickly and whenever there is a need, whether that be in hospital in the middle of the day or at home in the middle of the night.

In this book we identify the most important concerns raised by the interviewees about their efforts to provide social and healthcare services to their communities. We identify individual and collective approaches and solutions to the problems they encounter. We highlight problems that are relevant to many countries around the world. It is our conviction that all people, no matter where they live or what their income, share common challenges inherent to aging and demographic change.

Chapter 1 identifies one of the single most pressing concerns for healthcare systems around the world—demographic change. As the population ages in unprecedented numbers, new problems of scale arise in care.

Chapter 2 outlines the Swedish healthcare system. Though Swedish healthcare is among the best in the world, even here the aging population places novel demands on the system.

Chapter 3 describes long-term care as a unique branch of healthcare with very particular requirements and best practices. We find that many of these challenges highlight the best and worst of the healthcare system as a whole.

Chapter 4 asserts the need for coordination between care providers. Coordination across administrative and bureaucratic lines is essential for each person's primary care, specialty care, prescriptions, therapies, and rehabilitation services.

Chapter 5 looks at the mobile teams that have sprung up around Sweden in response to lapses of coordination. These teams are run by the county and municipality, and often fill the role of care coordinator.

They also provide concrete examples of best practice in homecare for the elderly.

Chapter 6 is an introduction to eHomecare technologies. These are devices designed to facilitate self-care and independent living for clients living at home. It is our opinion that, in the future, many healthcare services will be delivered at home, by patients and home healthcare providers, through care technologies and home health monitoring devices. These innovations mark a leap forward in a sector traditionally shielded from rapid change.

Chapter 7 considers the future of eHealth in Estonia, home to perhaps the most technologically unified government in the world. The Estonian model illustrates one possible solution to the issues of care coordination and data exchange.

Chapter 8 concentrates on the care of people living with dementia. Sweden is a world leader in this field. Dementia care is, in our view, an instance in which care homes become a viable option, by helping individuals who live with dementia.

Our conclusions include a brief look at several areas that we believe will become sources of major concern to the long-term care system moving forward: mental health, quality of life, training in homecare, and human resource management.

Although our research concerns Sweden, we believe best practices are universal. We have chosen Sweden for the initial study because social services and healthcare are well developed in this small, wealthy country. If Sweden has problems in adapting its long-term care, so too will many other nations. Similarly, if Sweden successfully tackles its care coordination issues, it paves the way for other countries to move towards integrated care models. Through coordination, innovation, technology, and specialized care, the vision behind Sweden's complex healthcare system can be realized in a manner applicable in many, if not all, other countries. Best practices in these spheres can improve the lives of people and help countries build sustainable healthcare systems.

The Reality of Demographic Change

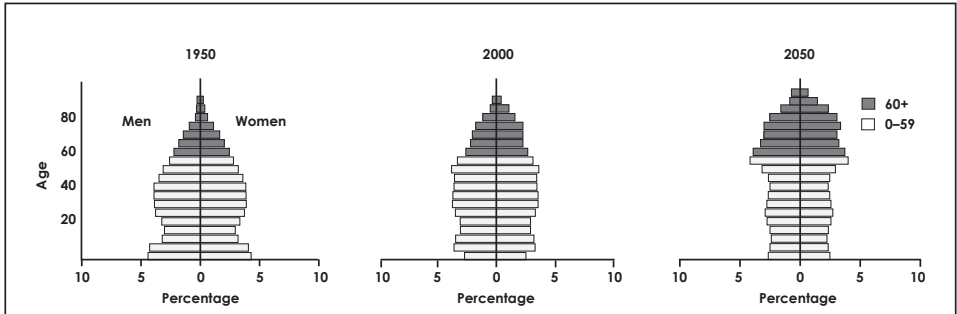
Demographic change is a defining issue of our time. Longer life spans are partly a result of improved medicine and economic growth. Aging societies are a sign of positive development. However, demographic change affects the fundamental social and economic structures of all communities. In most countries, demographic change stems from the growing number of older citizens. In many parts of the world, the problem is compounded by low birth rates. Migration of all sorts adds layers of complexity to the challenges posed by demographic transition.

Demographic change affects societies in profound ways and touches almost every aspect of life. Older rural populations are left without the support of the younger generation, who have left for urban centers or to find better opportunities abroad.

Longevity, Fertility, and Migration

Demographic change will affect all aspects of life around the world for at least the next two or three generations. In some parts of the world, including sub-Saharan Africa and India, the population is growing rapidly in a pattern typical of the early twentieth century. Many countries, including those with rapid population growth, face a different challenge: the exponential rise in the number of people aged between 65 and 70. Fertility rates are low in most high-income countries in Asia, Europe, and the Americas, adding further strain to the social and economic fabric. In other countries, the migration of the young from the countryside into the cities or from low-income to high-income countries has profound consequences for those left behind.

In this opening chapter, we will put the demographic challenges

Figure 1.1. Demographic change in Sweden.

Population Division, DESA, United Nations.¹

faced by Sweden in a broader global context. The demographic data summarized here point to the global nature of the challenge as well as to specific issues germane to Northern Europe.

Demographic Change in Sweden

For decades now, Swedish citizens have enjoyed long life spans. Life expectancy at birth is set to increase from 84 to 89 years for women, and from 80 to 87 years for men from now until 2060. For every ten years until 2060, life spans are predicted to increase 1.1 years for women and 1.4 years for men. In 2014, every fifth person in Sweden was 65 years or older. In 2060, every fourth person will be 65 years or older.² The Swedish population pyramid will look like a rectangle in 2050, if these trends continue. This is illustrated in Fig. 1.1.

The Swedish government is responding to the changing needs of an aging population, but the numbers are stacked against it. Almost 2 million people in Sweden are older than 65 years. This number is expected to increase by 300,000 people by 2025.³

Swedish nurses and doctors already struggle to provide care services for everyone in need. Those over 80 require the most care of all age groups. Most people in this age bracket are actively enjoying social activities and travel, but they also generally live with at least one chronic illness and need support from the medical profession. As this age group grows, healthcare costs are likely to increase to levels that will strain the financial resources of the country.

Demographic Change in Europe

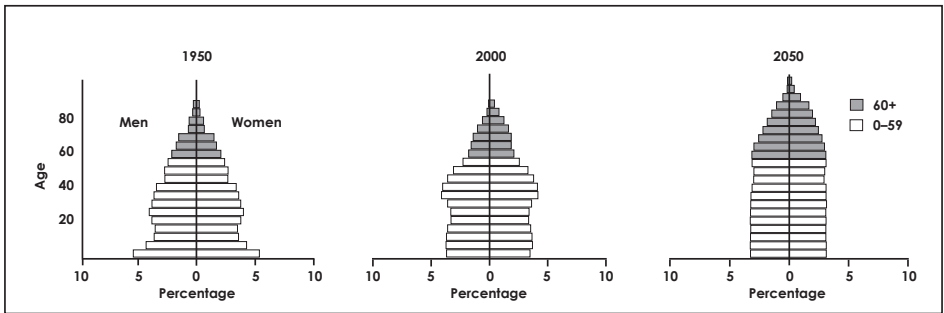
Sweden is in Western Europe, where the global financial crisis of 2008 had negative consequences on the quality of life and savings for parts of the population. In Greece, Spain, Italy, and Portugal governments had to reform pension systems after the crisis. “Cost-containment has been pursued by an array of measures, such as increased retirement age, more limited access to early retirement, less generous indexation, strict application of means testing for the provision of basic pensions, and a stricter link between contributions and pension benefits.”⁴ In the aftermath of the crisis, it has been difficult for governments across Southern Europe to allocate resources for pensions, healthcare, and social care.

The countries of Eastern Europe are set to experience a decline in their total population in the coming decades. “[C]ountries in the Western Balkans, Eastern Partnership and Russia, Bulgaria, and the Baltics display especially low life expectancy and fertility. Net emigration is also exacerbating aging in a few of them, especially countries in the Western Balkans.”⁵ The Eastern European countries will also age, and without the social welfare structure of the Western European countries, this demographic change has important implications for quality of life, especially for those who require home assistance and healthcare services. Many will suffer from chronic illnesses and disabilities related to old age.

Demographic Change in Advanced Industrial Economies

In the Americas and Central Asia, the shift in demography, like that seen in Europe, is also visible. “The countries of Europe and Central Asia are aging. The average age of the population increased from 29 years in 1950 to 37 years in 2015, and the share of people 65 and older in the total population rose from 6 percent in 1950 to 12 percent in 2015. According to simple extrapolations based on the United Nations’ medium-fertility demographic scenario, by 2050 the share of older people could reach 21 percent.”⁶ Both Europe and Central Asia need to prepare for their population changes. Policy responses need to address this in the coming years.

Figure 1.2. Demographic change in the US.

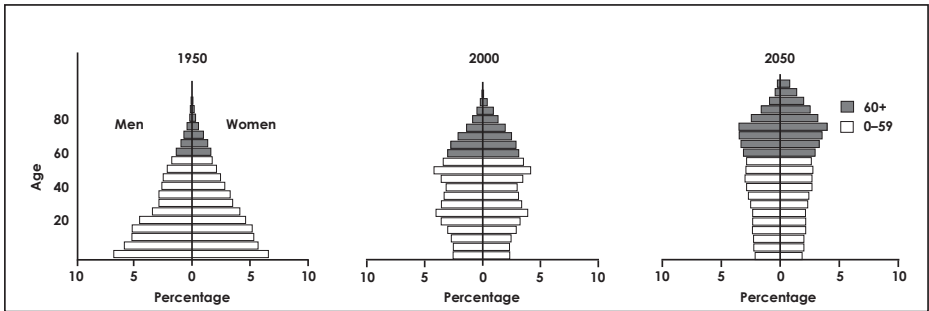


Population Division, DESA, United Nations.⁷

In the US, meanwhile, the percentage of the population over 60 is 21 percent (a demographic shift is illustrated in Fig. 1.2). The US is ranked among the top countries worldwide for the elderly, but there are significant variations in access to healthcare and quality of life across the country. Old-age poverty rates indicate that ethnic minorities are more likely to find themselves unemployed, and long-term unemployed at that. It is important to understand the differences in life span according to ethnic group and to provide services that correspond to those needs. There is no one-size-fits-all solution. Local care needs and patient preferences will dictate the appropriate policy and community responses.

Central and South America are rapidly aging too. In every country, the proportion of people over the age of 60 will increase significantly in the coming years. The same demographic change is seen in the Caribbean. “The ageing of this generation over the next 20 years will lead to a particularly rapid increase in the number of older persons: between 2015 and 2035, the number of persons aged 60 and over will increase from 1.1 million (13 per cent of the population) to 2 million (22 per cent). At the same time, low and falling fertility rates will continue to reduce the number of young people.”⁸ The aging populations of Latin and South America vary. The oldest country, Uruguay, and the youngest country, Guatemala, range from 19 to 7 percent of their respective populations older than 60 years. Every country is unique and faces a unique set of challenges related to aging. Two neighboring nations may face completely different problems. In the best case,

Figure 1.3. Demographic change in Japan.



Population Division, DESA, United Nations.⁹

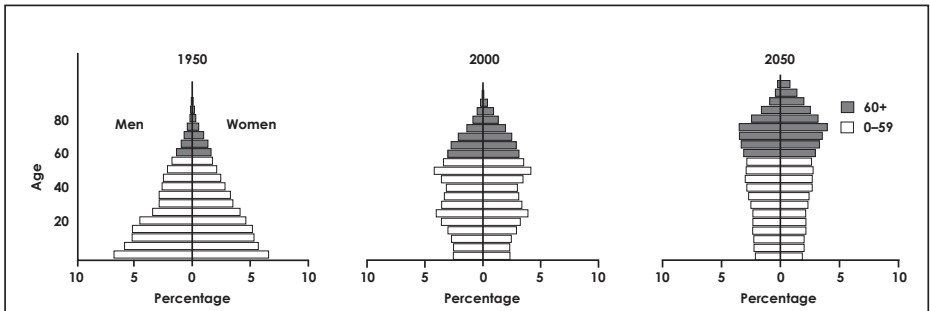
good practice in one policy area in the one country can help the other country improve its care services.

Rapid Demographic Change in Japan and Italy

Japan and Italy are two of the world's oldest countries. The lessons learned there will guide many other aging societies in the future. Japan is a hyper-aging society. One-third of the Japanese population is over the age of 60. By 2050, this fraction will increase to 42 percent. In Italy, 27 percent of the population is over the age of 60. By 2050, this fraction will increase to 42 percent. "Japan's population is aging at the fastest rate in human history as measured by the speed with which the share of the elderly (those aged 65 or older) in the total population has increased over time and is now virtually the most aged in the world."¹⁰ In Italy, 27 percent of the population is over the age of 60. By 2050, this will increase to 41 percent (see Fig. 1.3 & 1.4). Japan and Italy already face major problems that many other countries can anticipate by adopting better aging policies and long-term care models.

The elderly in Italy are struggling to access care services. The Italian government recently introduced social pensions to support its aging population. The pensions have led to a large budget deficit and forced the government to reduce funding to other social welfare programs. The result is a high unemployment rate among Italians aged 50–65. An Italian who loses her job at the age of 50 may find it impossible to find new work, which in turn makes it harder to pay for addition-

Figure 1.4. Demographic change in Italy.



Population Division, DESA, United Nations.¹¹

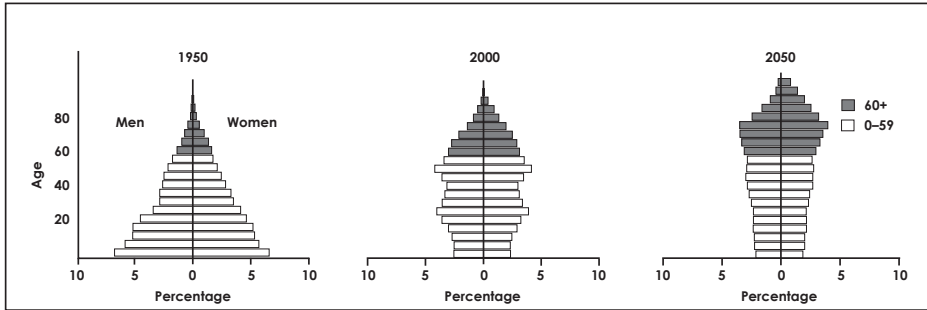
al healthcare services. To combat these problems, the government introduced new laws to encourage private savings in lieu of increasing public pension contributions. As Italians live longer, their pensions will need to support their livelihoods a greater number of years. Lower pensions make it harder to pay for healthcare insurance and meet out of pocket expenditures for long-term care services.

Governments face a difficult trade-off between promoting economic efficiency and meeting unfunded commitments to the elderly. The ability of governments to make immediate adjustments can be limited for legal reasons. For example, even if changes in pension rules are desirable for equity and efficiency, these changes may be difficult to achieve. A rise in the productive population corresponds to an increase in the resources allocated for the elderly, all things being equal. It is difficult to care for an aging population while managing the economy for the current workforce and funding the education of the future workforce.

Demographic Change in Emerging Economies

Many countries outside Europe and the US must also cope with demographic change. Emerging countries also have large numbers of elderly. In these cases, the situation may also be complicated by rural flight. By 2050, nearly 1.5 billion people aged 65 and over will live in what are currently less developed regions.¹² Many of these countries lack the well-developed welfare systems of Northern Europe.

Figure 1.5. Demographic change in China.

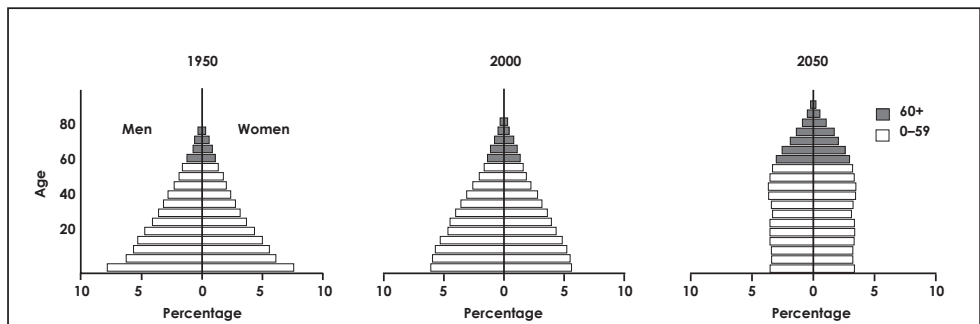


Population Division, DESA, United Nations.¹³

Populous countries such as China and India face enormous challenges due to the sheer number of older people. The proportion of people over the age of 65 is increasing rapidly in China—within the next thirty years, their proportion in mainland China is expected to rise from 8 percent to 24 percent. “By 2019 in China and [by] 2042 in India, the proportion of people age sixty and older will exceed that of people ages 0-14. Combined, more than 0.75 billion people age sixty and older will live in China and India in 2050, constituting 38.5 percent of the world’s sixty-plus population.” (see Fig. 1.5 & 1.6).¹⁴

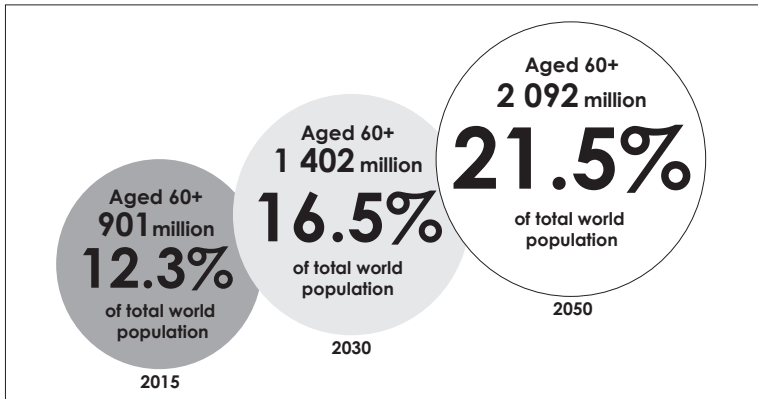
More than 70 percent of all women in India are wholly dependent on other people for their livelihoods; the figure for men is 30 percent.

Figure 1.6. Demographic change in India.



Population Division, DESA, United Nations.¹⁵

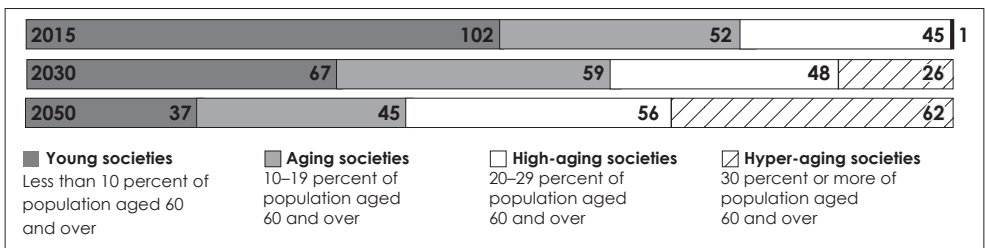
Figure 1.7. Number and proportion of older people globally in 2015, 2030, 2050.



Source: UNDESA Population Division, World population prospects: the 2015 revision, DVD Edition, 2015 page 5.

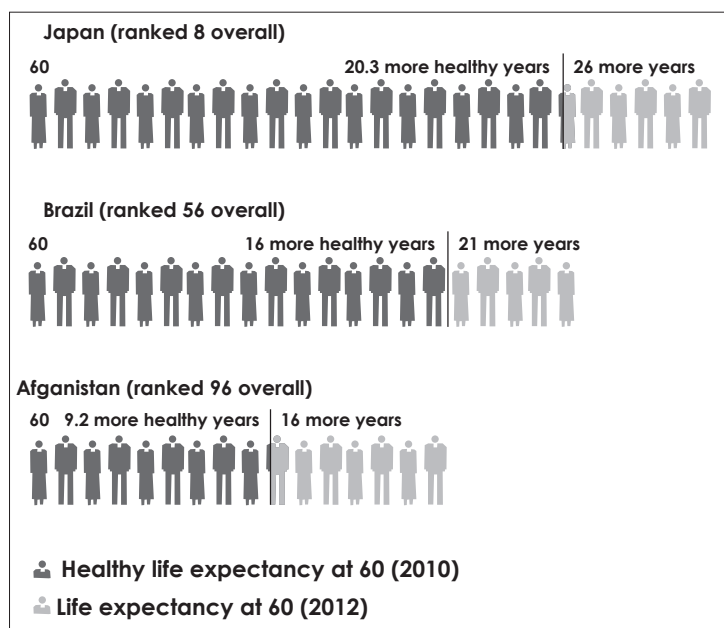
Women frequently depend on their husbands and children for food and access to healthcare, and may hesitate to seek medical attention, because out-of-pocket healthcare payments are around 70 percent of total costs in India. The system leaves many people vulnerable. Fewer than 30 percent of the total Indian population receives pension benefits. Access to high-quality and affordable care services is low compared to countries like Sweden and Norway. India is a young country today, but already more than 200 million Indians are aged 60 and older.

Figure 1.8. Number of young, aging, high-aging and hyper-aging countries in 2015, 2030, 2050.



Source: UNDESA Population Division, World population prospects: the 2015 revision, DVD Edition, 2015 page 5.

Figure 1.9. Life and healthy life expectancy at 60.



Source: Global Age Watch Index 2015: Insight report page 8.

Demographic Change Worldwide

Demographic change affects every country to some degree. In 2015, 901 million women and men were over 60 years of age, representing 12.3 percent of the global population.¹⁶ This figure will reach 1.4 billion by 2030, 16.5 percent of the global population (see Fig. 1.7 & 1.8). As many as three-quarters of these people will live in developing countries.

The Global AgeWatch Index assesses the factors that determine the social and economic wellbeing of older people around the world.¹⁷ The index compares quality of life in multiple countries and highlights good practice and areas for improvement. In 2015, Switzerland ranked first index; Afghanistan ranked last. Industrialized countries rank in the top nineteen. African countries are overrepresented at the bottom. Between these extremes, the countries that perform best take a broad approach to demographic change by investing in pensions, healthcare,

and the social inclusion of their elderly. This parallels the most basic finding we have gleaned from our interviews: when long-term care providers focus on the wellbeing of people and their families, the quality of life for older generations generally improves.

Average life expectancy beyond 60 differs widely across countries, and the gap continues to widen. On average, people live twenty-one years beyond the age of 60 according to the Global AgeWatch Index.¹⁸ However, people in Japan live an average of twenty-six additional years, while those in Afghanistan only live for an additional sixteen (see Fig. 1.9).

People in many countries enjoy long life spans, but they require more healthcare services in their final years. An Afghani citizen may seem older at the age of 60 than the average U.S. citizen of the same age. If people in low-income countries generally have shorter life spans, they may also have greater care needs at younger ages.

“People over 60 now outnumber children under five; by 2050, they will outnumber those under 15.”¹⁹ These demographic changes are occurring most rapidly in the developing world. Neither low-, nor middle-, nor high-income countries are immune to the implications of demographic change. Countries can plan by thinking broadly about these issues. Many of us will need accessible transportation services, age-friendly cities, and flexible assistance at home. The following chapters offer a new perspective on possible methods of improving care services for the future.

Implications of Demographic Change

Many people enjoy longer lives, which is a positive development. It is a mark of a successful society. As people age, they also live with many illnesses. Many individuals who live with multiple chronic illnesses receive medical assistance at home—some even receive advanced healthcare there. Others see specialists for each of their illnesses. Demographic change creates new opportunities for products and services to serve these people, but increasing medical costs will plague many countries unless healthcare systems are restructured.

Governments need to recognize the effects of demographic change, not merely on public services, but on the social climate of the nation. An aging population can create unsustainable fiscal deficits on a household level.²⁰ Each country needs to find a way to avoid these

scenarios. Aging societies are not automatically destined to experience stagnation or decline in living standards, though. Proactive policy responses can counter the negative effects of demographic change. Some countries, like Sweden, have already introduced reforms of their pension systems.²¹ An aging population is the mark of a successful country. We must keep this in mind. The behavioral changes in society that help reduce dependency and sustain productivity also require the correct policies and incentives to facilitate the transition.

A larger proportion of older people increases the pressure on pension systems. This will impact high-income countries first. Younger people will likely need to work until they are older, and save more carefully for old age. Low- and middle-income countries will need to develop public pension systems and encourage private savings among the working population.

Changed population pyramids force us to scrutinize our old ways of thinking, we must design new services for our populations. Governments need to plan decades ahead, studying the economic and social implications of aging. As societies age, all those involved in the healthcare and social care systems must adapt their services, and continuously learn.

Demographic change offers many opportunities, and it is fundamentally a successful aspect of a society. Countries can adapt by building age-friendly cities and housing. Countries can also adapt services and products to consumer needs. Healthcare professionals can change the way they work and allow patients to help themselves as far as possible. Healthcare systems can, to a much greater extent than is currently happening, involve patients in treatment plans and through home- based care. Governments need to respond to aging through a range of measures: “the policy agenda should be comprehensive, not limited merely to challenges facing central governments but including adjustments by municipalities, firms, and individuals.”²² Governments can seize the opportunity and meet the challenges of aging by facilitating behavioral change.

In this chapter, we identify the most important concerns of demographic change worldwide. In the coming chapters, we will turn our focus to Sweden and the ways in which this country provides social and healthcare services to local communities.

The Swedish Healthcare System

The following chapters examine the most pressing issues in the long-term care system worldwide, viewed in terms of Sweden's remarkable health services. Swedish healthcare has two key features to bear in mind: universal health coverage and decentralized provision. Swedish citizens have come to expect free or nearly free comprehensive health coverage from birth through old age. Swedish healthcare functions as a distributed system, leaving local municipalities and county councils responsible for the provision of care. Sweden spends around 11 percent of GDP on healthcare, financed mostly through taxes. The municipalities and counties raise taxes and distribute services largely independent of the central Swedish government. The central government provides funding for healthcare and social care through targeted programs. The central government also sets national treatment guidelines that local providers follow.

There are twenty county councils, and therefore twenty different healthcare systems in Sweden. County councils manage hospitals and primary care clinics. The county councils also contract with private providers. Under these care agreements, the private provider delivers primary or hospital care to county residents. Municipalities contract with private providers for long-term and social care. About half of all homecare providers in Sweden are private, while the public sector still plays a critical role in the provision of healthcare and eldercare services, beyond reimbursement.

Healthcare accessibility is high. Every resident in Sweden qualifies for healthcare services, and treatment is based on need, not the ability to pay. Tax-financed healthcare and social care mean that out-of-pocket expenditure is low. Most people in Sweden qualify for high-cost protection for non-institutional healthcare, which caps the amount the individual has to pay in a twelve-month period: once they have paid a certain amount

Table 2.1. Primary care doctors from ten countries report on their experiences with communication and care coordination, 2015

Country	Communication with specialists	Communication with hospital and ED		Communication with home care providers and social services		
	When patient is seen by specialist, primary care doctor always or often receives timely and relevant information when needed ^a	Doctor is always notified when patient is discharged from the hospital	Doctor is always notified when patient is seen in ED	Practice routinely communicates with home care provider about patient's needs and services ^b	Practice is routinely advised of relevant change in home care patient's condition or status ^b	Practice frequently coordinates care with social services or community providers
AUS	58%	18%	18%	29%	43%	45%
CAN	61	29	32	32	48	50
GER	61	27	20	51	64	63
NET	63	69	68	56	61	42
NZ	69	48	56	28	40	58
NOR	66	38	32	63	53	51
SWE	37	8	6	53	50	42
SWIZ	78	29	31	55	72	60
UK	47	37	49	34	47	65
US	62	31	32	52	63	43

Source: 2015 Commonwealth Fund International Health Policy Survey of Primary Care Physicians. **Notes:** Sample sizes are in Exhibit 1. ED is emergency department.

^aPhysicians who reported that they always or often receive a report back from the specialist with all the relevant health information, and the information they receive is always or often timely and available when needed. ^bExcludes those who responded "not applicable".

out of their own pockets (the equivalent of about USD 200), they qualify for free services. A small percentage of people in Sweden turn to private healthcare providers and pay the full cost of services.

The current and the previous government in Sweden focused on targeted funding for long-term care and cancer screening and treatment. Central government monitors the quality of healthcare and social care using municipal and county assessments. If the municipalities or councils find deviations from good practice, the local authorities can file a complaint with the national healthcare inspectors for further investigation.

Long-term and social care is financed with municipal taxes. Sweden's

Table 2.2 Primary Care doctors from ten countries report on their experiences with satisfaction with and views of their health care systems, 2015

Country	System works well, only minor changes needed ^a	Quality of care patients receive throughout the health system in the past 3 years			Somewhat or very dissatisfied practicing medicine	Job is very stressful	Amount of time practice spends on administrative issues related to insurance or claiming payments is a major problem	Somewhat or very dissatisfied with time spent per patient	Some-what or very dissatisfied with their income
		Improved	About the same	Gotten worse					
AUS	48%	24%	58%	18%	12%	21%	21%	25%	36%
CAN	36	25	53	21	16	27	20	33	22
GER	27	15	55	29	36	45	52	45	28
NET	50	21	44	34	15	18	60	55	19
NZ	57	32	52	16	13	24	20	41	26
NOR	67	33	58	8	8	24	9	33	19
SWE	19	21	42	36	24	56	27	58	18
SWIZ	54	13	65	21	14	31	50	32	28
UK	22	22	42	36	33	59	21	73	33
US	16	25	41	33	34	43	54	44	34

Source: 2015 Commonwealth Fund International Health Policy Survey of Primary Care Physicians. Note: Sample sizes are in Exhibit 1. ^aPhysicians were asked which of the following three statements best express their overall view of the health system in their country: "On the whole the health care system works pretty well and only minor changes are necessary to make it work better"; "There are some good things in our health system, but fundamental changes are needed to make it work better"; or "Our health care system has so much wrong with it that we need to completely rebuild it." This exhibit shows results for the first statement only.

municipalities are responsible for the provision of long-term care services, including home help services and homecare. In all counties apart from Stockholm County, the municipalities provide basic home healthcare services. A district nurse oversees a team of assistant nurses who treat wounds, distribute medication, provide insulin shots, and assist fragile and chronically ill patients at home. Municipalities can only hire district nurses and assistant nurses, who work at the county level in hospitals or primary care clinics, and cannot hire doctors. For this reason, most municipalities collaborate with physicians who are hired by the county councils to provide basic home healthcare services. These physicians are brought in as consultants to assist district nurses with treatment plans. District nurses can call on the general physicians for advice.

The United Nations' Active Aging Index measures employment, participation in society, independent living, and capacity for active aging. The index ranks Sweden as an international leader: "Three Nordic countries (Sweden, Denmark and Finland), and also the Netherlands are confirmed among the top performers across all the four domains of active ageing. This evidence shows that these countries have a balanced approach in achieving higher active ageing for their older populations."²³

However, since the county councils provide primary healthcare while the municipalities provide homecare and social care, there are inevitably issues with coordination. In theory, the specialization of each level of government ensures that citizens obtain the healthcare and homecare they need. In practice, the division of responsibilities can cause delays in communication and service delivery. These delays can compromise the quality of care. Regional and local government use different electronic communications systems, maintain distinctive work cultures, and employ their own idiosyncratic vocabularies. The first report by the Swedish Forum for Welfare spells out the problems:

Swedish healthcare shows a higher degree of specialization than many other OECD countries. ... Specialization creates problems for patients with unclear diagnoses. Patients are sent to many specialists. Patients obtain prescriptions from several specialists. The prescribed medications are sometimes incompatible. Every third acute visit to

Table 2.3. Primary care doctors from ten countries report on their use of health information technology, 2012 and 2015

Country	Use an electronic medical record		Routinely receive computerized reminder for guideline-based intervention or screening tests		Can electronically exchange patient clinical summaries with doctors outside practice		Very satisfied with their medical record 2015 ^a
	2012	2015	2012	2015	2012	2015	
AUS	92%	92%	51%	56%	30%	34%	80%
CAN	56	73**	19	26**	14	19**	68
GER	82	84	8	15**	23	22	77
NET	98	98	12	20**	58	70**	76
NZ	97	100**	46	61**	67	75**	69
NOR	98	99	6	10**	58	82**	64
SWE	88	99**	6	7	54	67**	37
SWIZ	41	54**	9	9	59	57	70
UK	97	98**	68	77**	46	60**	86
US	69	84**	33	47**	33	42**	52

Source: 2012 and 2015 Commonwealth Fund International Health Policy Surveys of Primary Care Physicians. **Notes:** Sample sizes are in Exhibit 1. Significance denotes within-country differences between 2012 and 2015. ^aAmong physicians reporting that they use an electronic record. **p < 0.0.5

hospital is related to incompatible medication. A third of the health-care costs in Sweden are related to patients with multiple diagnoses.

Older individuals who live with multiple illnesses suffer in particular when healthcare providers fail to communicate across organizations. Surveys show that only 37 percent of primary care physicians in Sweden receive timely and relevant information from the specialists their patients have already seen. Primary care doctors are notified when a patient is discharged from hospital less than 10 percent of the time. The same figures are true of patients who visit the emergency room. Only about half of all primary care physicians communicate frequently with municipal homecare providers regarding the healthcare status of their patients. When there is an important change in the condition or status of a person, homecare providers communicate these changes to primary care physicians less than half the time. In contrast, in Switzerland such communications occur more than 70 percent of

the time.²⁴ This situation often creates a stressful work environment for Swedish healthcare professionals. The figures paint a picture of a well-funded, equitable system in need of reorganization.

Many Swedish care providers discuss the need for integrated technologies to deliver better care. Requests include a consolidated electronic medical record system. According to the 2015 Commonwealth Fund International Health Policy Survey of Primary Care Physicians, almost every general practitioner uses electronic medical records, but these systems are suboptimal and frequently incompatible with one another. Only 7 percent of Swedish general practitioners routinely receive computerized reminders of guideline-based interventions or screening tests. This compares to about 60 percent in New Zealand and Australia.

Only about 3 percent of total reimbursements to healthcare providers are based on performance indicators, but the Swedish healthcare system is moving toward greater transparency. Outcome measurements across regions are increasingly posted online. The trend is exemplified by Open Comparisons, a system that compares the healthcare providers' performance in different counties. Through "De mest sjuka äldre", the Most Fragile Elderly Project, the quality of care is systematically registered, compiling data on care services throughout the country.

In summary, Swedish healthcare and long-term care are tax financed, cost efficient, and accessible. Issues still arise, due in part to the specializations of the municipalities and county councils. Specialty silos and incompatible patient record systems prevent providers from integrating work methods and treatment plans as effectively as they might. This problem is magnified in the case of those who live with multiple illnesses and require continuous support from many providers.

Low- and middle-income countries will face similar challenges in the coming years unless they too integrate their social care and healthcare services. Governments will need to consider new ways of delivering care to those with chronic illnesses, as the number of these patients is rising. In the following chapters we will discuss the way organizational decisions make the difference between failure and success, even in a resource-rich healthcare system.

A Different Kind of Patient

Aging populations force us to rethink how we design our systems.
(Maj Rom, coordinator (2010–2014), the Most Fragile Elderly Project)

Swedish long-term care is remarkable in part because local government guarantees it. As such, special healthcare issues relating to long term care surfaced early in Sweden.

Maj Rom was the national coordinator of Sweden's Most Fragile Elderly Project from 2010 to 2014. She offers her perspective on the special considerations of care:

Municipalities and county councils have known about problems with eldercare for a long time. We live longer today. More people survive heart attacks, stroke, and cancer. We remain healthier. We have the opportunity to enjoy life. But we accumulate diseases. A large group of people from 85 to 90 live with new combinations of diseases. Our healthcare system is not designed to care for individuals with these combinations. Our healthcare system is designed to care for younger people who break a leg or get appendicitis. ... [It] is not designed to treat large numbers of people who suffer from chronic diseases. Healthcare professionals in Sweden have known about this system failure for a long time, and they realize that healthcare costs are increasing rapidly because of it.

Coordination lowers healthcare costs. It is also a fundamental tenet of person-centered care. In person-centered healthcare, the full complement of healthcare professionals is integrated and focused on the needs of each patient. This includes geriatric physicians and nurses, occupational therapists, and psychologists.

In person-centered healthcare, quality of care reflects quality of

life. On the subject of nursing homes, Atul Gawande rails: “You’d think people would have rebelled. You’d think we would have burned the nursing homes to the ground. We haven’t, though, because we find it hard to believe that anything better is possible. When we are so weakened and frail, managing without help is no longer feasible. We haven’t had the imagination for it.”²⁵ Ädelreformen, the Swedish healthcare reforms of the early 1990s, did envision something better. In the quarter century since Ädelreformen, aging Swedes have increasingly been encouraged to live at home for as long as possible. “The reform reduced long-term care in Sweden,” says Rom. “The idea was to encourage individuals to live at home. We want people to be a part of society for as long as they can.”

Homecare places special demands on the coordination of professionally, geographically, and administratively varied specialists. The way Sweden administers care services can be confusing for those who use them. Even among doctors and nurses, few have a complete understanding of the entire care team surrounding a patient. The result is a kaleidoscope of care, a cocktail of medications and therapies, and often the compounding of complications.

“Patients follow an individual treatment plan for each condition,” says Rom. “Healthcare providers lose track of the overall perspective; they lose the holistic view of the patient. The current system may lead to a patient taking ten or fifteen different medications. No one knows the effect of this combination. When we do not look at the overall health of the patient, we miss something vital. Our system fails these patients.”

The failure also affects the family members of patients, who often must take on the role of care coordinator and point person for fifty or more care professionals. This is a stressful position that creates tension within families. Such tension is by no means unique to Sweden. As journalist Holly Holder notes: “Until 2000, publicly funded social care was nonexistent in Japan; caring for the elderly was a family responsibility. There were two main consequences of this approach. First, there were many reports of neglect and abuse toward older people being looked after by family members. In a survey conducted by the Japanese government, a third of carers reported feeling ‘hatred’ toward the person they looked after. Caring also restricted the employment options of a growing number of Japanese women.”²⁶

Sweden's care system is one of the best in the world, but even here there is room to improve. The rigidity of reimbursement systems and the limited hours granted to certain services often prevent care workers from delivering person-centered care as effectively as they might. People suffering from multiple chronic diseases demand teamwork between healthcare silos. Patients with complex needs require specialists to coordinate their care programs.

"An older population is a blessing for a country. But aging populations force us to rethink how we design our systems," says Maj Rom. "The range of treatments is expanding. We can now treat a great range of diseases. We can treat older patients. [But] we should ask ourselves what treatment creates the most value for the person. We must ask the person what he or she wants."

The Importance of Coordinated Care

I want one integrated information system.

(Pia Lagerström, care coordinator, Uppsala Municipality)

Ulla Andin, a senior physician specializing in geriatric care, describes the coordination issue in Sweden in this way: “Imagine a picture that illustrates Sweden and Denmark. Imagine that the two sides start building a bridge to connect the two countries. Both sides do an amazing job. Both sides are competent. However, the sides do not collaborate. ... they don’t meet in the middle. You are left with two disconnected half bridges. This illustrates our healthcare system. We work in silos. Each silo consists of competent healthcare providers working independently. We must work together.”

It is not unheard of for up to sixty people from different care organizations to be involved in the care of a single person in Sweden. Besides the inevitable divides between specialties, Swedish healthcare presents the additional chasm between county and municipal care administrations. In January 1992, the Swedish government introduced *Ädelreformen*, the reforms that divided the responsibility for different kinds of care between two levels of local government: the county and the municipality. County councils provide primary healthcare while municipalities are responsible for social- and long-term care. This includes care of the most fragile among the elderly—the people who often require a combination of homecare, primary care, and inpatient care that straddles the responsibilities of both the county and the municipality. When the county and the municipality are unable to coordinate care services, the quality of service delivery can suffer dangerously. The bridge does not meet up in the middle.

Carina Kumlin is the senior manager for the Department of Long-

term Care for Uppsala Municipality. She oversees the entire department and coordinates closely with Uppsala county council to improve long-term care services. “We have improved care coordination by establishing a central care coordination group in the municipality that did not exist before,” says Kumlin.

We have a central care planning group for the elderly. The care planning group includes a nurse, a support agent from the municipality, an occupational therapist, and the doctor from the hospital. The representative from the primary healthcare system does not need to attend the care planning meetings.

Primary care physicians, who are employed by the county, do not have time to attend most care meetings. They rarely travel from their respective clinics. The care planning group allows the municipality to act as a patient’s surrogate primary care physician. Kumlin admits,

There would be certain benefits for the patient if the representative from the primary healthcare clinics could attend the care plan meeting. The primary healthcare clinic at which the patient is listed should resume medical responsibility over the patient once the patient leaves the county hospital. The doctor from the primary healthcare clinic can support the district nurse who makes home visits once the patient has left the hospital. But not every primary healthcare clinic manages to provide this support to the nurse. This makes it difficult for the district nurse to plan the transition from the hospital to the individual’s home.

In this way, Uppsala Municipality has created its own central coordinating body. By design, the primary care system is intended to be the mechanism that synchronizes healthcare providers. A municipality assists in that role when it designs a care plan. Whenever possible, the primary care physician is also involved. As Kumlin notes: “If I were a general practitioner, I would find it difficult to understand the treatment plan fully if I were not present at the care plan meeting.”

Swedish frustrations with care coordination are mirrored in the findings of the 2015 Commonwealth Fund International Health Policy Survey of Primary Care Physicians, in which primary care physicians in ten countries were asked to compare their experiences caring for patients with complex health issues.²⁷ The Commonwealth Fund found

that only 42 percent of primary care physicians in Sweden coordinate care with homecare services. Coordination between healthcare and social services was a problem in all ten countries in the study.

Transitions between county and municipal healthcare providers in Sweden can be difficult. Peter Graf, chief operating officer at the care company TioHundra, puts it this way: “Individual transitions work well between county healthcare providers. In the municipality, transitions also work well. The problems occur when people transition across administrations.”²⁸ Erik Weiman, chairman of Uppsala county council from 2006 to 2014, echoes the sentiment: “The municipality and the county must collaborate to care for our aging population. We need to improve care coordination.”

Stéphanie Treschow, chief operating officer of Villa Nest care homes, describes the issue from the perspective of a service home provider: “The lack of coordination between county councils and municipalities is a critical problem. Our care home, Villa Nest, cannot solve this coordination problem on a systematic level. We can solve the problem for our residents. On a systematic level, I believe the county councils and municipalities should form one single public administration or create a neutral agency that could overrule both county council and municipality.”

Care providers and policymakers work constantly to fill the gaps in the system. If care is to remain divided between county and municipality, care continuity could be improved by restructuring the way primary and specialized care providers communicate and interact. Ideally, healthcare professionals would work *across* silos in teams led by a central entity.

Pia Lagerström, care coordinator for Uppsala Municipality, describes the transfer of a patient from a hospital back into county primary care: “When the primary healthcare clinic agrees to the care plan, the primary care clinic also assumes medical responsibility for the patient. At times we find that the primary healthcare professionals agree to a care plan automatically, without fully understanding it.”

There are other ways of coordinating care for the most fragile people. Doctor Eva Nilsson-Bågenholm, former national coordinator of the Most Fragile Elderly Project, refers to primary care clinics staffed with elderly nurses as an example of best practice:

Each primary care clinic in Sörmland County hires an elderly nurse. This is a nurse from the local clinic who cares specifically for the most fragile elderly. The elderly nurse keeps track of patients at home or in the hospital and can ensure care continuity for the most fragile elderly. The clinics need to identify the most fragile elderly and match those patients with an elderly nurse. Successful clinics achieve great results. The elderly nurse functions as a care manager for these patients. The nurse can call patients at home and ask how they feel and about their prescribed medication. We should have elderly nurses in every primary care facility. That would be a suitable healthcare reform.

This solution presupposes that primary care clinics have hired elderly nurses. The single administration proposed by Stéphanie Treschow merges the two levels of government, local and regional. It may be much more disruptive in the short term, but this is a more sustainable solution.

As it now stands, Swedish municipalities raise taxes to finance care services. Their responsibility is distinct from that of the county councils. Budget silos and work cultures sometimes prevent collaboration. The complicated dance between county and municipality is an inconvenience that Swedish policymakers address every day. Legislation moves slowly in every nation. In the meantime, local innovations are producing remarkable results in Sweden. Municipalities and county councils enjoy mutual savings when they fill the care gaps in a structured way.

In summary, Sweden is a resource-rich nation for long term care, but the coordination of resources remains a pressing issue. The Most Fragile Elderly Project has resolved the problem in some of the more desperate cases, but it has also accomplished much more than that: it has introduced systematic data collection on long-term care services throughout the country; it has improved care quality; and it has empowered nurses and assistant nurses with the help of quality registers. Innovative mobile care teams, such as mobile operational teams, palliative care teams, and mobile doctor services, have emerged in response to the need for better homecare and continuity for those with large care needs.

Erik Weiman remains optimistic. “We have come a long way since I started. In the past, the municipality and the county sued each other. The political leadership in Uppsala County invited the local municipalities to help us solve the problem of care coordination. ... Now, the county and the municipality try to work together.”

Filling the Gaps – mobile Teams

Our guiding principle is to be close to the patient.
(Christina Pettersson, nurse, Mobile Operational Team)

In recent decades, Sweden has seen a groundswell of innovative efforts in care continuity. Although support agents, municipal coordinators, and alternative living environments for those in need of coordinated care all provide solutions to the same problem, perhaps the most versatile among them are the mobile teams of various stripes that have emerged around the country. The efforts of these teams have led to increased care quality and financial savings at both county and municipality levels.

The Västra Götaland County Close Care Teams

Close care is the delivery of healthcare services as close to the patient as possible, preferably in the home. No problem can be ignored at close proximity. Christina Pettersson, a nurse in the Uppsala Mobile Operational Team, describes her team's ethos: "We assume responsibility. We do not complain. We never tell the person that he or she is the problem of other care professionals. We look at every problem. We make an honest attempt to help every person. Other care professionals believe that they will end up with more problems if they assume full responsibility for patients. That is a mistaken belief. To assume responsibility reduces your problems, at least in the long run."

The Mobile Operational Team, the Palliative Care Team, and the Lidköping Mobile Doctor Service are part of a system of close care in Västra Götaland County. The care teams and mobile doctors fill some of the gaps in service delivery in six municipalities: Lidköping,

Götene, Skara, Vara, Grästorp, and Essunga. These municipalities and Västra Götaland County finance the close-care system together.

The Mobile Operational Team provides one point of contact for a patient, assumes responsibility for all patient care, and communicates with that patient's family members. The team consists of a district nurse, a nurse, a doctor, and a part-time conversational therapist. The team currently cares for twenty-four patients. The target patients are those who have multiple illnesses and make frequent visits to the hospital, and who receive basic home healthcare services from the municipality. The Mobile Operational Team administers almost all treatment in patients' homes.

The team has seen remarkable results. Based on initial evaluations, the average saving per patient after the Mobile Operational Team assumed responsibility was SEK 70,000 (about USD 8,000). For one patient, the saving as high as SEK 270,000 (about USD 33,000). True, some patients' costs increased after the Mobile Operational Team assumed responsibility—for one patient, by over SEK 175,000 (about USD 21,000)—yet because of their shared responsibility, the municipality and the county moved resources from inpatient care to outpatient care, and this shift resulted in overall savings.

The Mobile Operational Team improves the quality of care in a number of ways. The team assumes total responsibility for the health and wellbeing of its patients, which creates continuity over time. Patients and healthcare professionals get to know one another. Patients always know where to turn with questions or problems. Even when patients visit other specialists, the Mobile Operational Team remains their first point of contact.

Mobile doctors come to the person rather than the other way around. Team members do a home assessment, and with their understanding of the home environment they can draw up a tailored care plan for each person. Familiarity exponentially improves rehabilitation, since nurses can fine-tune the plan to the particular circumstances of the patient.

The Mobile Operational Team can discharge patients to either the Lidköping Mobile Doctor Service or the Palliative Care Team. Stable patients are discharged to the Lidköping Mobile Doctor Service as not needing the specialized care of the Mobile Operational Team—they have largely recovered, but still require more care than the primary

healthcare system can offer. The most ill people are discharged to the Palliative Care Team. These individuals are expected to die in the near future as a result of natural aging or terminal diseases. The aim of the Palliative Care Team is to relieve symptoms and improve quality of life during the person's final days, again in the home.

As Marianne Alärd, coordinator of the Development Coalition Management Group for West Skaraborg, explains: "The teams cannot direct the individual to other care providers. This helps us overcome problems of care coordination that are endemic to the system elsewhere in Sweden. The teams *must* collaborate with the home healthcare teams from the municipalities."

This model could improve the quality of care services almost anywhere in the world, particularly for those with the most complex needs. Mobile teams fill the gaps in care coordination by assuming full responsibility for the healthcare and social care of patients. They are a mobile centralized service.

Some specialized care professionals in the municipality forget that they share values and objectives with the healthcare professionals in the county. The mobile teams, meanwhile, cultivate a culture of collaboration and mutual commitment. "We cannot be shortsighted," says Alärd. "We care for the same person in the municipality and in the county. We need to find smart ways of doing this. When budgetary issues arise, projects requiring teamwork will fail unless you share common values. Write these values down. Articulate these values. Remind people of these values."

The Mobile Emergency Team

Uppsala Municipality and the county council pooled resources to establish a Mobile Emergency Team. The team treats patients older than 65 who need unplanned, urgent care at home. The Mobile Emergency Team consists of two physicians and two nurses, with one doctor from the county and one nurse with experience in the municipality. The combination of the physicians' medical expertise and the nurses' specialized care experience yields a team more effective than any of its constituent parts. One of the nurses describes the situation before the team came into existence:

Before we established the Mobile Team, municipal nurses had to direct patients to the emergency room unless a doctor visited. This system increased the workload of the emergency room. Few doctors were able to visit the patient at home. Now, nurses know that we can visit the patient so we don't need to send the patient to the emergency room. ... One purpose of the Mobile Team is to support municipal nurses who lack the support of other doctors. Doctors at primary care centers help municipal nurses, but sometimes this support is minimal.

Christina Mörk, a senior geriatric physician on the team, says: "We treat almost anything. Sometimes, we treat serious conditions. We treat patients with chronic obstructive pulmonary disease who have difficulties breathing. We treat wounds. ... We treat patients after falls, minor infections, different types of pneumonia, and patients who experience difficulty breathing. We treat cystitis, usually caused by infections of the bladder. We also perform surgical sutures."

Bringing the emergency room into people's homes has its advantages. Magnus Gyllenspetz, a senior physician on the Mobile Emergency Team, makes the case simply: "Emergency care personnel always prioritize the most ill patients. Individuals who call us have urgent but not always life-threatening care needs. We visit the patient at home. The patient does not need to wait."

To further improve care coordination, the Mobile Emergency Team has placed a nurse coordinator in the emergency room at Uppsala University Hospital. The nurse, who works for the municipality, informs individuals and their families about the Mobile Emergency Team, in case a person requires urgent care in the future. The idea of the embedded municipal coordinator arose during the pilot project. Gyllenspetz explains how the municipal coordinator operates: "Ambulance staff can call our municipal coordinator in the emergency room. Our municipal coordinator looks to see if the patient obtains homecare. ... Our municipal coordinator contacts the municipal homecare organization to arrange homecare for patients that need help at home but currently lack formal assistance." The most common causes of visits to the emergency room by the elderly are general weakness, difficulty breathing, or a fall or injury. During the pilot study, 60 percent of

all patients older than 65 could return home after meeting with the municipal coordinator in the emergency room.

The Mobile Care Team combines mobile doctors with new technologies and specialized teamwork. If other regions were to adopt a similar model, they would need to train physicians and nurses to work together regardless of their organizational cultures. Few nurses and physicians at the primary care clinics in Uppsala know that they can direct the Mobile Emergency Team to patients instead of directing patients to the emergency room. Even among those who know about the Mobile Emergency Team, many still send people to the emergency room out of habit.

The initial investment in training and equipment is substantial. Governments and healthcare providers can set that investment against the long-term benefits of offering urgent care at home. Even when it is all about the bottom line, few people are likely to question the establishment of more mobile teams. On the contrary, most will question why the country has only one such mobile emergency team for the elderly.

The tendency of mobile teams to become *de facto* care coordinators reveals a vacuum in the system. The mobile teams provide exemplary healthcare. They become the touchstone for a patient's entire healthcare portfolio. That responsibility should not rest on the shoulders of a group with uncertain funding.

"We meet the patient in her home environment," says one nurse. "This brings advantages. The doctor takes his or her shoes off in the hallway. We meet the patient on equal terms. We are on patient's home turf. Traditionally, doctors always knew what was best for the patient. I think we take a different approach. We listen to the patient." This philosophy, common among the mobile teams, draws attention to one of the most significant shortcomings of a dispersed system of healthcare: levels of care often mask the needs of a person behind a veil of specific symptoms. We must understand each person's preferences and priorities and thereafter adjust our care services accordingly.

The same nurse continues: "We gauge a holistic picture of the patient's situation. At home, patients are perhaps more honest about their issues. We meet patients when they are more relaxed. This helps us diagnose. We also see what aids the patient may need at home. This

captures our philosophy. We meet the patient at her home and on her terms. We have met patients who contacted us for back pain. Later, we discover that the patient has cancer. We feel that we make a difference.”

eHomecare

People who have tried the Giraffe form a bond with the device. Some people name the Giraffe.

(Åsa Löwing, eHomecare manager, Västerås Municipality)

The mechanical Giraffe follows an aging Swede into his kitchen. The man grabs the metal neck for support while he fills a pot with water and places it on the stove. He walks quietly across to sit down at his kitchen table to rest while he waits for the water to boil. The Giraffe follows.

“Are you breathing okay, sir?” asks the nurse from the screen that forms the Giraffe’s head.

“I’m fine,” says the man. “Thank you for your help. See you tomorrow.”

Long-term care technologies encompass imaginative eHomecare devices—hence the Giraffe—and IT systems for the coordination of care organizations. Sweden has yet to coordinate digital record keeping in healthcare, but it has invested heavily in assistive aids through national programs such as Technology for the Elderly.

Västerås Municipality launched its eHomecare program in 2013. At time of writing, the Västerås eHomecare service offers four products: Arctic Touch, the Giraffe, a camera monitoring system, and a telephone service.

Similar to Skype, Arctic Touch is a telephone with a video screen. The Giraffe is a mobile video telephone. Åsa Löwing describes it:

The previous video telephone was stationary. A homecare staff member steers the Giraffe around the client’s house. Staff members also communicate via a big screen on the mobile Giraffe. Staff members can call the client from the office and look around the client’s apartment. The client can see the caregiver during the conversation. People

who have tried the Giraffe form a bond with the device. Some people name their Giraffe. It becomes a living object, almost. I think more and more people will adopt the Giraffe in the future.

When a staff member calls a client, the Giraffe makes a noise and starts automatically. The client can answer via remote control or by touching the Giraffe. Alternatively, clients can choose an automated answering function. With this function, users do not need to do anything to pick up the phone call from the homecare provider. In this way, the Giraffe can help clients at high risk of falling. The staff can steer the Giraffe around the house and find a client who may have fallen.

The Giraffe aids people with cognitive disabilities who want to live independently. The homecare provider can follow a client to the kitchen and support him while he is cooking or performing other daily activities. Some people use the Giraffe when they go to the bathroom. The Giraffe waits outside. This allows the individual to live independently. ... This capability provides security because the user knows that the homecare personnel are waiting outside on the Giraffe call. The remote caregiver could send someone in case something happens during the visit to the restroom. This feature provides independence and a sense of privacy compared to having someone from the homecare organization present every time the client uses the bathroom.

The camera monitoring system is used for nighttime checkups. Many of the clients need to be checked on during the night to make sure they are sleeping safely and have not fallen when going to the bathroom. The thought of a camera in one's bedroom may strike some as creepy, but in this context, the freedom from physical intrusions by staff, however benign, is priceless. Staff visits at night can be disturbing and confusing, even frightening, for patients living alone: "The clients feel that they can sleep better at night without the checkups," says Löwing. "Everyone wants to sleep well at night. Everyone has a right to feel safe. The camera is not on constantly. The camera is on at agreed upon times. The individual can see when the camera is on. The camera blinks when it is turned on for a few seconds."

From 2007 to 2013, Dr. Raymond Dahlberg worked as a research

and development coordinator for the national program Technology for the Elderly. He cites the cameras as the greatest success of his tenure. “Users have several checkups every night instead of one checkup. The home service staff likes the cameras. A staff member turns on a web camera during the night and watches an individual at home to see that everything is all right. Everyone wins with cameras in home-care.” Magdalena Marklund, program manager at Technology for the Elderly, agrees:

Some people with homecare lie awake at night until the homecare staff arrive for their short checkup. Some wake up in the middle of the night when the homecare staff enter their home. They may be nervous. They may fear that the homecare staff are stealing from them. After the nightly checkup, these individuals wake up. They search the apartment to make sure that their wallet is still there. When they search the apartment, they may fall. The homecare staff have left by this point and cannot provide assistance. Having a person in your home in the middle of the night may be a greater invasion of privacy than a small camera on the wall.

General eHomecare services include day and night supervision, social interaction, reminders, and responses to alarms, but eHomecare providers further customize their services based on the needs of the patient.

According to Dr. Åke Dahlberg, a Swedish researcher in the public sector, eHomecare investments become profitable in terms of savings within just one year. In 2013, the cost to establish eHomecare services for Västerås was SEK 5.3 million (about USD 600,000). A year later, the operating cost to continue eHomecare services was SEK 3.8 million (about USD 440,000). The municipal goal is to reach 300 users of eHomecare in Västerås. With 300 eHomecare users, the estimated net savings for Västerås Municipality will be between about SEK 5.5–20 million (about USD 650,000–2.4 million). The money will be used to hire more staff to provide homecare for even more people.

eHomecare offers more than financial savings. The technology frees patients from constant bombardment by medical professionals at home, and allows a patient’s family to spend quality time with their loved one instead of feeling like healthcare professionals themselves.

“Informal caregivers care for their loved ones every day, all year round,” says Marklund. “We want informal caregivers to discover how technology can help them care for their loved ones. Informal caregivers are important. If they are engaged, the elderly adopt technology faster. We want to ensure that informal caregivers gain the support that they need to remain healthy and strong. We must enable informal caregivers to care for their loved ones.”

Swedish official policy is designed to encourage and help older people to live at home for as long as possible. A matching goal is to increase their autonomy. Technical aids can replace some of the professional caregivers’ home visits, offering freedom and flexibility to both caregiver and patient. Again, as Marklund explains: “Technology can help an older citizen to contact his or her caregiver or primary healthcare center. The caregiver may not always need to travel to the home of the client to check up on them. ... Not everyone wants the social interaction with caregivers several times a day.”

Cameras and alarms can provide extra security for the clients who are living alone. In the words of Guje Boström, an eHomecare user in the city of Eskilstuna: “Before there were alarms, older people who fell could be there for days before someone noticed that they had fallen. I arranged for someone to call my mother every day just to check up on her. That bothered my mother.” Åsa Löwing has noted the same phenomenon: “An individual who has a lot of homecare services might meet ten different people for ten different checkups during one day,” she says. “If some of these can be conducted remotely, this person may feel calmer. It is exhausting, constantly welcoming people into your home. A short video checkup can be less exhausting. After the checkup you can rest.”

eHomecare options empower patients to receive care at home in ways that would have been impossible even twenty years ago. The same staff member can have a face-to-face conversation with a patient once or twice a day, five days a week. This level of continuity would be impossible in homecare reliant on physical visits. We believe that eHomecare, given with consent and correctly designed, is a patient-centered means of supporting clients in their homes.

Henrik Ahlen, a Swedish digital health strategist, argues that the greatest need for eHealth is in the field of chronic illness: “On average,

75 percent of the healthcare budget goes to support chronically ill people. Thanks to modern treatments, many individuals can manage chronic diseases well. Today, individuals sign up for annual or biannual appointments. The appointments are to check the progression of their chronic disease. Individuals who feel fine must still attend their annual checkup. A smart eHealth service can help individuals monitor their condition at home. When the data indicates worsening health, the individual can book an appointment. Specialists have tried this system in Stockholm and observed a 40 percent drop in the number of visits.” This improves access to care at critical times.

This encouraging step lifts eHomecare into the wider eHealth network, but there are more sweeping applications of healthcare technology than the experiments in Stockholm or the eHomecare initiatives by Västerås Municipality. For a dramatic example, we will turn our attention to the eNation of Estonia.

When to Leapfrog – the Case of Estonia

You could implement a similar program, but you do not have the courage.

(Taavi Kotka, chief information officer and deputy secretary, Ministry of Economic Affairs and Communications, Estonia)

As we study the Swedish healthcare system, we conclude that issues around care coordination and data-sharing arise. One country that has found solutions to some of these issues is the Republic of Estonia. With an innovation platform that is specifically designed to leapfrog the obstacles in the path of other countries' development, they have managed to connect healthcare providers, users of healthcare services, and various government departments under one umbrella in their eGovernance system.

Estonia is famous for its eHealth system. The term eHealth refers to digital services used in healthcare. Estonia uses integrated digital services across the board in the acclaimed e-Estonia movement. Citizens of Estonia use these services to vote in elections and to apply for child benefits and driver's licenses, among other things. E-Estonia has reduced wait times for public services across all governmental departments. Sweden and many other countries that want to improve their integrated health systems could well look to Estonia for inspiration. Its system has streamlined permit applications and medical examinations, reduced the administrative burden for companies and citizens across the country, increased national tax revenues, improved the business climate, and, crucially, enhanced the quality of healthcare services.²⁹ Estonian eHealth services include digital prescriptions and digital patient records, as well as application software.

One key to the success of Estonia's eHealth is the comprehensive-ness of the eGovernance of which it is part. Dr. Ain Aaviksoo, deputy secretary general of eServices and innovation in the Estonian Ministry of Social Affairs, explains:

The Estonian digital governance structure has helped us to develop a digital eHealth structure. We did not build a specific eHealth system. We relied on an overall governance structure and added specific requirements for healthcare, such as secure logins and identifications. We built a system based on trust and transparency. The public controls their personal data. A person can see who has access to their data. Users also see who has accessed their data. ... That transparency gives Estonian citizens the feeling of security that their data cannot be misused.

The eHealth Foundation was established in 2005 with funding from the Estonian government. The foundation promotes and develops digital solutions for the national health service in response to three main objectives: streamlined documentation processes; timely, accurate information for healthcare providers; and high-quality patient-centered care for Estonians. The largest of the projects is the electronic health records system—the basic infrastructure for the integration of all healthcare data in Estonia. Digital images, digital registrations, and digital prescriptions all use the same message administration, authorization, and central data storage. Most importantly, every individual patient has access to all of his or her own data. Few countries, including Sweden, offer citizens access to their test results at the same instant as the doctor. “We are witnessing a big shift in healthcare: patient empowerment,” says Henrik Ahlen. Artur Novek, implementation manager and architect at the Estonian eHealth Foundation, agrees:

Medical reports for laboratory test results and radiology test results are also available online. Patients can access the test results at the same time as the doctor. ... Transparency is the key to building trust and engagement in the doctor–patient relationship.

The purpose of the electronic health record is to obtain medical documents. We store detailed information on each procedure. We

store laboratory data as well. The electronic records detail diagnoses. Doctors can digitally sign the patient records. All of this information is centralized. The information cannot be changed once the doctors have signed off. This signature provides a high level of security.

Most countries balk at an overhaul of this scope. Taavi Kotka, chief information officer and deputy secretary at the Ministry of Economic Affairs and Communications of Estonia, believes this is a serious mistake. “Legacy ... is costly,” he says. “Ninety percent of your government information technology budget goes to legacy. Finland still has core programmers using a language that was invented in 1959.” He continues:

You need the right policies. ... [You] need silos. Every ministry is responsible for their information, but they exchange data. Swedes are extremely good at faxing and using older systems. I admire your efficiency with the fax and paper system. In Estonia, everything is automated. In Estonia, queues do not exist. I must teach my children the meaning of a queue. If there is ever a queue, it is because something inconvenient has happened. There will be a huge debate in the news.

As a key figure in the design and implementation of Estonia’s remarkable eHealth system, Kotka’s commentary on how it works is revelatory. Here, he describes ePrescriptions:

I am most proud of our ePrescription system. I think it has been voted the best eService in Estonia for many years. Medical prescriptions affect everybody, while digital signatures are only used for online services. Many elderly people only use digital signatures when they vote. ePrescription impacts everybody. Everybody needs medicine at some time. In most countries, you need to go to your doctor to renew a prescription. In Estonia, you can call your doctor for a renewal. The doctor will send the prescription digitally to the pharmacy. Research indicates that digital prescriptions can reduce the number of abortions. Some women may be uncomfortable asking for renewed contraception, while they feel less uncomfortable calling their doctor.

The doctor can see if patients collect their prescription at the pharmacy. Previously, if the patient claimed that the medicine was not working, the doctor might double the dose. Now, the doctor can see if the person took the medication. Technology could allow us to put a chip in every pill in the future. If you take it, the chip tells the computer that the pill was taken. Doctors will follow the pill. This solves a problem of poor medical adherence. You cannot cheat this type of system. Not only the doctor can see this information. Your family can also remind you to take your medication.

The message for Sweden and the rest of the world is that this technology, partnered with vision, can transform healthcare if the commitment is complete. “You first need a Patient Portal to change in the current system,” says Kotka. “Sweden has good communication platforms, social security identification, and electronic object identification. You need input from another system to create a Patient Portal. In Sweden, you could implement a similar system to Estonia.”

Artur Novek is complimentary about the current Swedish system. He is optimistic about the potential to centralize it digitally, though he warns: “[Sweden’s] regions are the size of Estonia. India is a very big country. ... too big for one kind of central system. Our system is suitable for 5 million people. That is the limit. If more than 5 million use the system, it becomes difficult to manage.”

The skeleton key of Estonian eGovernance is the digital personal identification card. Novek holds up his own:

This is an identification card that I can use to identify myself. Wherever I need identification, I can show this card. It has a chip that I can use for electronic services and to identify myself safely. The card employs two-factor authentication. I need to know my pin code. If I lose my card, nothing happens because the person has to know the pin to use it. ... You apply for this card at the police department.

We use this card everywhere we need a digital identifier for public services. If I want to go to the Patient Portal, I can use my card. There is also mobile identification, but to obtain mobile identification you first need this card. At the end of last year, 5 percent of Estonians

used the Patient Portal. Still, I think electronic usage is quite high. About one-third of Estonians use the card for electronic voting.

Such a digital overhaul was perfectly feasible for a nation that experienced economic liberation in 1991, at the exact moment that digital technology was coming into its own. We believe it remains possible for nations such as Sweden and the US to follow suit.

“I think the key is shared financial responsibility,” says Dr. Aaviksoo. “If you bundle the financial responsibility, healthcare providers must solve the problems together. With shared financial responsibility, care coordination becomes much smoother and creates a demand for information technology to innovate further.”

Barriers to Implementation in Sweden

“Differences in healthcare governance are a big obstacle for the adoption of new eHealth services,” says Henrik Ahlen. “There are twenty-one counties in Sweden. Sweden is a small country with about 10 million citizens. Eighteen of those twenty-one counties are quite small. Each county follows a slightly different set of rules and uses different reimbursement models.”

Another, related problem is the mountain of extant data to be absorbed into any new system. “This data integration is impossible today,” says Ahlen. “The existing regulations prevent the data merge. We lack IT communication tools that can receive patient generated medical data. If you measure your blood pressure at home, this data is unofficial healthcare data. You must go to your primary healthcare clinic to take your blood pressure. The separation between official and unofficial data seeks to ensure high-quality data, but today many home medical gadgets are certified by the Food and Drug Administration or are CE marked. We must solve this practical obstacle.”

Patrik Sundström is program manager for eHealth at the Swedish Association of Local Authorities and Regions. He says the challenge to implementing eHealth is establishing a legal framework. “Legislation is the foundation of our work. Laws can restrict innovation ... We need to communicate and package the message of digitization and eHealth properly. We must move our focus from information technology to

operational issues. We should focus on strategic operational development with the help of digital technology. The technology is the tool, not the final objective.”

No other reform would be more valued and useful on the front lines of care than an integrated eHealth information system. A nurse from the Uppsala Mobile Emergency Team describes the current digital climate and its direct correlation to disorganized care:

Cosmic is our patient journal system. The municipality uses a separate system. We cannot share patient journals online. We fax the journals to one another. We can communicate via an older system called Prator. We use Prator to send simpler messages to the municipality. A new meta system will allow counties and municipalities to upload information to a shared platform. ... We need compatible communications systems. National medical records systems are being developed. However, this process has been underway for several years. We see few concrete results. Since we know that the patient journal systems are incompatible, we have started to conduct follow-up visits. ... As a former municipal nurse, I know that municipal caregivers lack important information because they cannot access the patient record in Cosmic. Patient records contain large amounts of information.

Aaviksoo stresses the wider digital context. “When we introduced eHealth in 2008, we already had six years of digital history. We could file our taxes electronically. We had a cutting-edge eBanking system. This brings up another point of our information technology infrastructure, which enables an exchange of information across the public and private sectors. Each participant adds to the trust of the system.”

Neither Sweden nor the US has this advantage. Their digital systems came of age independently. They communicate in their own languages, across their own networks, connected to their own servers. We believe the Estonian model proves that a national eHealth system is a goal worth pursuing. Demographic trends will soon make it a necessity.

Dementia Care

I find it ridiculous that an individual who suffers from dementia must formally apply for respite care.

(Christianne Simson, Support for Relatives program, Uppsala County)

The World Health Organization estimates that about 36 million people worldwide suffer from dementia.³⁰ The figure is likely to double by 2030 and to triple by 2050. The Commonwealth Fund survey of primary care physicians in ten countries paints a troubling portrait of dementia care and mental healthcare worldwide: “For patients with dementia, those in need of palliative care, and those in need of homecare services, the percentages reporting that their primary care practices are well prepared were typically less than seventy percent and, in many countries, less than 50 percent. For severe mental health or substance use related problems, with one exception (Norway), fewer than half of primary care doctors reported their practice to be well prepared; and in Sweden and the US, fewer than one in six reported that their practice was well prepared.”³¹

Few people who suffer from later-stage dementia can argue for their own care rights, including the rights to self-determination, a normal life, social interaction, and friendships. Care homes sometimes fail to cater to the needs of people who live with dementia. Linda Martinson, manager of a care home in Stockholm, explains:

Our patients still suffer from isolation and struggle to find meaning in life. This is a hard task for my staff to address. Imagine that you arrive at a care home with seven other unknown patients. The other people may not be the people you would choose as friends. Then you have staff coming from other countries, with other cultural competence. You may experience cultural clashes for the first time.

Despite these challenges, life with dementia can still feel like a life worth living. The right care can help a person feel happy, safe, and strong. It can reduce anxiety and instill some sense of normalcy into daily life. Several care homes in Sweden provide this kind of care. “We listen to classical music when we eat to create a peaceful atmosphere that surrounds you,” says Martinson. “We also use different colors. People who suffer from dementia appreciate the contrasts on their plate. Potatoes, meat, and salad are nice colors together. The different colors of the food help our residents to understand what is being served.”

Dementia care in Sweden is among the best in the world, thanks in large part to government-funded research into the disease and its treatment, and the initiatives of Queen Silvia of Sweden to raise awareness in the field. Widespread quality registries also improve research and care. Many researchers in Sweden devote their careers to the study of dementia. A great wealth of knowledge about the physiology of the disease is concentrated there. Dr. Maj Rom, a doctor specializing in gynecology and obstetrics, was the national coordinator of the Most Fragile Elderly Project from 2010 to 2014:

The government of Sweden funded research in healthcare for people who suffer from dementia. Much dementia research in Sweden lies at the forefront of dementia treatments and care systems. We can incorporate more research in other areas. Now, the government of Sweden focuses on healthcare for older patients. The Swedish government budgeted SEK 1 billion, which is approximately USD120 million, per year for the Most Fragile Elderly Project. Before the Most Fragile Elderly Project began, the Social Democratic government in power in the early 2000s allocated funds for projects to improve care for the elderly. 30 percent of the funds went to the county councils. 70 percent of the funds went to the local municipalities.

There are twelve symptoms of dementia [in our survey]. Each person can score from 0 to 12 on each of the symptoms, so the person can obtain a total score of 144 points. We have numerous stories about people who score over 100 points during the assessments, but these symptoms decrease significantly once the patients obtain the correct

treatment. These persons also need less medication once they obtain appropriate treatment for their particular symptoms.

In some cases, nurses can improve quality of care without prescribing medication. For example, a person might dislike bright light. Care providers might need to use a dimmer in this patient's room. Other patients might like music. Care providers might need to turn on the music. A person might be confined to a small room in the care home. The person might want to take walks and stay active. These are simple services that reduce or eliminate some symptoms of dementia. The Symptoms Register helps us to find the cause of the symptoms and to eliminate them.

Stiftelsen Silviahemmet runs a day-care center known for its expertise in dementia care. Lotta Roupe, manager of the day-care center and Silvia Nurse at Stiftelsen Silviahemmet, describes their philosophy: "The objective is to provide the highest possible life quality for individuals who suffer from dementia and for their families. The Silvia Sisters and the Silvia nurses use four main methods."

The first component is control of symptoms. It involves an active prevention and focus on reducing the symptoms of dementia. If an individual starts looking for the bathroom and cannot find the bathroom, a staff member may intervene early to guide that person to the bathroom. This intervention prevents that person from feeling confused, anxious, or frustrated ... Caring for people who live with dementia requires knowing the person, being able to read signals, being able to step in and provide a hand of support, but also being able to carefully reflect upon when to help and when to step back.

The second component of the palliative dementia care philosophy is communication and relationship. To deliver person-centered dementia care, every caregiver needs to take time to get to know the person. ... They do this by spending time and talking about what matters to individuals. The caregivers eat together and sit down to have coffee with visitors. It is important to create trust. The person who lives with dementia must trust you. The palliative dementia care

philosophy is not an 'us and them' divide. The staff members are not viewed as caregivers and they do not view themselves as caregivers. The staff members view themselves as friends of the visitors and communicate in that way. This is an important element of the care philosophy, especially for the young elderly who suffer from dementia. The young elderly do not want to be treated as patients. They want to participate in activities and enjoy some company during the day. They need support, but want to feel normal.

The third component is teamwork among the caregivers. Caregivers need to create relationships with each other ... They need to talk to one another and build relations with other team members at the care home. Caregivers also need to create relationships with important people in the sufferer's life, such as relatives, homecare workers, and other healthcare professionals. Caregivers need to understand that teamwork is a critical aspect of dementia care and that their team is broader than the colleagues at the care home.

The fourth and last component is to provide support for relatives. Stiftelsen Silviahemmet invites family members to the day-care center, educates them about dementia, and makes sure that the wishes of family members are heard. If relatives want to be actively involved and learn about what their loved ones are doing at the day-care center, then the staff members brief them daily. If relatives prefer to have less intensive contact with the staff members, then their wishes are respected. Staff members keep a journal to make sure that they touch base with relatives at least once a month. We communicate with relatives over the phone, by text messages, or by email or other avenues. Stiftelsen Silviahemmet strengthens the role of relatives and ensures that relatives obtain the highest possible life quality as well. This is a critical element in the palliative dementia care philosophy.

Dementia makes it difficult to maintain relationships. Close relationships suffer tremendously. Anyone who has cared for a person living with dementia knows how hard it can be for family members and friends to watch what the illness does. Christianne Simson has worked with relatives of patients since 1998. She had been working with the emergency room at the University Hospital in Uppsala when

she noticed that many of the patients' relatives soon returned to the emergency room for treatment themselves. Simson initiated a support program for patients' families—Support for Relatives. “Let me tell you about a young couple in their thirties,” says Simson.

The wife developed Huntington's disease, a terrible genetic disease. Huntington's disease is a combination of dementia, Parkinson's, and other illnesses. The woman's illness was fairly advanced. The husband had to assume more and more responsibility at home. He abandoned all his activities. He was about to lose it. I used the Caregivers Tool to assess his needs. I asked the husband what he liked. It turned out that he was a musician. He had played concerts all over Sweden before his wife became ill. Music was an important part of his life.

I asked the husband how often he played music. He told me he had not played any music for several years. I explained to him that I thought he should go back to playing music again. I told him that we could apply to the support agent for some help a couple of hours a week so he could go to rehearsals with his band. I explained to him that he would gain energy by playing music. I understood that he derived a lot of joy from his musical interests. Going back to music helped this caregiver a lot. The wife is still alive. She is in her forties now. She is very ill. But the husband has found a way to care for his wife and to enjoy life.

In countries such as India and China, where dementia is not yet a widespread specialization for nurses and doctors, more training from institutions like Stiftelsen Silviahemmet is needed. It will become critical in the near future. Training and education for family members is taken seriously in Sweden, as is the special care that families require as loved ones worsen. In this respect, Sweden provides an ideal model.

The Swedish practice of encouraging individuals to live at home for longer can be comforting for those who live with dementia, due to the confusion that moving to a different home can create. GPS technologies can support some individuals, by offering a link to loved ones in critical situations. This technology is not for everyone, but some prefer to use it at early stages of the illness. Markus Merne, CEO of

Everon, describes how Everon's Vega watch facilitates self-care for a person with dementia while coordinating her caregivers:

The Vega is a wristband watch that uses GPS. The wristband is equipped with an emergency button that the wearer can press to call for help. ... Many caregivers—both formal and informal, professional and family—may be involved in the support of those who suffer from dementia. We connect one watch with the suitable number of people to support the needs of the individual. Everon can connect the watch alarm with family and professional caregivers.

A person living alone at home might choose eHomecare with camera checkups instead of in-person visits exclusively. But dementia creates unique problems of consent. "Someone who suffers from dementia may not be able to give informed consent, or approval," says Magdalena Marklund. "It then becomes the role of a relative to approve homecare via camera. This is an area under regulatory development. If we are to care for an aging population, we need these sorts of solutions."

We need to take privacy concerns seriously and, as far as possible, let each person and caregiver determine whether new technologies are helpful or not. Sweden's strict surveillance laws make approval by relatives problematic. Jeanna Thorslund, a lawyer for the Department of Digitization at the Swedish Association of Local Authorities and Regions, explains: "The Social Care Act, the Personal Data Act, and the Camera Surveillance Act regulate camera checkups in eHomecare. The National Board of Health and Welfare instructs us that we need consent to use technology in care. This is a controversial area. Some argue that an individual with dementia is unable to give informed consent, and we cannot implement cameras for checkups if we lack consent. Others argue that it is possible to implement technologies, such as cameras. ... Some municipalities have developed a model where they continuously seek consent to use technology, and a staff member documents when he has obtained consent. This is a good model."

Many people go years with cognitive impairment before receiving a dementia diagnosis. This may be a side effect of the dispersed system of care, in which few healthcare professionals have continuous contact with a patient. Constant exposure is indispensable for detecting

early symptoms and behavioral changes. And Martinson notes the importance of continuity of care even after diagnosis:

We match those who have obtained a dementia diagnosis with a contact nurse. The contact nurse stays in contact with the person throughout his or her life. The nurse also keeps in contact with the person's relatives. The contact nurses are like a lawyer for the patient. On the first day at the care home, the contact nurse writes an implementation plan together with the person's relatives. The plan covers the rights and interests of the person. The plan also outlines the person's routines. All employees have access to this implementation plan.

The Swedish Dementia Register (SveDem) is a national register set up to improve the quality of dementia care. The register encourages early investigation, diagnosis, and continuous observation of dementia. National stimulus funds were directed to providers who reached certain registration rates in the register. Between 2011 and 2014, the number of affiliated health centers rose from 82 to 880. In 2011, about 500 patients were registered in the primary care system with newly diagnosed dementia. This number grew to almost 19,000 in 2014. The Swedish care model has systematically developed these tools and data collection to drive research in the field.

The number of patients with dementia who completed annual follow-up assessments in 2011 was negligible; this figure jumped to about 15,000 in 2014. In 2011, around half of the people with dementia had undergone a basic examination in the primary care system, compared to 66 percent in 2014. The percentage of persons who received an unspecified dementia diagnosis fell from 50 percent in 2011 to 36 percent in 2014. The number of persons prescribed antipsychotic medication decreased from 7 percent in 2011 to 4 percent in 2012. This is a good improvement.

To sum up, care and support for those living with dementia has improved remarkably in Sweden. The best practices cater to the needs of each individual. They have moved to a model of demand-based care, providing services that clients value. The best practice providers focus on the individual, not on the disease. These care providers consider

patient engagement and recognize that the patient is an expert on the disease.

When healthcare professionals cannot treat an illness, like dementia, they look at reducing the symptoms of the illness. They focus on creating quality of life for people. What we have seen in Sweden is that the best examples consider a care home to be first and foremost a person's actual home and secondly a workplace for care professionals. In a series of case studies available at www.accessh.org from Denmark, Norway, and the Netherlands, we develop these and many other aspects of long-term care further.

Devoted professionals like Linda Martinson improve care methods and continuity of care every day. We would recommend care homes in other parts of the world adopt the practices exemplified by the likes of Stiftelsen Silviahemmet. Each person living with dementia is unique and has different care needs.

"It is also important that we think of our patients as palliative care patients," says Martinson. "Care homes do not have the goal of healing their patients. Instead, we create quality of life. Our patients have multiple diseases, or else they would not be here. We must create a safe environment where we can ease the patients' symptoms."

Atul Gawande argues that a nursing home is a home, not a place where nurses go to work. We need to listen to the priorities of the individual because otherwise that person's physical strength and autonomy may be lost.³² Populations are aging worldwide. Dementia may take on the complexion of an epidemic if governments do not begin laying the groundwork for large-scale care now. We encourage them to look to Sweden as a leader and example.

Conclusions

I find it hard to work in systems that do not work.
(Dr. Jesper Poucette, home healthcare physician, Lidköping)

Demographic change is a defining issue of our time. An aging society is considered a successful society. As the number of people requiring long-term care rises, so too will the pressure of providing and coordinating that care. In Sweden, an excellent decentralized system has proven itself remarkably adept at long-term care, dementia care, and innovative change at the local level. This, we argue, is a system so good that the professionals in it never fail in their hopes of improving it. Swedish citizens have come to expect nearly free healthcare. They have also come to expect that care be of the highest quality.

Swedish physicians, nurses, and administrators deliver superlative healthcare despite the shortcomings of the system. Dr. Jesper Poucette articulately sums up the attitude of his fellow professionals:

I am impatient. My lack of patience motivates me to improve systems. I want to influence my work environment. I want to have the freedom to change aspects that I dislike. I like the idea of close care. Close care describes care delivered as close to the patient as possible, preferably at home. I was frustrated with the healthcare system for the elderly and disabled patients. The large gap in the system prevented my colleagues from doing a good job.

Throughout Sofia Widén's wide-ranging interviews with Swedish healthcare professionals, this was the prevailing stance on care. The system is excellent, well-funded, and so close to ideal that the parts that fail to work are excruciating to those on the ground. Most of those interviewed had taken some form of action to make the system better. This, we would argue, is the sign of a healthy healthcare culture.

Poucette responded by developing the Lidköping Mobile Doctor Service in Västra Götaland:

My idea was to add a physician to the basic home healthcare team that is run by nurses. The healthcare reforms divided responsibility of care between counties and municipalities. Physicians work at the primary healthcare centers. The doctors do not follow patients to their homes. The municipal nurses help patients at home. These nurses do a great job, but sometimes they need help. When doctors work at the primary care clinic, they tend to stay in the primary care clinic. ... The idea with the Patient Responsible Physician was to provide one point of care contact for the patient. This structure does not [currently] work for patients who receive home healthcare. Doctors lack the overall picture for those patients. The nurses provided the continuity. We wanted to reform this system. We had to reform the system to encourage doctors to leave the primary healthcare clinic.

Continuous care is a concern on all fronts in the Swedish healthcare system. The efforts of professionals such as Jesper Poucette, Magdalena Marklund, Linda Martinson, and the various mobile units have already gone a long way in introducing continuity and consistency to the provision of care for the elderly with chronic illnesses.

Dr. Maj Rom helped found the Most Fragile Elderly Project with this in mind. "We needed to improve healthcare for the most fragile elderly," says Rom. "We had a good understanding of this need when we launched the project. We agreed on the objectives. ... Every year, we developed guidelines for the regions and the municipalities to align with the agreement with the government." The healthcare systems of high-income countries are rarely designed to cater to people suffering from multiple chronic conditions. Rom says reformers must create an environment in which reform becomes attractive: "We informed the regions and municipalities of the Most Fragile Elderly Project and that it would provide payment for performance. We explained what kind of funding the county councils and municipalities could receive."

Swedish healthcare professionals are making the most of an excellent system. The need for innovation does not imply brokenness. We would argue that the determination to succeed indicates an atmosphere in

which professionals care about their patients and believe success is within reach.

Long-term “care has changed in Sweden,” says Magdalena Marklund. “In the past, we had ... more nursing homes. Today, we support the ability of individuals to stay at home longer with homecare services. In Sweden, you live at home until you are very ill. You stay until you cannot live on your own. We provide homecare services up to ten times a day to support people at home.”

By way of conclusion, we would like to draw attention to the needs that will soon become central to long-term care in Sweden and around the world.

Mental Health

High-quality care encompasses all aspects of wellbeing, from the absence of physical and mental pain to the certainty that individuals feel part of their community. Still, integration of social care and medical care is an ongoing process. Some individuals who live at home alone feel lonely and depressed. A recent article by Holmén et al. describes a study of over 700 people aged 75 and over living in Stockholm: “Thirty-five per cent experienced loneliness. A higher percentage was found among women. A gradual increase in loneliness was found up to the age of 90, after which it leveled off. Persons living together with a partner experienced less loneliness. There were no significant differences between those with and without children.”³³ According to Marielle Nilsson, vice unit manager of Sjöglinten Short-term Care Home, homes need to focus more on social and mental health issues:

We need a psychologist at our short-term care home, as well as a conversational therapist. The people who stay with us are traumatized. They come from hospital. For some of them, it has been their first time in an ambulance. ... Some patients suffer from fall-related injuries. These individuals need to talk to someone about their injury. These individuals need to cope with their trauma. Some patients have had strokes. They need physical rehabilitation and they need to discuss the incident with someone. Some individuals have suffered a heart attack. They also need someone to talk to.

In many cases, caregivers treat patients' injuries, but neglect to address the psychological impact the experience may have had. Care homes, homecare organizations, and short-stay homes may all see great improvements in patient satisfaction in the future as they begin to offer conversational support and hire psychologists onto their staff.

Quality of Life

Carina Kumlin explains how her municipality uses Health Coaches to encourage active lifestyles and social networks to reduce depression and anxiety: "Health Coaches is a web-based tool for seniors. You can work out at certain meeting points. You can also watch a training program at your computer at home if you prefer to work out independently. We focus on physical meeting points and on restaurants for older residents. We believe in activity. We try to match the person with whom they can walk. We try to encourage the pensioners to go out to restaurants, to work out before or after the meal, and to meet others. We try to avoid individuals eating prepared meals at home."

Atul Gawande describes how our care services often focus on medical conditions instead of on quality of life. In the last years of our lives, he says, we often receive medical treatments that weaken our bodies and minds. At an advanced age, we do not always see the benefit of this medical treatment. Many of us spend our last weeks in regimented intensive care units or nursing homes, isolated from everything that matters to us in life.³⁴ By listening to what matters to the individual, and by filling lives with meaningful activities, we can change this. By encouraging more active lifestyles, caregivers may be able to reduce loneliness among patients and increase their quality of life. The future of long-term care will focus on improving the quality of life by looking at what matters to people instead of blindly focusing on what might be wrong. This goes for all people who need support and care, no matter their age.

Training in Homecare

It is our opinion that many healthcare services will soon be delivered at home by care professionals, or even by the patient with the help of technology. That does not mean that the need for better-trained

homecare physicians and nurses is not growing exponentially. It is. Dr. Patricia A. Grady, researcher at the National Institute of Nursing Research in Bethesda, Maryland, explains: “To best meet the needs of an aging population and to improve the health of older adults, it is critical to train future nurses and nurse scientists in the field of aging.”³⁵

Demand for geriatric nurses and physicians is likely to grow substantially in the coming years in high-, middle-, and low-income countries. This is a universal problem, in no way unique to Sweden or Scandinavia. Åsa Löwing, a former project manager at eHomecare Västerås, emphasizes that new technologies in care will not lead to staff reductions, as one might imagine: “There is no way we can cut staff in homecare organizations today. The demand for homecare far exceeds the supply. We are aging, and our aging population requires homecare. This trend will continue.”

The number of individuals who will require assistance in the future will create a large demand for assistant nurses, nurses, and geriatric physicians. Ann-Sophie Holgersson, manager of Grind Care Home, points to the lack of geriatric physicians in Sweden: “Geriatric physicians from TioHundra, the care company, come to our care homes. We find it difficult to find geriatric physicians today.”

Active government policies can attract individuals into the care sector. The adoption of new technologies may also make long-term care more attractive as a career choice. As Åsa Löwing argues, “technology can improve efficiency and make these sectors more attractive to work in. As with other sectors in the economy, we need technology. Technology is fun. ... Why should we not use technology when every other sector uses it?” Moving forward, we will find that the introduction of new technologies and the training and retention of staff often go hand in hand.

Human Resource Management

A great range of skills must come together to create quality care, according to Ann-Sophie Holgersson: “We employ nurses, occupational therapists, and paramedical staff. We also employ a physiotherapist. The paramedics, occupational therapists, and the physiotherapist visit the short-term ward three days per week, but we need their support

every day. I would like there to be a physiotherapist, an occupational therapist, and a paramedical staff member at my short-term care home every day. This would improve the rehabilitation of patients who stay with us.” When this eclectic group of care professionals works together as a team, they improve the quality of care. In the future, training will focus on improving communication and teamwork among disparate disciplines.

Ulrika Carlsson, manager of homecare for TioHundra, sees an urgent need to train more homecare workers: “The homecare sector is growing. As more care homes open, homecare providers demand nurses and assistant nurses. Last year, two new care homes opened in Norrtälje. We compete with them for the same individuals. We compete for staff.” The demand for homecare workers clearly exceeds the supply. As large and populous countries such as India and China develop new care services, those countries will face similar shortages.

Final Thoughts

Long-term care will remain a significant sector in the foreseeable future. It remains to be seen whether other nations will respond with the speed and facility of Sweden. It is our belief that Swedish healthcare provides an ideal litmus test by which other nations can judge their own efforts in healthcare. It is our hope that this book will be a resource from which leaders can draw ideas and inspiration as they adjust to the reality of the dramatic demographic change that is already upon us.

Notes

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Further Reading

The full texts of the further reading for each chapter are available at accessh.org/agingwith-dignity.

Chapter 2

ACCESS Health Report, “Swedish Forum for Welfare”.

Chapter 3

“Case Study: The Most Fragile Elderly Project”.

“Interview with Maj Rom”, about Swedish healthcare and long-term care.

Chapter 4

“Coordinating Care for the Elderly: Interview with Carina Kumlin and Pia Lagerström”.

“Interview with Erik Weiman”, about future challenges.

“Interview with Stéphanie Treschow”, about entrepreneurship.

“TioHundra Case Study Part One: Company Overview”.

“TioHundra Case Study Part Two: Care Homes and Integrated Elder Care”.

“TioHundra Case Study Part Three: A Focus on Quality”.

“TioHundra Case Study Part Four: Homecare, Home Healthcare, and Integrating Care for the Elderly”.

“TioHundra Case Study Part Five: A Changing Organization”.

Chapter 5

“Case Study: The Lidköping Close-care system and Mobile Teams”.

“Case Study: The Mobile Emergency Team for the Elderly in Uppsala”.

Chapter 6

Dahlberg, Åke, “Is the Use of Welfare Technology Profitable?”

“eHealth Technologies and the Future of Healthcare: Interview with Henrik Ahlen”.

“eHomecare: How Technology is Revolutionizing Homecare in Sweden”.

“Interview with Magdalena Marklund”, about the Swedish government program Technology for the Elderly.

“Technology for the Elderly: Focus Group”.

“Technology for the Elderly Program: Interview with Raymond Dahlberg”.

Chapter 7

ACCESS Health Report, “Case Study: The Estonian eHealth and eGovernance System”.

“eHealth in Sweden: Interview with Patrik Sundström”.

Chapter 8

ACCESS Health Report on the lecture by Jeanna Thorslund, “In the Name of the Law: Harmonizing Legal Requirements with the Needs of the Welfare Sector”.

“Aleris: Improving Dementia Care and Care of the Elderly”.

“Interview with Markus Merne”, about telecare technology.

“Stiftelsen Silviahemmet: A Palliative Approach to Dementia Care”.

“Supporting Relatives and Informal Caregivers: Interview with Christianne Simson”.

About ACCESS Health International

ACCESS Health International is an independent, non-profit think tank that works for the provision of high-quality, affordable care for all, including the chronically ill. Our method is to identify, analyze, and document best practices in helping people, and to consult with public and private providers to help implement new and more cost-effective ways to offer care. We also encourage entrepreneurs to create new businesses to serve the needs of this rapidly expanding population. Our goal is to inspire and guide healthcare professionals and legislative leaders in all countries to improve care for their own people.

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