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Preparing for
an Elder Friendly Hong Kong
共創長者更美好明天



賽馬會長者計劃新里程
A Jockey Club Initiative for Seniors





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CADENZA Symposium 2007

Introduction

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The Faculty of Social Sciences of The University of Hong Kong and The Hong Kong Jockey Club Charities Trust jointly presented the “CADENZA Symposium 2007: Preparing for an Elder Friendly Hong Kong” on January 8-10, 2007. The Symposium brought together over 500 participants, including renowned scholars from Hong Kong and abroad, professional practitioners from non-governmental organizations, government departments, the Hospital Authority and senior citizens. The 3-day Symposium officially kicked-off the educational component of the CADENZA project.

The CADENZA symposium was the first international, cross-disciplinary, academic and professional symposium co-hosted by The Hong Kong Jockey Club Charities Trust and The University of Hong Kong (HKU). The Opening Ceremony was hosted by Professor Lap-Chee Tsui, Vice-Chancellor of HKU, and Mr William Y. Yiu, Executive Director, Charities, The Hong Kong Jockey Club, and was attended by distinguished guests including Dr the Hon York Chow, SBS, JP, Secretary for Health, Welfare and Food, and Dr the Hon Leong Che-hung, GBS, JP, Chairman, Elderly Commission.

Professor Lap-Chee Tsui welcomed active exchanges of experience and insights, and the fostering of a vibrant research culture effective and relevant for our society. He said the CADENZA symposium “marks the formation of a platform for long-term collaboration, interaction and exchange of expertise amongst academia, social enterprises and government for building an elder friendly Hong Kong.”

Mr. William Y. Yiu explained that CADENZA: A Jockey Club Initiative for Seniors was launched by The Hong Kong Jockey Club in May 2006. The project name is an acronym for “Celebrate their Accomplishments; Discover their Effervescence and Never-ending Zest as they Age.” CADENZA, which is a musical term for a virtuoso solo passage near the end of a concerto movement, is used figuratively to refer to the apex of one’s life and one’s cumulative accomplishments. The CADENZA project is therefore designed to foster positive community attitudes towards our elderly people and improve the quality of care and quality of life for them.

Officiating at the opening ceremony, Dr the Hon York Chow noted that in designing elderly policies, one had to understand the basic needs of our elderly, which he summarized under three main categories, that (1) the elders need to have both physical and mental health to gain independence; (2) they would like to have the care of their family members; and (3) the elders have to be made to feel that they have the potential, ability and interest to make their lives worth living. To meet these needs of our elderly and to provide them with the best environment, the Government, service providers, academia and non-governmental organizations should work together. He concluded that the CADENZA project could play an important role in this respect.

Dr the Hon Leong Che-hung in his keynote address said, “Experiences tell me that our elders would like to remain active, to project a positive image and to age at home. Ageing should never be equated with uselessness,” he added, “the well-being of our elders depends very much on a partnership amongst the Government, the non-governmental organizations and the business sector.” The CADENZA project could serve as an initiative to achieve this goal.

Chapter 1

**Understanding the Ageing
Experience:
A Life Story Perspective**





Chapter 1.1

Population Ageing and Longevity: From Global to Local

Professor Ada C. MUI

Columbia University School of Social Work

In the next 50 years, the number of older persons in the world will nearly quadruple, growing from about 600 million to almost 2 billion people. Today, 1 in every 10 people in the world is aged 60 or older. By 2050, that number is expected to be 1 in every 5, and by 2150, it is expected to be 1 in every 3 (United Nations, 2002). In some developed countries and countries with economies in transition, birthrates have fallen below replacement levels; this means that the number of older persons will be the greatest in developing countries, where the older population is expected to quadruple over the next 50 years. The ageing of the world's population is a matter of concern for everyone - all generations in all countries, all sectors (private, public, nonprofit, businesses, medical, & social services), and all communities. This transformation in the composition of the population will have profound effects on every aspect of life - for individuals and for societies. Hong Kong is no exception. According to Hong Kong census population projections, up to 27% of the city's residents will be 65 or older by 2033. This is an increase from about 796,000 in 2003 to more than 2.26 million in 2033. In preparation for the ageing of its citizens, Hong Kong, like many other ageing communities worldwide, must be increasingly elder friendly. The first step of this elder-friendly community-building effort is to start educating and training the minds and hearts of all people. Workforce preparation for all professions and services are critically important. CADENZA: A Jockey Club Initiative for Seniors project has been designed to foster positive community attitudes towards older people and improve the quality of care and quality of life for Hong Kong elders through innovative training and community programs. The CADENZA 2007 symposium was the first citywide training program of the CADENZA project designed to educate the whole community across sectors on a proper mindset in the preparation for Hong Kong's population-ageing phenomenon.

CADENZA Symposium Conceptual Framework: Environmental and Narrative Gerontology

The symposium was conceptualized based on the environmental gerontology and narrative gerontology frameworks. Environmental gerontology is a multidisciplinary field that examines the impact of environments on quality of life among older people. Recent gerontology developments in Europe and the United States have advanced and integrated these concepts in geriatrics, social work, nursing, psychology, geography, and many other related disciplines. Time dimensions and active use of space are essential for understanding ageing individuals and microenvironments as well as changing populations and macro environments. Research has found a positive correlation between an elder-friendly environment, on the one hand, and quality of life and quality of community care, on the other (Golant, 2003). The researchers found that older people were more likely to enjoy autonomy and independence if the environment was elder friendly. With its proven responsiveness to social and policy priorities, environmental gerontology is now providing strong conceptual and empirical bases for advancing healthy ageing and elder-friendly societies.

Elder-Friendly Community is an International Agenda

The International Plan of Action on Ageing (United Nations, 2002) has confirmed “ensuring and enabling supportive environments” as one of the three major priority areas. The Research Agenda on Ageing for the 21st Century, produced by the United Nations Office on Ageing and the International Association of Gerontology (2002) for the Second World Assembly on Ageing, lists research priorities that address environmental determinants of healthy ageing and quality of life. If governments, markets, and the public at large are well informed by good research, they can create and preserve environments that effectively and efficiently enable vulnerable older people to maintain their identity, independence, and well-being. Action on behalf of older people benefits greatly from a foundation of research-based knowledge and theory in environmental gerontology.

In the United States, the concept of an elder-friendly community is focused on ensuring that a community’s elders have a sense of well-being brought about by dealing effectively with life’s changes and challenges, by sustaining positive, meaningful, and dynamic relationships, and by living with purpose and joy, while remaining in their communities and homes as long as it is safe and practical. In order to prepare for population ageing in Hong Kong, it is important to start thinking about and planning to make Hong Kong elder friendly. The commitment to make Hong Kong an elder-friendly community requires all stakeholders across sectors (government, private, business, NGOs, health, medical, social services, senior citizens, family members, and community leaders) in the community to take steps to build such a community. The primary objective is to provide a friendly, supportive environment for our elders (who are, in fact, us, our parents, and our friends) so that they can feel a sense of security, of being supported, of being safe, and of belonging as

well as have a motivation to engage. It is assumed that a community that values its elders will be a strong community for all generations. Coupled with the commitment to make Hong Kong an elder-friendly community is the reality that the lasting success of the process will totally depend on the network of individuals and organizational relationships built along the journey. In the United States, many communities are working very hard to increase awareness of impending increases in the population of adults over age 65 living in their communities; to encourage local communities to assess their own elder friendliness; and to engage research and community groups to develop elder-friendly assessment tools. Many communities from across different States are encouraged by the larger community to become “certified” as elder-friendly communities and have the continued commitment to improve the quality of life for their elders. In some other places, the elder-friendly community is a network of organizations that work collaboratively to enhance the community’s capacity to respond to elders from a macro perspective.

As its ageing population increases and its baby boomer generation reaches retirement, Hong Kong can anticipate greater challenges in creating physical and social environments that support the needs of these retirees. In order to develop an elder-friendly Hong Kong, to assess the community’s elder friendliness and to undertake planning and action steps to build it, the Hong Kong community, across sectors, needs to be educated on what it means to be elder friendly. To begin the process of building an elder-friendly community, multiple stakeholders, both public and private, need to be involved. These stakeholders include (1) the government department officials, NGO leaders, and community leaders; (2) planning and zoning departments; (3) and any other entity in a community that affects physical and living environments and the operation of programs. In addition, those who have special expertise in matters related to ageing, those who serve the older population, those who are emerging elders, as well as the public at large, should be part of the process. Preparation for an elder-friendly Hong Kong is a joint effort that requires participation from people and organizations across all sectors.

Social Integration of Older People and Elder-Friendly Community

One of the primary goals in establishing an elder-friendly community is to foster social integration instead of social segregation of older people. If older people can use, manipulate, or perform tasks in the environments with which they are familiar, they will experience a sense of autonomy. It is clear that the environment can facilitate or impede activities that are valued, or necessary for older people. The majority of older people are healthy and mobile, but a small percentage of them may be physically challenged. In many cases, a person with disability can still be functional, but if the environment has a lot of barriers, the environment itself is disabled. If restaurants or public facilities are user friendly, with easily accessible ramps and enough space, any person with special needs, regardless of age, will be able to access and use them. What is elder friendliness? Who defines it? It is consumers, service users, businesses and social services. Therefore, older people’s own views and intentions are essential for understanding the processes by which they choose in

various environmental settings. This understanding is an important paradigm shift because present research in the field concentrates on a range of “snapshots” rather than the time sequences that better characterize people’s lives. Gerontologists in this era suggest that people’s experiences of a current environment are influenced by the context and meaning of their past environments as well as by their anticipation of the future. Further, a given environmental feature or change can have either positive or negative impacts on older individuals and their sense of self. Indeed, the meaning and use of home can be inseparable from life continuity and identity. Finally, personal changes in the competencies and other characteristics of older people both influence and interact with environments and their consequences. In preparing for population ageing in Hong Kong, we need to understand that the ageing process itself must concern time and that lifespan perspectives have always been central to gerontology.

Research in the field must constantly face the challenges and benefit from the insights of multidisciplinary perspectives in understanding and resolving “problems” important to the lives of older people. More recently, environmental research momentum has been driven by the social and government priority accorded to community care, caregiving, self-care, health promotion, and related concerns for proactive older people who wish to stay healthy and at home. Broader social trends and policy directions can also be influenced significantly by research on ageing and environments. The social and political moves towards an “age-friendly” society, now prominent on the international stage, can be traced fairly directly back to international research showing environmental influences on ageing experiences.

What Do We Do to Prepare for an Elder-Friendly Hong Kong?

The mission of CADENZA is to enable our elders to live more vibrant lives, so we need education and programs to make that happen. The friendly environment for our elders not only comprises their physical or external community environment, but also concerns their social, family and emotional environments as well as their inner psychological needs. Physically, an elder-friendly community will be able to fulfill elders’ needs in the following areas:

1. Address basic needs: *sense of security*
2. Optimize physical and mental well-being: *sense of satisfaction*
3. Maximize independence/autonomy: *sense of choice/freedom*
4. Promote civic and social engagement: *sense of meaningfulness*

A community’s level of elder friendliness determines elders’ quality of life. An elder-friendly community requires sound town planning and intelligent design. Achieving this will require collective wisdom and effort across all sectors and among all stakeholders in Hong Kong: government organizations, NGOs, transportation systems, private businesses (food, clothing, real estate, nutritional food products, leisure, etc), and grassroot organizations.

The environmentally, emotionally, and socially friendly community will be one that provides elders access to community resources and services as well as an environment in which they can enjoy freedom and convenience. This approach to community building, both physically and socially, will make elders feel respected and welcome in the community.

An Elder-Friendly Community: A New Mindset and a Caring, Respectful Attitude

In addition to making the community environmentally friendly, it is extremely important to understand how to create an emotionally friendly environment. We need to recognize and respect elders as individuals who each have a full life history, like a book with amazing contents. We need to understand that elders have made enormous contributions to their families and to the community, regardless of their physical appearance or the way they are perceived by society. We also need to change our mindset and attitude towards elders; without them, we would not be here today. They are our role models - heroes and warriors of life - and they have made countless sacrifices for their families, without ever vacationing or retiring. Does the community recognize the value of elders and treat them with respect and appreciation, so that they can live happier and more fulfilling lives? Public education and advanced professional training in gerontology is very important. We need to prepare human minds because knowledge is power. Many people, including elders, have misconceptions and biases about the ageing process and older people. Ageing is not a problem but *ageism* is. In this presentation, we do not have enough time to talk much about gerontology. One of the most important cornerstones of gerontological knowledge is that ***normal ageing and disease are two different processes***. In the normal ageing process, disease is not inevitable. If family, elders, or elder care professionals assume that disease is part of the normal ageing process; elders may be less likely to receive timely, quality treatment for illness. If service providers do not value elders, they are less likely to provide vigorous intervention and preventive medicine for them. Disease requires medical intervention regardless of the patient's age, and older patients can benefit from proper medical procedures just like everyone else.

For example, Dr. Michael E. DeBakey, of Baylor College of Medicine, Houston, underwent cardiovascular surgery in 2006, when he was age 97, he is back at work now. Who is Dr. Michael E. DeBakey? On May 28, 1965, *Time* magazine featured him on its cover for his pioneering work and innovations in cardiovascular surgery and the artificial heart. Over the past 60 years, Dr. DeBakey has changed the way heart surgery is performed. One of the first to perform coronary bypass operations, he trained generations of surgeons at Baylor; operated on more than 60,000 patients; and in 1996, was summoned to Moscow by Boris Yeltsin, then president of the Soviet Union, to aid in his quintuple heart bypass operation. In 2006, Dr. DeBakey made history in a different way - as a patient. He is the oldest survivor of his own operation, proving that a healthy 97-year-old man can endure the toughest medical procedure. Dr. DeBakey's junior colleagues initially refused to do the cardiovascular surgery on him because, not believing that a 97-year-old unconscious patient

could survive the surgery, they worried that he might die on the operating table. When Mrs. DeBakey insisted the medical team do the surgery to save him, they determined to give him the best surgery, the best postoperative care, and the best rehabilitation program. Mrs. DeBakey's intervention is an example of the important role of family support, and the junior colleagues' initial refusal is an example of ageism at work. Many people in our society value older people less than younger ones. Some doctors treat older patients with less vigor than they do for younger patients because they do not believe that older patients can benefit from medical intervention. This is not just an ageism issue but also a human rights issue. Love and respect come from the heart, and people need to be educated to understand that each elder is valuable and a unique life book with a life story. Unless we open that life book, we will not understand and appreciate what kind of life journey each elder has had. To understand each elder's life history, narrative gerontologists advocate for a life story narrative approach. In the next presentation, Professor Denise Burnette will give a more detailed discussion about the life story perspective.

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Chapter 1.2

Understanding the Ageing Experience: A Life Story Perspective

Professor Denise BURNETTE

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Things have their root and their completion.

Affairs have their end and their beginning.

To know what is first and what is last

will lead near to what is taught in the Great Learning.

-Confucius, The Great Learning, II: 130-2

Estimates from 2002 World Health Organization (WHO) data show that life expectancy at birth for men and women in Hong Kong SAR are 78.0 and 83.9 respectively - the highest life expectancies for men and second highest for women in a ranking of 191 WHO member states (HKSAR, 2003). Perhaps even more significant for planning purposes, Hong Kong citizens enjoy one of the highest healthy life expectancies in the world. Using the same 2000 WHO health assessment data, demographers (Law & Yip, 2003) found that healthy life expectancy (years lived without premature mortality or disability) of Hong Kong men (70.3 years) is surpassed only by men in Japan and Switzerland, and Hong Kong women (75.7 years) were second only to their counterparts in Japan.

The purpose of this symposium was to initiate efforts to prepare Hong Kong for this rapidly ageing, relatively healthy population, particularly in terms of enhancing the city's status as an elder-friendly community. As Professor Mui suggests in the introduction to these proceedings, such a community may be characterized as one which 1) meets the basic needs of its older adults; 2) optimizes their physical and mental well-being; 3) maximizes their independence and autonomy; and, 4) provides opportunities for their civic and social engagement. In order to effectively plan for the needs of older people in these essential quality of life domains, practitioners and policy makers must understand the nature and character as well as the magnitude and scope of Hong Kong's current and near-future cohorts of older people.

Narrative methods, and more particularly life story narratives, offer an opportune window into the subjective dimensions of human experience. Josselson (2006) describes the aim of narrative research as striving to preserve the complexity of what it means to be human and to locate its observations of people and phenomena in society, history and time. Though long the dominant purview of the humanities, social scientists have recently turned their systematic attention to these methods to examine the inextricable linkages and transactions between personal biographies and their larger structural contexts (see Czarniawska, 2004).

In his seminal contributions to the literature on narratives in cultural psychology, Jerome Bruner addresses the central question of how people create meaning through narratives about their life experiences within the contexts of culture. It has been asserted that this body of Bruner's work has been foundational in the development of the field of "narrative gerontology" - a field that enables us to explore the "local spheres of meaning" (Gubrium & Holstein, 2002, p.20) that shape the everyday lives of older people.

James Birren concurs, and speculates that the upsurge of contemporary interest in personal narratives reflects a desire to round out the scientific and experimental study of ageing. In his foreword to Kenyon, Clark, and DeVries's (2001) book titled *Narrative Gerontology*, Birren notes: "The world has many accounts of what ageing looks like from the outside, but we have little insight into what ageing looks and feels like from the perspective of older adults." He continues, "questions about what makes life worth living to individuals are answered only by asking the individuals themselves" and narrative gerontology thus seeks to reveal the "inside view" of ageing people's lives through the stories they tell (p. viii).

It is in this spirit that I use the life story narrative of a Hong Kong woman who was born in 1949 to illustrate the utility of life stories in planning for an elder-friendly city.¹ Specifically, the objectives of my presentation are to: 1) demonstrate the universality and the uniqueness of human development and ageing; 2) consider how broad socio-cultural and historical contexts influence human development across the life course; and 3) show the use and prospects of life stories for building theory and for informing professional practice and public policy-making. I will begin with a brief overview of key features of life stories as a specific genre of narrative method.

¹ Space limitations in the Symposium Proceedings preclude the inclusion of detailed information on this particular life story narrative.

Life Story Narratives

In his influential book titled *Acts of Meaning*, Bruner (1990) argues that there are two basic intelligences, or modes of cognitive functioning, which use different types of causality to connect events. The first, a logico-scientific modality seeks overarching laws to explain connections between and among events, while in the narrative mode; the mind uses language to link particularistic events in the form of stories. In order for you to make sense of our experience, we need to be able to explain things and to make connections between events. The narrative process is a cognitive strategy that enables us to achieve these tasks by structuring and organizing our everyday lives into temporally meaningful episodes that are connected with a plot. Narrative plots typically reflect human purpose and desires as well as the opportunities and limitations posed by physical, cultural, and personal environments. An awareness of time and change are thus essential features of narratives, as are the goals, motives, and agents who help to shape the plot.

A genre of narrative, the life story seeks to understand human experience across the life course and human development within the context of broader social change. The focus of life stories is not the autobiographic details of a specific individual or a particular personality, nor is it the elucidation of general patterns of social and cultural life via the individual. Rather, the objective is to understand the particular “individual *qua* individual” in relation to the social and cultural contexts within which he or she lives. The approach thus extends beyond examining one life over time to look at how individual lives interact with the whole - aiming to achieve a synthesis of history, biography, and social structure.

With respect to data collection, life story narratives are typically recorded in personal interviews, transcribed as text, and then finally subjected to analysis and interpretation. Analysis of the text should extend beyond mere description and focuses on issues of temporality, thematic content, and meanings. I will briefly discuss each of these analytic objectives next.

To establish temporality, the analyst examines the text for instances of change and continuity and determines how these processes interact over time. One might ask, for example, how a narrator’s sense of self has developed over a given time span. Transitional experiences and key events are referred to as transitions and turning points in the life course. These markers are helpful in understanding such processes. Transitions are the movements of individuals and families within socially constructed timetables for major life transitions - in other words, the normative timing of life transitions in areas such as education, work, and family life. Examples are joining the workforce, leaving home, and getting married. The timing of transitions varies across cultures and under different historical conditions. And since they involve a change in life path, transitions require certain strategies and choices and may extend over a lengthy period of time. All transitions are potentially turning points, or benchmarks, in the life course. Turning points represent a person’s subjective assessment of the continuities and discontinuities in his or her life story and often bridge these junctures. The impact of earlier life events on subsequent ones is thus especially significant.

Thematically, life stories may cover the full range and complexity of human experience. Examples might include personality development, social roles, relationships, and behaviors, stressors and coping strategies, inner struggles and feelings, sense of self and personal identity, spirituality, social and cultural experiences, and the construction of life meaning. Life stories may also focus thematically on people's experience with a specific facet of life, such as gender, ethnicity, occupation or ageing.

Finally, in addition to temporality and themes, the life story analyst is interested in the concept of meaning. Since the process of meaning-making is a mental operation that is not directly observable, the narrative perspective is necessarily subjective. This does not imply that narratives merely reflect the preferences or opinions of the analyst. Rather, narrative subjectivity refers to the social and cultural forms through which people express their sense of themselves in history. A genuine interest in and respect for the narrator's perceptions and constructions of the world move the analyst towards a fuller comprehension of the person's perspective and helps to create a shared, or inter-subjective, understanding of that person's experiences. The objective here is narrative truth in the service of coherence, continuity, and understanding- not a historical truth that mirrors some factual past. It is therefore more important that a life story be deemed trustworthy (meaning the narrator relates a consistent interpretation of how she or he presently understands the past, the experienced present, and the anticipated future) than it is for the story to correspond faithfully to a factual set of events and experiences.

Temporality, thematic content, and meaning all rely heavily on the structure of life stories. And with its emphasis on plots that organize human situations, structure in turn strongly influences the individual and societal functions of these narratives.

Life stories are undergirded by a uniform inner structure of narrative discourse, the subject of which is the ever-changing directions and goals of human action. To qualify as a narrative, an account must organize events so that they both demonstrate directionality or movement over time and convey a sense of coherence. The story need not be related in a linear fashion; rather, it is the patterns and connections that people use to make sense of events that are important. The plot organizes the story into a coherent whole by identifying the significance and connections of these events, and the process of employment thus functions as a major strategy for meaning-making. Human predicaments and their attempted resolutions are central features of plot structures and it is these conditions that underlie and shape the individual and societal functions of life story narratives.

At the individual level, organizing the events of one's life in ways that promote coherence and a sense of direction facilitates an ability to evaluate how and why these events occur; the actions and motives of other characters; and the meaning of these events and actions. Similarly, collective narratives lend coherence to group life by promoting and preserving shared socio-cultural knowledge, attitudes, and beliefs and by providing a vehicle for the transmission of this body of experience over time and space. Naturally, these functions of personal and group narratives bear immediately on the applications of life

story narratives in theory-building, professional practice, and public policy-making.

Applications of the Life Story Approach

It is contended that basic human needs of autonomy, competence, and relatedness become harder to satisfy at older ages, and that it is precisely this difficulty that makes late life an ideal time to study these needs and ways to best meet them. The fundamental role of life story narratives in human development and ageing makes this approach ideally suited to practitioners' and policy makers' efforts to improve quality of life for older people.

Understanding the lives of older people can significantly advance knowledge of personality development over the life course. Examples of work in this arena might include the study of personal agency, life themes, continuities and disruptions, integrity and generativity, as well as simply determining what matters to people as they age (see Hooker & McAdams, 2003). Likewise, attention to recurring themes in the narratives of older people, such as continuity, purpose, commitment and meaning, could further our grasp of how lives are experienced and events interpreted at different stages of life and in different cultures and historical times. This type of knowledge could shed important light on risk and resilience over the life course - and on how people use adaptive strategies to resolve conflict and are able to not only overcome but also benefit from adversity (Cohen, Greene, Lee, Gonzalez, & Evans, 2006).

Given its emphasis on inner experiences and developmental factors in personal narratives, it is not surprising to witness the recent, rapid growth of evidence-based interventions in the field of narrative therapy. Clinicians are now making extensive and effective use of narrative perspectives in therapeutic and health care settings, both independently and in conjunction with other treatments that focus on problem-solving efforts, educational strategies, and the provision of resources and services. These interventions are helpful for personal and interpersonal problems, such as illness, loss and grief, loneliness and trauma, and for fostering individual growth, tapping sources of strength and everyday wisdom. Engaging in the life stories process also often improves the quality of the therapeutic relationship.

Turning now to the wider social and political spectrum, life narratives serve as a rich repository of information about larger structural issues such as cohort formation and identity, interactions between generations, the dynamics of generational succession, and processes and outcomes of social and cultural change. Personal and collective narratives are also valuable sources of information about political action and social movements, as these phenomena usually originate in and emanate from the motives, personalities, and characters of individuals and small groups. Indeed, some of the widest and most effective applications of life stories in public policy are rooted in social advocacy.

Life narratives can also contribute to our understanding of larger problems of social structure and social mobility. We have learned much about the social forces of oppression, for instance, from individual and group narratives of discrimination on the basis of sex, race, and age (Ray, 2002). For this reason, it has been suggested that life stories should be routinely incorporated into community and institutional investigations as important “touchstones” for abstract theories of person and community and for testing implicit assumptions about human beings in larger sociological studies.

Finally, the life story narratives of older adults can make a significant contribution to practice and policy-making in the area of resources and services. Detailed descriptions of individual experiences are a common route to identifying new and emerging social problems, and this type of data also helps to extend and deepen our insight into existing problems. Accounts of personal experiences with issues of health and illness, elder maltreatment, and nursing homes are but a few outstanding examples. Finally, narrative accounts of individual and group service needs and service use can provide professionals with vital data for needs assessments, planning and implementation phases of service delivery, and evaluation of the adequacy and efficacy of these resources.

Conclusion

I began this presentation with a description of some of the basic features of life story narratives. With this background in mind, I discussed the significant value of this approach for furthering our current understanding of the universality and uniqueness of human development and ageing, and the critical reciprocal influence of socio-cultural and historical contexts on these processes. Lastly, I proffered a number of examples and suggestions for using life stories to advance social science knowledge and to improve professional practice and public policy-making with older people, their families and communities.

Clearly, life stories exemplify the unique value and worth of each life, just as they convey common motifs, themes, elements and issues. To understand both these singular and ubiquitous facets, it is important to bear in mind that life narratives are a dialectical process with reciprocal praxis between individuals and social systems. Understanding the social and historical contexts in which cohorts of older people were born, came of age, and matured is and will continue to be a crucial professional skill. Careful, respectful attention to the life narratives of clients can validate their lives and enable them to integrate and find meaning in their experiences. At the same time, these stories will furnish social workers and other professionals with invaluable information for service planning and delivery.

In closing, then, I refer to the wisdom of Confucius in the epigram of this paper. As practitioners, planners, and policy-makers seek to improve quality of life for current and future cohorts of older people in Hong Kong, they will do well to first seek to understand the end and the beginning of their life stories.

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DISCUSSANT 1

SMART Story Telling: Clinical Applications

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Story Telling

Everyone has a story to tell. Some are more interesting than others. In order to understand subjective experiences of older adults, asking people to tell their stories is an effective way. Experiences and feelings that are close to people's hearts are often being rewritten into movies, songs, music, poems, story books, drama, history books, cartoons, painting or biography so that personal experiences can be shared. Such sharing that can illicit large echoes would become popular songs, books, movies because the stories are touching.

In counseling, social work and social science research, there is an increasing use of narrative methods, and discourse analyses to understand people in the context of contemporary societies. Psychological techniques of projective tests, reminiscence and experiments often tap into the subjective experiences of older adults. Clinical use of metaphor, life review and time line are also useful methods in helping older adults to integrate their life experience for better self understanding. Gillies & Neimeyer (2006) proposed that individuals can reconstruct their sense of meaning after experiencing major losses in life. The process of meaning reconstruction involves sense making, benefit finding, and change in identity or self-perception. Under a constructivist paradigm, realities are actually socially constructed. We can attempt to understand subjective experiences of individuals through experience-near technique so as to maximally encompass informants' lived realities (Gelso, 1985; Schneider, 1999).

Research, Clinical Practice and Knowledge Building

The purpose of getting to know the ageing experience of older adults is to equip professionals with an understanding the needs and strengths of clients we serve as well as to enhance our professional competence in bringing about change among our client groups.

Topics of story telling can include celebrations and festivals, family rituals and collective rites in the extended family or kinship network, traditional wisdom and knowledge passed down from elders, forms of leisure activities and fun things done as a child, intergeneration gatherings and how grandparents and parents interact with them when they were children. Each episode of first day in school, first date, first job, major illness, most difficult moments in life, and depressing experiences are all good entry points to get to know stories of older adults. Going through their photo album is a quick and easy access route to life stories of older adults. Through sharing of photos taken during important occasions such as birthday parties, naming and describing members of the family, close friends who are present in such key occasions can help a therapist establish a web of important social networks in one's life. Through the photos, interaction patterns, decoration at home, food on the table, games and activities can all lead into discussion of resources and enjoyable moments in life. There are often stories behind each photo, and further stories behind stories. Stories of endurance, perseverance, and re-bouncing after traumatic life events can often be empowering. Through sharing their path to recovery, individuals can re-collect personal strength and resilience as well as develop a sense of pride. In moments of depression and loss of hope, retelling stories of how one overcame previous hardships can energize individuals in a process of consolidation and integration.

Clinical Application: SMART Story Telling

Our team at the Centre on Behavioral Health advocated for a SMART approach in clinical intervention. SMART represents Strength-oriented, Meaning-focus Approach to Resilience and Transformation (Chan, Chan, & Ng, 2006). The possible draw back of reminiscence is that the individual may become stuck in obsessive recall of negative or painful experiences. Each narrative of a stressful experience can act as a re-traumatization and cut deeper into past wounds. SMART story telling focuses on an integrative approach of enabling individuals to start with a life review using an autobiographical time-line (Leung & Chan, 2006). The core components of the sharing will be guided to talk about resilience and meaning, the significance and impact of negative events while positive personal growth and transformation that result as a consequence. Not every individual can articulate their transformation through pain. The social worker or clinician can help older adults by using simple metaphors of self and growth. We can also use short meditation and relaxation to help them express their true self in figurative language or metaphor.

In a study by Pamela Leung, she interviewed cancer survivors. One survivor described herself as being an arrogant cat before her cancer. 'I was arrogant; I did not bother to connect with others. Just like a cat sitting alone. When friends asked me to go out, I would make excuses and turn them down.' She cared about her family but she felt very lonely. 'I only gave, I always refused to be taken care of.'

‘I am the eldest in the family, I am the one to make sacrifices ... I am the one who takes care of others ... It’s more important that my younger brothers and sisters are happy ... It’s better that I bear the burden of the family by myself rather than sharing it with them ... I am the eldest, I should shoulder it ...’ Owing to this self compromising position, the client developed a negative view of life. ‘I think that to live is to suffer, life is painful.’

Cancer was a turning point in her life. She described herself as a naughty cat after her cancer experience. ‘I now enjoy every day of my life ... I am learning flower arrangement and knitting. I joined the Church choir ... I go out hiking and do Taiji ... I am now a happy person; very blessed.’

‘I have learnt what equality (reciprocity) and love mean. In the past, my giving of love to others was one-way and I rejected others who tried to give me love. Equality means every human being is capable of giving and receiving love.’ This client can now reconstruct her life meaning and is able to be fully contented with herself.

Towards Growth and Transformation through Illness, Crisis and Loss

The process of story telling can be transformational. The following steps are necessary ladders to climb to attain transformation.

1. Acceptance of illness and disability
2. Effective emotional expression
3. Search of new meaning in life
4. Take action in helping others
5. Change in life philosophy and spiritual growth

Meaning Reconstruction in Story Telling

Meaning reconstruction is a process through which people integrate their current loss of experience and come to view the self in a new way. People review, reevaluate and rebuild their pre-loss meaning structure through re-aligning their life priorities, self perception, worldview, as well as interpersonal relationship after traumatic losses (Gillies and Neimeyer, 2006). Story telling can be widely used as an experiential technique in research & clinical practice. Through the touching story of how Ada has transcended her life, dedicated to serve Chinese societies after her vision degeneration diagnosis, we are humbled by her exceptional strength and resilience. The story of Ada, her family roots, her parents’ impact on her, her losses and gains, her spiritual path and the life journey she traveled are all inspiring to us as clinicians.

The 10 “As” in Clinical Use of Story Telling

Asking open ended questions may facilitate older adults in sharing their ageing experiences. The following ten “As” approach may be helpful to practitioners when guiding older adults in telling stories related to:

1. Appreciation of the unique essence of one’s being. Articulation of self appreciation to foster self confidence and self esteem.
2. Actions that are congruent with one’s core value and belief that one takes pride in.
3. Achievements, competencies and what they have done for a beautiful completion of life mission.
4. Active search for meaning and continuous learning in their life.
5. Acceptance of adversities and limitations, frailty and disability so that they can take pride in their level of resilience and strength. Accept the different aspects of one’s self.
6. Affirmation of values such as collectivity, sustainability, eco-friendly attitudes that can be passed from one generation to another.
7. Action to life enrichments and removal of regrets in life, including moves to reconcile and seek forgiveness from loved ones.
8. Advocacy for a just social systems such as help keep the neighbourhood clean or participate in collective action in promoting policies on pensions and protection for old age.
9. Accommodation of diversity and selfless devotion to help others in need.
10. Ascending to heavenly peace - regard death as a graduation in life deserving of celebration.

Limitations of Narratives

The use of words, terms and concepts change over time. As working adults, can our questions be understood by the older adults whose life stories we want to learn from? Must we develop background in history to fully grasp the essence and stories behind their stories? In 40 years time when we all become old, what kind of language and narratives will young people be using then? Will they be able to understand our subjective world through our narratives?

Wisdom from the East, philosophical thoughts from Daoism, Confucianism, Buddhism and Christianity, techniques from Traditional Chinese Medicine and indigenous forms of exercise, Zen practices, non-attachment and silence meditations may move us further away from the use of words. In what ways should we generate new knowledge and wisdom that can foster an integrative well-being of the mind, body and spirituality of meaning?

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DISCUSSANT 2

From Medical History Taking to Story Listening

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The ancient roots for “disease” in English and “病” in Chinese both signify “being unwell” as told from the patient’s story: the English origin of “disease” was “dis-ease”,¹ while “疾”, the Chinese root of “疾”, symbolized a sick person resting in bed in a propped up position.²

Advances in medicine in elucidating the aetiologies of “dis-ease,” often to microscopic and molecular levels, led to the emergence of objective, scientific concept of “disease” from earlier subjective ideas of “dis-ease,” so much so that nowadays more emphasis is being put on structured medical history taking to detect a particular disease pattern rather than listening to the patient’s story of “dis-ease.” Thus, the sick man “disappeared” in the modern society as “doctors directed their gaze not on the individual sick person but on the disease of which his or her body was the bearer.”³

In medical history taking, a patient may be viewed as a set of symptoms instead of a person. When an elderly patient dwells on her discomfort or dis-ease without fitting into the patterns of diseases described in medical texts, a doctor may label the patient as a “poor historian.” “Geriatric patients are sometimes described as ‘poor historians’ because they do not ‘give a good history’. But an historian is a person who writes history, not one who provides the facts. Taking the history is the real intellectual challenge of medicine. The “good historian” is the good physician. Patients are never “bad historians”; doctors sometimes are.”⁴

If “dis-ease” is not recognized, a diagnostic pathway won’t occur, and an elder might be labeled as “social problem,” and the solution thought to be social or institutional care. The dichotomous view of an elder with “dis-ease” as either “medical” or “social” would not fit into her fragile ecosystem of diseases, drugs and adverse social factors with complex interactions. In the words of Bernard Isaacs, “Elderly patients are admitted to hospital not

because of social problems, but because of medical problems with social consequences, or social problems with medical consequences.”⁴

Comprehensive geriatric assessment is a process of knowing the elderly person: recognizing “dis-ease”; detecting causative diseases and environmental factors (drugs, social); matching “dis-ease” to diseases; in order that “dis-ease” can be reversed or reduced through appropriate interventions, thus protecting a frail elder from functional decline and premature institutional placement.

In narrative-based medicine, the aim is to ensure that the life-world voice of a patient is listened to and heard, rather than being drowned out by the scientific-technocratic voice of medicine.⁵ With narrative gerontology, the elderly person can be cared for and understood in the broader perspective of his background, beliefs and values, fears and concerns, and preferences and wishes. For example, a hospitalized 78-year-old man was reported to be “poorly motivated” to undergo rehabilitation. On further questioning and listening, he unravelled a story of fear of further falls after a fall while bathing, as well as depression from loss of function and a sense of being burden to his family members; all these stood in sharp contrast to the splendid photographic scenes he captured few months prior to hospitalization. Further investigation revealed drug-induced unsteadiness as a cause of his falls. His balance and mobility improved upon reducing the offending drug and subsequent rehabilitation. His morale and self-esteem were boosted by listening, encouragement, and involving him in artwork creation.⁶

To tune in with the Cadenza symposium’s theme of “advent of an elder friendly Hong Kong,” adopting a life-story perspective can help in the provision of coordinated services to elders through collaboration and listening to an elder by asking the right question “*who* is this elder?” (listening to his/her story so as to provide person-centred care), instead of just focusing on “*where* should he/she be placed?” (a decision that is often resource-driven). In the words of Stephen Watkins, “The purpose of community care is to promote privacy, dignity and independence and provide resources for living. It is a philosophy, not a place.”⁷



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Chapter 2

**Creative Ageing:
Meaningful Social
Engagement**





Chapter 2.1

Creativity, Social Participation, and Elder Friendly Environment

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Environmental gerontologists have advocated for quite some time about the need for building elder friendly communities. The kind of community environment that can foster elders' ability to be creative and opportunity for meaningful social engagement. Many cities around the world have already implemented rules and standards to have cities certified for being elder friendly. The Elder Friendly Communities project in Australia (<http://www.wtcc.sa.gov.au/site/page.cfm>) is one of the good examples. The project intends to support elders to maintain creative social participations and expand enjoyable social networks throughout the community. The objectives of the project are 1) to enhance the quality of life of elders living in the community; 2) to provide supportive emotionally and physically friendly environments for elders with challenges; and 3) to encourage meaningful participations in social, cultural, and political activities. The creative and innovative part of this project is the elders' involvement in the planning and implementation process. Elders meet regularly to discuss their ideas for initiatives that will benefit all elders in that city and throughout the broader community and the whole country.

Another such example is the U.S. Michigan Certified Elder Friendly Communities in Otsego County. This project is also run by elder consumers called Michigan Vital Ageing Think Tank. Michigan Commission on Services to the Ageing (<http://www.otsego.org/efc/>) provides overall support to this project. As a result of their collective wisdom, one of the project outcomes is the development of an assessment tool to evaluate the level of elder friendliness of a city. The following are categories of standards of an elder friendly community. City facilities and environments that can meet these criteria will be certified as Elder Friendly Community. A city will be considered as elder friendly if community facilities, human services, and businesses can meet elders' needs and provide quality of life benefits in the following areas.

- 1) Address basic needs: the community can meet elders' basic food, shelter (safe living arrangements), medical, and safety needs and foster their sense of security.
- 2) Optimize physical & mental well-being: the community can support and maximize elders' physical, mental, and spiritual health so that they have a sense of life satisfaction.
- 3) Maximize independence and autonomy: the community can maximize elders' access to accessible, acceptable, affordable, adequate transportation, facilities, and living arrangements so that they can have a sense of freedom and independence.
- 4) Promote civic & social engagement: A community that can provide opportunities for creative and meaningful social participations will give elders a sense of importance and opportunities to be creative.

How do we encourage meaningful social engagement and opportunities for creativity? Ways are to strengthen their home life and to improve environmental friendliness.

Creativity example: Generational exchange

A college student challenged a senior citizen, saying it was impossible for their generation to understand new materials. 'You grew up in a different world, the student said. Today we have television, jet planes, space travel, nuclear energy, computers...'

Elder's Creative & Wise Answer

Taking advantage of a pause in the student's litany, the elder said, 'You're right. We didn't have those things when we were young; so we invented them. What are you doing for the next generation?'

Creativity is not only for the healthy elders. Frail elders can be creative too. The following is an example of how a wheelchair bound elder supported her peers using her own emotional assets. Ms. Lee was an outstanding volunteer in her community although she went through multiple life challenges, including widowhood, blindness, amputation of both legs due to diabetes, loss of her son due to AIDS, and being victim of house fire. Many people may say she is very unfortunate. But she responded by saying that she had experienced life to the fullest, successfully enduring every aspect of life's challenges. She served as volunteer team leader in the community-based senior program. Her responsibility was to call and check on ten frail elders in her community every week to make sure they were fine. With a special device for placing telephone calls, she was able to provide meaningful emotional support to her peers. She herself had a vibrant support network from her church. She was a choir member at her church. She also went to local nursing home to visit frail residents by their bedsides. She encouraged bedridden residents to attend Sunday services in the nursing home's chapel. She also advised nursing home chaplain to prepare lyric of praises and Bible verses in overhead transparencies and project

them onto ceiling so that bedridden residents can be physically present during Sunday worship services. For elders with faith, this was the best social and spiritual engagement. Through Ms. Lee's creative volunteering, she felt a sense of mission and worked very hard to support other elders who were much more impaired than she was physically. Creativity can take different forms, e.g. volunteering, grand-parenting, writing, printing, learning music, dance, drama, etc. For Ms. Lee, creativity and meaningful social engagement came hand in hand. Volunteerism is beneficial both to the caregiver and the care-recipient. Ms. Lee felt satisfied psychologically, intellectually, socially, and spiritually. Her volunteering work gave her a daily routine, a purpose, a meaningful activity, an opportunity for social and emotional connection, and a sense of usefulness.



Chapter 2.2

Creative Ageing: Meaningful Social Engagement

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Population Ageing

The longest lived human being was a French woman who lived to be over 122 years old (Jeanne Calment, 1875-1997). In 2002, the oldest living person was a Chinese woman (Du Pinhua) in China. She was 116 years old. Centenarians are increasingly common in United States with 50,454 centenarians currently, 834,000 centenarians by 2050, and 2% women can expect to live to 100. In the world, there are 300-450 super-centenarians (110+).

The development of the “third age” of life

Our conceptualization of the life course is changing in the face of this longevity revolution. Never before have people spent so much time in the ‘third’ age of life (see the following figure: childhood is first age; adult is second age, older adult is third age). In the first age, we focus on the development of human capital. The second age, we focus on work and rearing families. And then in more modern history, we have created this third age of life, when people live into their 80s and beyond. There is no absolute time when this stage of life starts, but it has generally been viewed as post-work and post-primary family responsibilities. The third age is a time of continuing family responsibilities; and some people have to continue to work because of economic reasons. But very often, it is thought of as a time of leisure, of unobligated, uncommitted time. There is lots of room for us to be creative in how we should best put this time into use.

Youth	Adulthood	
Youth	Adulthood	Older

The demographic changes have really reportioned these stages of life. In the last 100 years, the last stage of post-retirement years has developed, in face of the longevity revolution. We now need to ask: how are we going to define this third age of life?

Creating a new vision for the third age

We are faced with very challenging questions:

- What can we do with these extended years of life?
- How can we make the third age more meaningful and fulfilling?
- How can we creatively shape this “new stage of life?”

Current vision of third age:

- ❖ Continuing roles in family
- ❖ A time for leisure
- ❖ Loss of roles in workplace and community
- ❖ Loss of financial security
- ❖ A time of boredom
- ❖ A time of confusion about purpose

Current view: Age Drain

- ❖ Drain at the population level
 - ◇ Bankrupt national budget
 - ◇ Strain health care system
 - ◇ Overburden younger population
- ❖ Drain at the individual level
 - ◇ Dependency
 - ◇ Depression
 - ◇ Dementia

We need to ask ourselves:

- Is this current perception accurate?
- Is this current perception helpful?
- Can society, families, and individuals afford these perceptions of the third age?

I think the answer is “NO” to the questions above. There is some truth in all these perceptions, but they are not completely accurate and they are harmful to individuals and society. We need a new perspective.

New perspective:

- ❖ Age as Asset
- ❖ Years of experience to be utilized
- ❖ An abundance of human capital
- ❖ An opportunity to be seized

This new perspective is based on evidence. People over the age of 65:

- ◇ 80% functionally independent. Maybe compromised in how they function, but in general, they are making it on their own.
- ◇ 90% cognitively fit
- ◇ Increasing levels of education with each generation
- ◇ Frailty and need for assistance occurs 80 years and beyond

Older adults generally have more time and motivation to be productive.

People over the age of 60:

- ◇ Can expect 20-30 years after retirement
- ◇ Are motivated to contribute to families and community
- ◇ Seek purpose in life
- ◇ Desire continued personal growth

In sum, the older population is a wealth of human capital. We need to think about older people as “assets”, not “drains.” We need to ask “how can we reconfigure our programs and policies to take advantage of this human capital?” The time is now to be creative in shaping a new ageing experience, given this new human capital.

Heart of the new vision: Ongoing meaningful involvement in social and civic life

Active engagement in social and civic life is good for older adults and families, as well as communities and society in general. For older adults, active engagement has been identified as a key element in successful ageing (Rowe and Kahn, 1998). Older adults actively engaged in society have higher levels of physical and mental health and increased life satisfaction. And family members express gratitude and relief when older family members have meaningful activities.

At the community and society level, there are also benefits:

- ❖ More experienced, more reliable workers
- ❖ Less reliance on post-retirement income
- ❖ Less health care costs if older population is healthier and more functional
- ❖ Stronger civic society through increased involvement in volunteer roles and participation in local organizations

How do we achieve an actively engaged older population?

We need to change programs and policies to:

- ❖ Increase opportunities for engagement in social, work and volunteering roles
- ❖ Transform work, educational, and volunteering programs
- ❖ Extend work life

The rationale for extending worklife: Research shows that older adults are more committed, reliable, and satisfied workers, who are interested in being generative, that is, assisting younger workers. There is a business case, using cost benefit analysis, to justify the retention of experienced workers longer as opposed to training new workers. Older adults and baby boomers want to work longer for financial reasons and also for meaningful engagement. But they also want to have more flexibility and a different balance of work and leisure. Surveys indicate that older workers want to transition out of work more slowly and this benefits companies in the transfer of knowledge

Some ideas for expanding employment:

- ❖ Transition programs (bridge jobs; phased retirement)
- ❖ Increasing flexibility (shared jobs, part-time jobs)
- ❖ Training programs, so that older adults can gain any skill needed
- ❖ More life planning programs usually through the workplace
- ❖ American Association of Retired Person gives annual recognition of exemplary employment practices toward workers over the age of 50 (companies judged on: recruiting practices, opportunities for training & career development; workplace accommodations; alternative work options, such as flexible scheduling, job sharing, and phased retirement; employee health and pension benefits; retiree benefits, and age diversity of the workforce)
- ❖ American Association of Retired Person recognizes best practices:
 - ❖ Full time employees are eligible to move to part time work on a permanent or temporary basis

- ❖ Flexible or compressed work time is available
- ❖ Workers can apply for lower-level positions which may increase work-life balance
- ❖ Retirees are offered opportunities for temporary work assignments, contract work, telecommuting
- ❖ Current employee has responsibility for retiree relations (regular communications, invitations to workshops/events, volunteer activities)
- ❖ Flexible Spending Accounts for Dependent Elder Care program (workers can allocate \$5,000 in pre-tax earnings to elder care expenses)
- ❖ Recruitment practices that target mature workers (ex: database of people who have been laid off)
- ❖ Intergenerational daycare program (grandparents paid to come and help with the children)
- ❖ In-house wellness program: flu shots; exercise, weight loss and smoking cessation programs

An example: the senior community service employment program:

- ❖ Authorized by federal legislation and administered by the United States Department of Labor (30 yrs old)
- ❖ Part-time employment and training for low-income adults age 55 and older
- ❖ Jobs in community service agencies so that the community benefits
- ❖ 18 - 20 hours per week
- ❖ Goal: develop job skills that will lead to a permanent, unsubsidized position

New vision: Extending education throughout the life course

The rationale for extending worklife: Research shows that older adults want to continue to learn; that they have the capacity to learn; and that older adults enjoy being in intergenerational learning situations. Also, studies show that certain courses increase knowledge related to health behavior (ex: health literacy courses).

Some ideas for expanding life-long learning

- ❖ Courses for older adults in college and university settings, hospitals, senior centers, & other community-based programs
- ❖ Course content on health promotion, art, music, writing, humanities, life skills and leadership
- ❖ Funds generally come from grants, private contributions, fees

An Example: OASIS is a National non-profit organization that offers classes to older adults and the classrooms usually are inside large department stores.

- ❖ 350,000 older adults participate in 26 cities in the U.S.
- ❖ 1 to 15 session courses, \$5-\$80
- ❖ Courses offered year round
- ❖ Arts, humanities, computers, health promotion (Safety in the home; Positive Attitudes-Positive Ageing)
- ❖ Space is provided in department stores
- ❖ Good for stores to have people in and out
- ❖ Money raised though sponsorships, donations and fees, grants

Example of an OASIS program: Story telling program

- ❖ OASIS partnered with an non-profit arts organization
- ❖ Offer 10-session course on storytelling for older members
- ❖ Members learn to share personal & historical stories
- ❖ Members take part in as well as initiate storytelling events
- ❖ Many events are intergenerational
- ❖ Older adults experience enjoyment, life review; children learn about life and history

New Vision: Serving others in volunteer roles

The rationale for extending volunteer opportunities: Research shows that in the US, 25% of older adults provide volunteer services, with a median amount of 96 hours per year. Volunteer contribution by older adults was valued at 70.5 billion dollars. If agencies use volunteers, they have increased capacity to fulfill their missions. More services can be provided (tutoring, socialization, transportation, delivery of meals). Clients receiving these services from volunteers report satisfaction and improved outcomes (increased reading scores, less loneliness). Also, it is documented that older volunteers experience benefits, such as increased life satisfaction and better mental health, as well as engaging in higher levels of physical and cognitive activity. In the US, the most recent estimates from the Current Population Survey (CPS, Bureau of Labor Statistics, 2004) indicate that 24.6% of people 65 and over volunteer. Once in volunteer roles, older adults devote more time, with a median of 96 hours per year recorded by the Bureau of Labor Statistics in 2004. In 2000, the Independent Sector valued the contribution to society of older volunteers at 70.5 billion dollars.

Some ideas for expanding volunteering

- ❖ Development of high-commitment volunteer roles aimed at community problems
- ❖ Social marketing to attract older volunteers (campaign adds)
- ❖ Incentives to offset costs of volunteering and reward volunteers (tax incentives; Silver Scholarship - if an older adult puts 500 hours a year into the education system, they would get \$1000 in an account for use in their own education or any child.)

An example: Experience Corps in the United States

- ❖ 2,000 people 55 years and over serve as tutors and mentors to children in urban public schools in 18 cities.
- ❖ They teach children to read and develop the confidence and skills to succeed in school.
- ❖ Research shows that Experience Corps improves student academic performance, strengthens ties between schools and surrounding neighborhoods, and enhances the well-being of the volunteers.
- ❖ Program sponsored by various social service and ageing organizations; funds from private foundations, donations, school districts

Another example: Executive Service Corp of Chicago in the United States

- ❖ Retired managers and executive work with non-profit organizations, schools and governments
- ❖ Volunteers work with organizations that need help with strategic planning, human resources, marketing and board development
- ❖ A non-profit organization which charges fees to companies to provide consultation service operates this volunteer program
- ❖ The non-profit agencies benefit (“Work with Executive Service Corps propelled us forward in acquisition of a larger facility for the school.”)
- ❖ The volunteers benefit (“Working with clients through Executive Service Corps has been so rewarding. It’s a wonderful way for me to give back.”)

Another example: Environment Alliance for Senior Involvement: Pennsylvania, United States

- ❖ 2005 volunteers gave 175,000 hours to protect environmental interests in Pennsylvania.
- ❖ Environmental activities include preparing water quality data, collecting historical data on Pennsylvania's waterways, empowering seniors to speak with local environmental officials, improving environmental education for youth, and promoting public health programs against indoor pollution.
- ❖ Funded by state and local government, private and/or community foundations and individual contributions.

Connecting older adults to opportunities in work, education, and volunteering

We must develop ways to connect older adults to new and existing opportunities. Educational institutions, libraries, social service agencies, and non-profit organization have programs to coach older adults in life planning and finding opportunities. The following are some of the examples:

- Lifespan's Bridge Employment Services Group
- Volunteer match (volunteermatch.org)
"connecting good people with good causes"
- Life option centers/Next Chapters
- Pathways to Living, Learning & Serving

Summary

Developing programs and policies to increase the social and civic engagement of the older population is a good investment. First of all, we already invest a great deal in developing the human capital of younger people. We should maximize our return on this investment by engaging the capacity of these people in later life. There are multiple benefits to the engagement of older adults. Not just older adults, but families and communities benefit. Finally, the active involvement of older adults in social and civic activities may be one the best health promotion programs available.

Reference

- Rowe, J. W. & Khan, R. L. (1998). *Successful Ageing, USA*: Pantheon Books.



DISCUSSANT 1

Entering a New Era of Ageing: An Active Ageing Framework

Professor Alfred C. M. CHAN, PhD BBS JP
Vice-chair, Elderly Commission

The Vision: Active ageing as a policy framework

In asking what sort of life people want over a life span, most would say that they want to enjoy life as much as they can. But if they have one or more chronic diseases, especially those coupled with pain, they would rather die quickly. With longevity now a part of reality, we live happily too short, but die too long. The essence of active ageing ironically is what almost everyone wants in life, but rarely anyone practices in modern living. Perhaps this is what I feel about innovative and ‘creative’ programmes promoting active ageing.

More specifically, as defined by the WHO, active ageing is a policy frame for an all-sectors (i.e., individual, community, public and private) approach to ageing that aims to maintain and improve the physical, and psychosocial (including emotional and mental) well-being (i.e., healthy ageing) of older persons. Active ageing is also a partnership between service providers and individuals for an optimal state of life quality. In achieving these aims, active ageing strategies need to be culture and gender sensitive, and should include three key life domains:

Health domain, for examples:

- Preventing, postponing or reversing adverse health conditions
- Maintenance or recovery of function after health problems
- Enhancing quality of life through improved physical and psychosocial well-being
- Compressing disability to the end of life span
- Minimizing incidence of illness through life
- Enhancing older persons’s capability in caring for themselves (independence) and to care for others
- Maintaining and enhancing family’s function to care for older persons

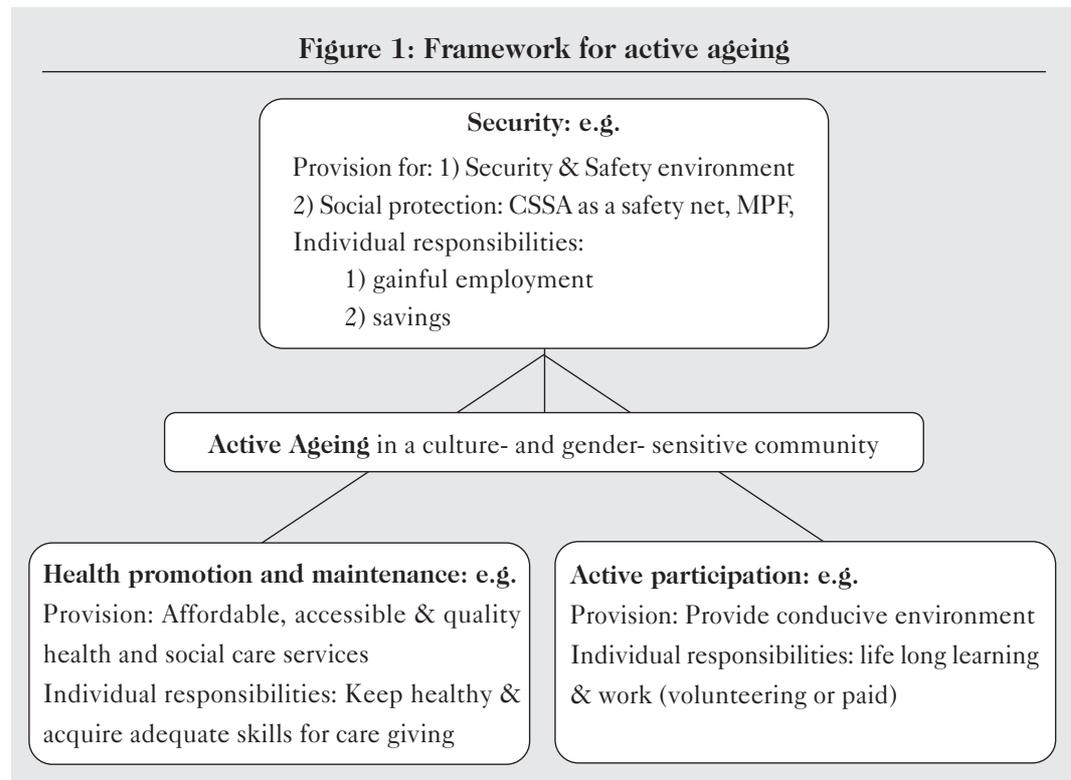
Security domain, for examples:

- Ensuring an age discrimination-free society
- Ensuring a secured environment for healthy ageing, including adequate financial means for basic living
- Ensuring a safe and barrier free environment for all people
- Encouraging young and working people to save for their own old age expenses
- Encouraging young and working people to support older persons
- Maintaining and enhancing family support for older persons

Participation, for examples:

- Mainstreaming ageing into all major policies
- Encouraging and enhancing older persons' capability to participate in all sector activities, from policy to programmes
- Ensuring a continuous participation in paid or unpaid work
- Encouraging and enhancing life long learning
- Encouraging and enhancing older persons' involvements in voluntary services
- Encouraging and enhancing intergeneration (family and community) solidarity

Attempting to be free from diseases for as long as possible and to achieve the optimal quality of life is a life long process for an individual. It extends beyond the needs for health and welfare of an individual covering the enhanced functioning of the community in socio-economic production, family and social interactions, employment, housing and transport. For the community and the wider public, active ageing is both an orientation and a daily practice worthy of having collectively. For policy makers, it is the people's choice and a cost-effective measure, particularly for health and social care expenditures. It can be shown diagrammatically below: (Figure 1)



Subscribing to current policies

Notably the active ageing policy framework has been developed within the socio-cultural context of Hong Kong with reference to current policy initiative. There are two principles with three initiatives for services to older persons in Hong Kong. The two principles are 'ageing in place' and 'continuum of care'; both entail a one-stop service for the older service users and service integration in the hope that a person could live through his/her age, for better or for worse bodily conditions, in places he or she desires. General goals of public services should aim at achieving '*a sense of security*', '*a sense of belonging*' and '*a sense of worthiness*'. Indeed, these are healthy and active ageing concepts advocated by the WHO for ensuring old age with income security, maintenance of health and active participation by such means as health education, volunteerism and improved relationship with children and grandchildren. Indeed our Active Ageing Work Plan and many of our proposed strategies and demonstration programmes for the two years (a revised list shown in Appendix I) fall within these priority areas. Many have been achieved.

Appendix I: The proposed programme plan for 06-07

建議工作

<p>(i) 積極樂頤年(老有所為)</p> <ul style="list-style-type: none"> * 創建新思維 * 宣傳推廣正面形象 * 糾正誤解，矯正歧視 	<p>傳媒推廣</p>	
<ul style="list-style-type: none"> * 銀髮市場： 銀髮市場推廣 —長者作為受眾：商品優惠，商品多種類（由保健、輔助醫療器材到高消費產品如旅遊、酒店、美容、時裝設計）（讓營商者得知長者將會是個新興且龐大的消費市場） —長者作為營商或投資者：需要一定的知識及風險評估 	<p>(1) 種籽計劃： 開拓商機，銀色風華工商展。</p>	<p>(2) TV/Radio, API 節目製作，銀髮市場推廣。</p>
<ul style="list-style-type: none"> * 長者自我形象提升 —活躍、富人生經驗，合群 —家庭支柱：凝聚多代溝通、支援 —肯學、肯做，肯為青年人犧牲，作為典範 (Mentors) —生命教育之源，共創社會和諧生活之（資）本，如常務、義工 	<p>創造長者為本跨代共融平台，設立退休長者專家名錄</p>	<p>種籽計劃： (3) 開放中小學予區內長者進入校園作「亦師亦友」教學相長計劃，如學生教導長者電腦，長者給予學生生命教育！擴展至每區一校參與。</p>
<ul style="list-style-type: none"> * 終生學習 —長者自理能力提升： (a) 一般保健疾病及長期病患自理學習知識和技巧 (b) 日常生活和理財安排，退休前準備 (c) 家庭、人際關係延續、融和相處 (d) 保持躍動，創建成就（受薪及非受薪工作） (e) 不斷學習，跨代融和，自我完善 	<p>年輕到年老的終身跨代共融學習模式，建造一個不斷學習，自強不息，永不言休，長時間貢獻家庭社會培育下一代的模範長者形象。</p> <p>增強疾病自理能力的學習尤為重要。從自理引發至幫助家人、鄰居。</p>	<p>(4) 設立長者學苑（中央）資源庫，提供專家名錄，免費網上資料下載。</p>
<ul style="list-style-type: none"> — 創建終身學習平台： (a) 設立長者學院、書室：由長者或退休專家任教主理或由年青一代（如大學生、中學生）主理任教 (b) 設立中央長者學習及專家：給予有心開展長者終身學習的人士或團體的資訊中心 		

<p>(c) 設立多渠道學習機會：正規、非正規、函授、遙距、面授、旅遊學習等</p> <p>(d) 學歷確認及評審：非正式課程接軌上正式學歷確認以技術為本的評審機制（資歷架構）如 City & Guilds, VRQ</p>	<p>種籽計劃：各區大中小學增值計劃，加設有關課程，資料庫，開放電腦室等</p>	
<p>— 全民覆蓋健康推廣及護老培訓</p> <p>(a) 確立社區護老知識技巧：提供基礎培訓包括防止感染、簡單傷口處理、扶抱、急救等</p> <p>(b) 廣泛建立護老者互學互助網絡</p> <p>— 鼓勵跨年齡、跨專業、跨界別的無牆 (Wall-less) 學校學習（如開放大學，中學課堂讓長者旁聽）</p>	<p>基礎社康護老技巧培訓課程</p>	<p>(5) 種籽計劃：利用現有團體 / 機制，試行增值計劃，如區內大中小學聘請長者教導學學生手工藝或做專題學習。</p>
<p>* 社區參與：</p> <p>— 政策與政治：從政到參政 如成立老人中心管委會</p> <p>— 受薪或非受薪（義工）貢獻專長</p> <p>— 社區發展植根，睦鄰互助，如區內學校作為發揮長者所長平台</p>	<p>不同層次 不同類別、範疇</p>	<p>(6) 培訓大量社區照護人員</p>
<p>(ii) 長期照護(老有所屬)</p> <p>* 辨識不同需要人士</p>	<p>引入一體化 入息審查及制定完善 評檢分流機制</p>	<p>(1) to (6) are suggested projects to start for the coming 2 years</p>
<p>* 締造良好及安全的居家照顧環境</p> <p>— 無障礙環境設計</p> <p>— 基礎醫療（尤其是慢性病）服務提供</p> <p>— 家居及院舍照顧（由於此等長者多已屬身體情況穩定，所需服務可由一般技術人員應付，如家人若已獲基本個人衛生、OT、PT及社心健康培訓者，及有醫生專業支援</p>	<p>需要大量具備基礎照顧技巧的社區照顧者（受薪或非受薪）</p>	
<p>* 長期照護服務質素監控</p> <p>— 受眾監管</p> <p>— 政府監控</p> <p>— 提升服務人員素質</p> <p>Step down care } training Step up care }</p>	<p>如S.Q.S、院舍分級、「錢跟老人走」、「院友之友」計劃、照顧人員培訓、資歷確認</p>	



DISCUSSANT 2

Professor Nelson CHOW

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Faculty of Social Sciences

The University of Hong Kong

In echoing the speech delivered by Professor Nancy Morrow-Howell regarding the issue on creative ageing, there are several noteworthy points that can be applied to the local context:

Employment for Seniors

In Hong Kong, working full time is the most prevailing pattern of employment. People will be very curious to know why one has to work on a fractional basis; they will be suspicious of the reason(s) for one not taking up a full-time position. Similarly, employers and managers would also have difficulty working out the terms of a part-time job. They often deploy staff to their fullest capacity and hence are unprepared, both psychologically and in actual operation, to accept someone working on a fractional basis. If senior people wish to be productive and creative after retirement, there must be a change in the societal culture and related practices regarding employment at later age.

Life Long Learning

Learning will undoubtedly enhance a person's skill and knowledge and the importance of life long learning is well known and generally accepted. However, a learning friendly environment is also important to make it possible. One of my PhD students has recently finished writing a thesis on life long learning and found that the most motivated group is comprised of middle-age housewives; the reason simply being that they have time. For local senior people, I believe that a positive learning environment is most crucial for them in realizing their dreams of picking up new knowledge.

The Chinese Culture

The Confucian philosophy has been most influential in shaping the Chinese idea of learning. For senior people in Hong Kong, they have learnt, for centuries, to rely on their children for decisions. Even today, they still keep to the teaching that one should “follow the views of one’s children when old.” If we wish our senior people to be more creative, more independent and more productive, we must work hard to introduce changes in our traditional practices which, on the one hand, will not delineate senior people from their children and, on the other hand, will motivate them to be the masters of their own lives.

Recorded by Mr. Tony Leung, CADENZA Programme Manger (Community Project)

Edited and agreed by Professor Nelson Chow, the Speaker

8 March 2007





DISCUSSANT 3

董桂榕

退休教師

各位朋友：今天我是來說故事，正如白頭宮女細說玄宗盛世，所講的都是我個人及身邊朋友的事，電視劇集常打出，故事純屬虛構，如有雷同，實屬巧合。但我要特別聲明，我的故事句句是真，並無花假。不過有時可能由於社會接觸面不廣的緣故，以訛傳訛，在所難免。

三年前我退休了，在退休前我是一個小學教師，是一個工作狂，也是一個“人老心不老”的怪物，可說是只知工作，還不知老之將至。到正式接到通知，“你夠期退休了”，我才醒覺到，吓！我已60歲了！吃過同事們的送別晚餐，真的要走了！

回到家裏，電視的英文台正播出“60分鐘時事雜誌”，正播出美國一個年過60的老婆婆，走路時已是顛危危的，在工作間還在學習使用電腦工作；原來美國制度只要她不願意退休，她還可以繼續工作的，因為法例不能有年齡歧視的，唉！真的是同人不同命！

退休前，我的先生早就對我說：（他比我早三年退休），你退休後就好了，好多事物享用都不用花錢，我不知他是安慰我還是哄我開心，我說：“好多嘢唔駛錢，讀書呢？”

“那我知道了，可能會減費吧！”原來好多嘢唔駛錢是指：60歲的長者參加康文署的活動，例如長者日營，只要你抽籤抽中了，當日就有旅遊車免費接送，午餐是19元，10人一圍，「四饊一湯，白飯任裝」，裏面所有活動時間都是安排由上午9時至下午3時，回程坐旅遊巴，其他康文處的長者體育活動如球類、各類中、西舞蹈有專人教授，都是免費的！

參觀太空館、藝術館、博物館、科學館等半價優待，觀看文化表演節目，參加體育活動如租場進行球類活動，打乒乓球，羽毛球等，享有特價。多間電影院的早場電影，有十元一場優待長者。

退休後，等到 65 歲申領長者卡後就可以免費遊海洋公園，坐天星小輪，銀行不夠存款額可以免手續費。坐巴士、地鐵、火車、電車、輕鐵、纜車有半費，公共巴士星期日及公眾假期只收 2 元。

至於在醫療方面：有特為長者進行免費身體檢查，排期大約三年多，有朋友說她的媽媽排期做白內障手術，由 2002 年排到 2006 年，我就有這麼一偈疑問，排隊是指長者跟長者一條龍，或男女老少一同排一條龍，我就知道了，會不會……有些長者輪到時已不需要用這種服務了。

我有又另一個疑問：既然規定 60 歲退休，但所有的半費免費福利都要在 65 歲才可以享有，這五年中我們是不是要足不出戶，或者出外只是用腳行路，又或者退休前要儲備一筆交通費，我想政府都是用心良苦，他鼓勵我們多行路、多運動，在五年裏從步行中練好一副金剛不壞身，也是一個保健方法，反正現在很多老人中心都有鼓勵長者參加防跌太極十八式，或者正如社署所說的，“多行幾步”的強身健體活動？

我常在想 60 這個數字，似分水嶺，60 歲前你可以申請持續進修基金，之後呢，可以享受康文處提供的文娛活動。等到 65 歲，拿到長者卡，車船半價，等到 70 歲，可以拿到 705 元生果金。

中國人有一句老話“民以食為天”，社會對長者“食”的照顧也用心良苦、無微不至，如剛才我舉例的長者日營，只收 19 元一餐“四饊一湯，白飯任裝”，真是一個對長者的福利德政，我不知是政府或私人機構對老人特別照顧，端午節派粽子，中秋節派月餅，每年一度的千歲宴等都是對長者的恩惠，有沒有想到老人家的腸胃可以適應嗎！愛他會不會害他？可以換另一種方式去愛他嗎？

有一次，我參加一個長者飯餐，這種午餐好公平，12 人一圍，食物放在大碟內，蝦餃，燒賣當一定足 12 份的，上到叉燒飽時，其中兩個孖着黏住在一起，一個婆婆夾起之後一對放在自己的碗中，她吃了兩個，同枱中一定有一個人沒有得吃，那個人就是我，你一定以為我少吃一個叉燒飽，一定懷恨在心？不、絕不！我只是想：我們有沒有細心想一下，長者都需要接受教育，我們只知道，尊敬他們，盡量給他們多吃點，天氣冷了送衫送圍巾。我們有沒有設計一個課程，教他們在社會做一個受歡迎的老人，體諒別人，我們學習怎樣和長者相處，相反有沒有教他們怎樣和後輩相處！不要讓老人成為年青一輩的多餘的贅疣。

我知道在“自在人生計劃中”就有類似這種課程設計，那次我參加他們的檢討會，其中一個學員說出來他的子女說“媽，讀書後，你說話的語氣溫柔多了”，我們不想聽到“恃老賣老”這個貶義的詞加在老人身上，長者要追求更高的、更專一點的學問，暫時是沒有的，工聯會有一些專為長者的課程，中大、港大、浸會長者報讀課程都有折扣，公大長者讀學課程是有折扣的！

我們期待着，有精神體力可以工作的，讓他們工作，因為只有工作才能令長者更年青，更有自尊和自信，讓他們學習：婦女大學、長者大學、長者持續基金，和長者的生活息息相關，不要讓他學了又重來，不經不覺地浪費社會資源，值得嗎？停一停！想一想吧！

Chapter 3

**New Ways of Thinking
about Long-term Care**





Chapter 3.1

Group Residential Settings

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This presentation focuses on developments in long-term care (LTC) for older people over the past 20 years with an emphasis on group residential care - that is, care in settings to which the older person has specifically moved in order to receive that help. It is, therefore, compatible with and a counterpart to Kevin Mahoney's chapter about care and services for people living in their own homes. With an emphasis on developments in the United States, this paper briefly discussed trends, principles, quality, culture change, and ends with some general issues. By way of background, the article begins with a definition of LTC, a discussion of its goals for LTC, and brief background on the historical evolution of residentially-based LTC in the United States and the quality challenges it has presented.

Background

Definition

Long-term care (LTC) is a wide range of personal care and related health and social services that are provided to people who need assistance with daily functioning (R. A. Kane & Kane, 1987). In the United Kingdom and parts of Europe, these services are sometimes called personal social services (Kahn & Kamerman, 1980). Younger activists with physical disabilities in the United States have also used the terms personal attendant services or personal assistant services (Litvak, Zuckas, & Heumann, 1987). By the twenty-first century, many authorities in the United States have been using the term Long-Term Supportive Services (LTSS) rather than long-term care, partly because the latter is sometimes interpreted to mean institutional care such as nursing homes. This chapter uses LTC and LTSS interchangeably to refer to the services people need wherever they live. The most central services are personal care-meaning the hands-on assistance or supervision with activities of daily living (ADL), including bathing, dressing, walking, using the toilet, transferring in and out of bed or a chair, and eating or drinking. Closely related are services

to assist people with instrumental activities of daily living (IADL) such as preparing food, cleaning one's house, washing clothes, purchasing food and other necessities, and getting from place to place outside one's home. LTSS can be facilitated by various kinds of technology, ranging from prosthetic devices to enhance functioning, information technology to monitor conditions, and a wide range of gadgets and devices in the home environment to help seniors with various kinds of functional, cognitive, and sensory impairments function better. In the last analysis, however, LTSS is labor-intensive. Family members and friends in the so-called informal network (particularly spouses and adult children) often provide that labor without financial compensation. Indeed, it is often when no family help is available or when the care needs exceed family capacity that the older person moves to an institution.

Goals

It is helpful to think of two general kinds of goals for LTSS. First, there are therapeutic *goals*, meaning that the care providers strive to improve functional status and restore or maintain capabilities for self care (R. A. Kane, 1999). Therapists of all kinds - physicians, nurses, physical therapists, occupational therapists, speech therapists, and mental health therapists - are accustomed to measuring success through objective progress that shows that their clientele improve in some type of functioning, or they maintain their current level of functioning better than those who do not have the services. These therapeutic rehabilitation-oriented goals remain important. Too often long-term care involves custodial services for people who could, in fact, regain some functional abilities if given the help. Identifying the right prosthetic devices and education to show people how they can function despite failing mobility, strength, eyesight and hearing, and showing family members how to help memory-impaired relatives to function are all part of necessary rehabilitative services.

Therapeutic goals are insufficient for LTSS, however. Many people of all ages must live with permanent functional limitations. Part of the goal of LTSS is to help people with disabilities having lives as meaningful as possible. We use the term *compensatory goals* for this effort. My focus is on group residential settings where part of the service is the provision of supportive dwellings, and where the client has needed to relocate to a place where services are readily available. But establishing and achieving both compensatory and rehabilitative goals are just as important for older people who have moved into some sort of residential care as for those who have remained in their own homes.

History of Residential Care and Quality Assurance

Although the United States has a long history of boarding homes and other group housing settings for care, including homes for the aged organized by NGOs, by the 1960s nursing homes modeled after hospitals became the dominant out-of-home setting for people needing LTSS. This growth was due in part to the need to move people quickly from hospitals, the availability of construction money, and, after 1965, the availability of limited funding through Medicare for skilled post-hospital care and funding for on-going care for

low-income people without financial assets through Medicaid. With the Medicaid coverage, in essence a medical benefit was being used to finance services that were not only medical in nature because they included housing, room and board, and personal care. Nonetheless, the concept of “medical necessity” was used for this coverage even though social necessity was usually heavily involved in the decision to move permanently to an institution.

Ironically, these mini-hospital nursing homes proved to be problematic for both the intensive rehabilitative focus needed for many older people after strokes, heart attacks, or hip fractures, and generally after the first few months of care, they relinquished rehabilitative goals and instead concentrated on giving care to compensate for the residents’ impairments. At the same time, because they were modeled after hospitals rather than homes, the residents were not assisted to live as meaningfully as possible according to their own preferences and interests. They tended to be in shared living quarters and subjected to rigid routines that foster increased dependency and learned helplessness. Putting it succinctly, the traditional nursing home met neither therapeutic nor compensatory goals (R. L. Kane & Kane, 1978).

Since the enactment of Medicare and Medicaid in 1965, the United States has experienced forty years of quality problems in nursing homes, despite substantial regulation of the industry and forty years of quality improvement efforts. Nursing home care is purchased from for-profit and non-profit NGOs rather than being delivered directly by government-owned facilities. The federal government promulgated standards in the form of *conditions of participation* for providers who wished to be certified for payment under Medicare and Medicaid, and developed a process by which State-level governmental entities inspect homes for compliance with the conditions. State governments may exert their own standards for Medicaid-funded services, which is a program administered by the States. Also State governments are responsible for licensing nursing homes, and typically they combine licensing inspections with certification inspections. Despite all the inspections, which facilities perceive as onerous, the quality of clinical care has been on the whole unacceptable in United State nursing homes (Institute of Medicine, 1986; Wunderlich & Kohler, 2001). At the same time, the situation of living in an institution modeled after a hospital with lack of privacy and strict routines has been well noted (Agich, 1993; Lidz, Fischer, & Arnold, 1992).

Over the years, a quality assurance system for nursing homes came to be seen as a three-part cycle: development of standards for quality; assessing practices to determine that the standards are met; and introducing corrective strategies to improve the problems found. These corrective strategies range from education and consultative efforts to punitive sanctions such as monetary fines holds on admissions, or even withdrawal of license. Standards themselves can be expressed in terms of structural standards (that is, requirements that pertain to the entire facility or program, for example, affecting the physical plant, the health records, the administrative and committee structures, and rules about the qualifications and deployment of different types of staff members. After quality reforms in

1987, work was undertaken to develop a comprehensive assessment protocol, known as the Minimum Data Set (MDS) to be used at regular intervals for assessing all nursing home residents (Morris et al., 1990). Researchers used this instrument to develop Quality Indicators (QIs) by which nursing homes could be compared (Zimmerman et al., 1995). The QI's refer largely to negative outcomes - such as bedsores, malnutrition, depression, use of physical restraints, weight loss, decline in physical functioning - or negative processes such as use of antipsychotic medication without a diagnosis of psychosis, unjustified use of psychoactive medications, lack of toileting plans for people who are incontinent, or unjustified use of urinary catheters. The QIs barely deal with psychological or social outcomes or processes that might result in improvement of psychological or social outcomes.

By the 1990's, however, this cycle of quality assurance was widely felt to represent a minimalist approach geared to identifying and minimizing unacceptable quality rather than improving overall care and working towards excellence. Thus, even at the same time as refinement of the MDS and the indicators was occurring, a movement towards quality improvement rather than quality assurance was also underway. Based on principles of Continuous Quality Improvement (CQI) or Total Quality Management (TQM), quality improvement (QI) programs require a support from top management but also a "bottoms up" approach where quality problems are identified and solved at the level of the work unit. Nursing assistants and other non-professional personnel are typically involved and sometimes residents and family are also involved. QI approaches are data driven and tend to entail a cycle that begins with identifying a problem and measuring its extent, then trying to remedy the problem, and then re-measuring to see if the problem is abated. QI can be applied to medical issues such as bedsores or social issues, such as enjoyment of meals, and in either case appropriate measures would be applied.

Trends in Residential Care

The historical discussion above focused on nursing homes and attempts to improve their quality. We now turn to general trends that have affected residential care in the United States over the last 20 years.

Differentiation of Types of Residential Care Settings

Although nursing homes, modeled after hospitals have been the dominant group residential setting in the United States and the one using the most public funds, other residential settings have become more prominent since the mid 1980's. These other residential care settings developed partly as a result of provider marketing and partly because potential residents with their own financial resources have shied away from nursing homes. In the United States such residential settings are licensed at the State level and, in contrast to nursing homes, they do not conform to a particular federal definition. Instead, numerous labels are applied at the State level, including residential care facilities, rest homes, retirement homes, assisted living facilities, small group homes, boarding homes with services,

family group homes, and adult foster care. In general, 3 broad types of provisions have become available for older people: 1) small family homes, sometimes called adult foster homes serving no more than a specified number of residents (typically from 2 to 6, depending on the State); 2) residential care facilities that are structured some what like nursing homes with either private rooms or shared rooms; and 3) purpose built assisted living settings comprised of private apartments. In any of these settings, the clientele housed may be similar to those in nursing homes; it is up to States to determine whether they use criteria to restrict the characteristics of residents who may be admitted to or retained in the settings (Mollica & Johnson-Lamarque, 2005). When a state government reimburses for nursing home care for low-income people, the State pays a per diem that includes both the room and board and the services, but when a state reimburses for residential care such as assisted living, it pays for the service package only and expects the room and board to be paid for by the resident out of income. Arguably, separating the price of lodging and board from the price of health-related services creates a truer accounting, and also paves the way for more consumer choice about living situations (R. A. Kane, 1995). Some states have also introduced assisted living programs into low-income housing; in such programs it is somewhat difficult to distinguish between home-care services that tenants receive in their apartments and assisted living services, although the latter tend to be a more comprehensive package.

The term assisted living has sometimes been used normatively to refer to homelike settings where people with nursing home levels of need can experience privacy and considerable control over their lives (R. A. Kane & Wilson, 1993). Typically, the individual's private space includes a full bathroom with shower or tub and at least a kitchenette with the capability of refrigerating and heating food. From the assisted living world, a useful formulation for looking at the challenge of generating good residential care services is built on the notion of a three-legged stool, each with three prongs (see Figure 1) (Wilson, in press).

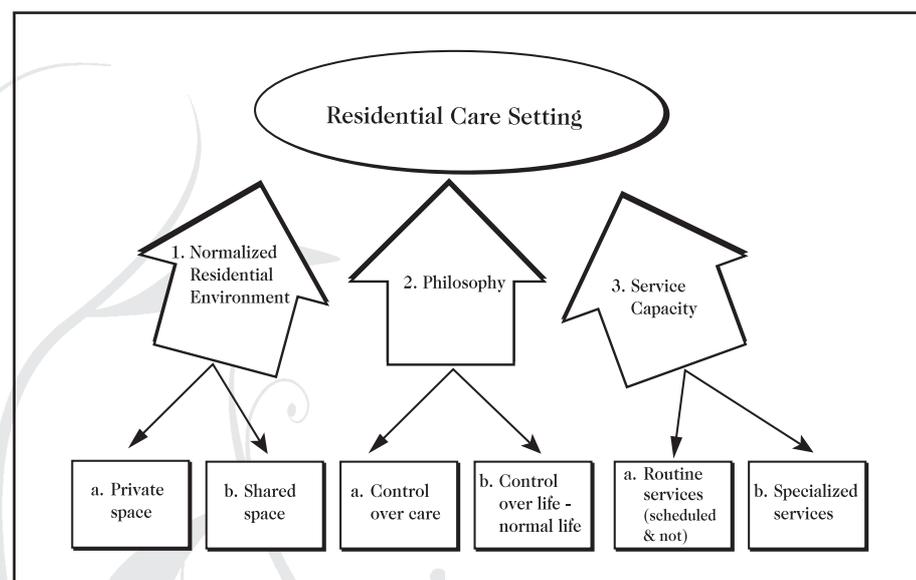


Figure 1. The three-legged stool framework for residential care settings.

As Figure 1 illustrates, the first prong is a normalized residential environment in both the private space belonging to the resident and the shared space that all residents use. Single-occupancy is one key to the private space, along with adequate room for personal possessions and to conduct chosen activities. Often the key to making shared space residential rather than institutional is in developing smaller-scale rooms, and the kinds of furnishings, fabrics, and decorations used. Another major prong is the service capacity, which includes the ability to deliver routine services, which may or may not be amenable to scheduling; for example, bathing and some nursing procedures may be scheduled but toileting assistance or overall supervision for safety cannot be scheduled. Nurses and personal attendants are needed routinely. Specialized services include mental health services, various therapies, audiologists, opticians, dental services, and any number of professional services that may be needed from time to time. Such services can be arranged rather than be provided by staff members in the smaller assisted living settings. Finally, the philosophy of care must be one that promotes resident and family choice and control over daily life (including how they arrange their time and space in their unit) and over care decisions. The criteria for determining that a setting was succeeding in implementing a philosophy that allowed old people to flourish would vary across cultures and is not expected to be identical in Hong Kong and in the United States. The diversification of residential care settings has led to reconsideration of the nursing home settings themselves and the extent to which nursing homes satisfactorily meet the challenge of the three-legged stool.

Diversification and Specialization in Nursing Homes and Residential Care

In traditional nursing homes, the clientele is diverse, including short-term and long-term residents, residents who primarily have physical disabilities and illness and residents who primarily have dementia, residents who are receiving palliative care and residents receiving rehabilitation. Optimal physical environments and services will vary by subgroup. There has been a trend towards specialized units within nursing homes; the most common are the special care units for people with dementia and units for people receiving physical rehabilitation. Units for people who are ventilator dependent are also sometimes developed. Specialization also occurs within assisted living and other residential settings. In this case, the entire assisted living setting or adult foster home may be specialized (for example, for dementia, or for multiple sclerosis, or for technically complicated care) or specialized units may be developed within a larger assisted living setting.

Use of Technology

Another growing trend is towards employing technologies to make care in residential settings more efficient or effective, to make residents more independent, to make residents' lives more enjoyable, or some combination of these aims. For example, ceiling lifts enable one-person transfers of individuals who need complete help transferring and, in turn, make it possible for staff to help residents in and out of bed at night when fewer personnel are working. Other devices may enable residents to open doors remotely, or make use of

telephone and televisions despite sensory or motor impairments. Seating technology has advanced to the point where individuals can be made much more comfortable and functional in chairs and wheelchairs, and gradually seating specialists are seen in nursing homes. (Seating specialists are more common in Scandinavian service houses than in United States nursing homes.)

Information technology can be used to develop more effective recording and tracking systems for clinical care, including with built-in resident-specific reminders and care milestones. Hand-held wands can be used to register care at the bedside and generate information that later can be downloaded into an electronic record. Information technology can also be used to create personalized communication and entertainment systems hooked to televisions or computers; a firm called Its Never Too Late (IN2L) has developed such computer programs that can be used for activities or by individuals (see website <http://www.in2l.com>). At the upper of technology, a few organizations have advertised a “smart house” environment where the beds and toilets and other parts of the physical environment keep a record of physiological parameters. Oatfield Estates, an assisted living facility in Oregon, uses biomarkers and high technology to create what it calls an Autonomy-Risk Equilibrium™ and to inform both residents and their family members and staff of changes in resident status (<http://www.elite-care.com/oatfield-tech.html>). Residents and family would need to understand the tradeoffs with privacy in deciding to enter a facility that uses passive measurement techniques such as these.

New Thinking on Physical Environments

Building on the widely respected ecological theory of M. Powell Lawton, who posited that environments for frail older people need to support their functioning while providing some challenge and stimulation (Lawton & Nahemow, 1973), appreciation is growing about how physical environments affect the behavior of those who live and work in them. A nursing home or assisted living setting is a workplace for staff, but more importantly a living place for residents. Both functions should be served, but the first is most important. New measures have been developed to assess physical space in terms of quality of life, along with easily administered scales to gauge properties of the environment such as privacy-enhancing features, independence-enhancing features, life-enriching features, and extent of resident control over the environment (Cutler, 2000).

New Thinking in Quality Assurance and Quality Improvement

Some of the developments to enhance and monitor quality of physical care include teaching staff how to use information to observe when a resident’s trajectory is moving in an unexpected direction. Even under good care, the likely trajectory for many health conditions of older people is a decline, but altering the trajectory to have less than the expected decline is positive, but quality monitoring can be developed based on clinical expectations (R. L. Kane, Ouslander, & Abrass, 1984).

At the system level several trends are apparent. Many policymakers are interested in “Pay-for-Performance” policies whereby providers receive a bonus for achieving outcomes that are stipulated by the government or other payers. Another idea gaining currency is to make quality information available to residents and families, and to those who advise residents through website posting of data comparing nursing homes on a variety of parameters.

Quality of Life

The growing and welcome emphasis on quality of life is a trend worth discussing in its own right. In the last decade, aspirations to a better quality of life (QOL) for nursing home residents have been taken more seriously and research has been conducted to develop measures of QOL. Because QOL is a subjective phenomenon, the information about a resident’s QOL must come as much as possible from the residents themselves. Considerable research is available to measure resident’s appraisals of QOL and to show that even residents with substantial dementia are capable of reliably reporting their QOL (Brod, Stewart, Sands, & Walton, 1999; R. A. Kane et al., 2003). Although single short instruments have been developed, most authorities acknowledge that QOL is multidimensional. The dimensions typically include functional well-being, pain and discomfort, emotional well-being, and cognitive well-being (Birren, Lubben, Rowe, & Deutchman, 1991; Noelker & Harel, 2001). In a project particularly designed to identify psychological and social dimensions of QOL for nursing home residents, a group of investigators at the University of Minnesota ultimately included 11 QOL domains, namely comfort, safety, relationships, social activity, enjoyment, functional competence (which means that within the limits of physical capability, the person is as independent as he or she wishes to be), individuality, privacy, autonomy, dignity, and spiritual well-being (R. A. Kane, 2001; R. A. Kane, 2003; R. A. Kane et al., 2003). The investigators distinguished between measures (which were based on self-report of residents) and indicators (which are programmatic, staff, or environmental features that might be related to the measures). For example, characteristics of the activity program such as the type and frequency of activities or the training of staff would only be a good indicator if they were correlated with a better result in the proportion of residents with high meaningful activity scores. The very process of asking residents questions about their quality of life enhances staff awareness of individual differences in resident preference and is likely to improve staff care. Substantial staff training is needed before they can administer QOL items without jumping to conclusions, hurrying the resident, or otherwise biasing the response (King, 1997).

Culture Change

Since about 1995, a national grass-roots social movement in the United States has emphasized the need for thorough, comprehensive change in nursing homes to emphasize a good quality of life, a nurturing social milieu, and individualized services. Stimulated by a group known as the Nursing Home Pioneers, this movement has come to be known as

the culture change movement (Fagan, Williams, & Burger, 1997; Lustbader, 2000). Culture change is both a process and an outcome, and as a process it is expected that the necessary change will be gradual and difficult and must come about in a process that engages all staff. The goal is to develop a habitat where old people and their direct caregivers can both flourish. The interventions that fly under the culture change banner are diverse but can be fall into general categories: interventions designed to empower residents and provide a more individualized, resident-centered, or even resident-directed kind of care (such as changing daily routines to conform to resident's individual preferences); interventions designed to reduce the hierarchy of a nursing-home and empower the least educated staff members; and interventions designed to improve and normalize physical environments (such as designing small neighborhoods within large nursing-homes, and transforming dining). Some culture changes are small scale, meant to affect a part of a nursing home and a circumscribed group of outcomes and some are exceedingly comprehensive, entailing comprehensive changes in all elements of the organization, staffing, and environment of the nursing home (Weiner & Ronch, 2003). One of the principles in the culture change movement is that in order for staff to be free to help resident's exercise choice, care staff themselves must be empowered to exercise discretion. Another principle is that risk is a part of adult life and that nursing home residents must not be so protected that they are not permitted to live normally or move independently. Perfect safety and absence of all bad outcomes is seen as impossible. Good management of chronic diseases and competent performance of care is taken for granted as necessary, but the emphasis is on quality of life as each resident might define it. With reference to care of people with dementia, some of whom might be unable to enunciate their preferences, techniques such as dementia-care-mapping are used to discern what kinds of circumstances seem to offer pleasure to residents and what circumstances create behavior problems and catastrophic reactions (Innes, 2003; Kitwood, 1997).

Some of the developments loosely associated with the culture change movement are themselves complete systems of service, and may be trademarked. For example, the Wellspring Alliance is an approach where nursing homes join in collaborating organizations that work in teams vertically within nursing homes and horizontally across nursing homes (for example, all the directors of nursing, or all the directors of social work) in a data driven approach to improving quality (Stone et al., 2002). The Eden Alternative, developed by William Thomas, is an approach to improving nursing home life through application of a series of principles to deal with his conceptualization of major problems in nursing homes, namely, boredom, loneliness, and lack of purpose or meaning (Thomas, 1994, 1999). William Thomas also conceptualized the concept of Green House, an entirely new organizational structure to deinstitutionalize nursing homes, which is discussed as an example in another chapter (Rabig, Thomas, Kane, Cutler, & McAlilly, 2006).

Evaluation culture change is somewhat of a challenge. Targeted interventions (for example, to improve bathing or dining or the experience of residents who are awake at night) can be studied with pre- and post-data collection using continuous quality improvement methodologies to examine the ability to achieve specific goals. Broad interventions need to be studied looking at broader outcomes such as quality of life, functional abilities, resident participation and autonomy, and resident and family satisfaction. If the intervention itself is multifaceted, it may be challenging to identify the elements of the change that most affected the outcome.

Unresolved Issues

Group residential care in the United States, including nursing homes, have difficulty obtaining and retaining qualified staff. Nursing shortages have been found at all levels. Efforts are underway and will continue to be needed to identify staff configurations that work well to achieve good results for residents, to explore various kinds of substitution among staff, and to identify ways to create worthwhile jobs for unlicensed assistive personnel. Considerable controversy surrounds the question of whether specific resident-to-staff ratios should be established for nursing personnel as opposed to encouraging creative development of new configurations.

Another controversy concerns the merits of specialized care of people with Alzheimer's disease and other dementia in segregated Special Care Units versus mainstreaming them in the general population of a nursing home or assisted living center. Here the challenge is to consider the results not just of people with dementia but for others without dementia in the same environment.

Numerous issues concern how to best promote a good quality of life. Residential care settings strive to provide opportunities for privacy and achievement of individual resident goals, but they also seek to enhance a sense of community and social interaction in the residence itself. Sometimes these goals do not seem compatible, and it well may be that the individual goals are more important for some residents and the community goals more important for others. Also resident settings are challenged not only to maintain activities and interactions within the facility itself, but also to help residents stay connected to their larger community outside the nursing home. Family roles are relevant to community integration. In assisted living, expectations for family members to provide services are high, but their expectations are fewer in assisted living (Gaugler & Kane, 2001). Finally, how to balance safety and protection against freedom and normal quality of life is a never ending challenge in residential care settings.

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Chapter 3.2

New Ways of Thinking about Home and Community Based Services for Elderly and People with Disability - Consumer Choice and Quality Management

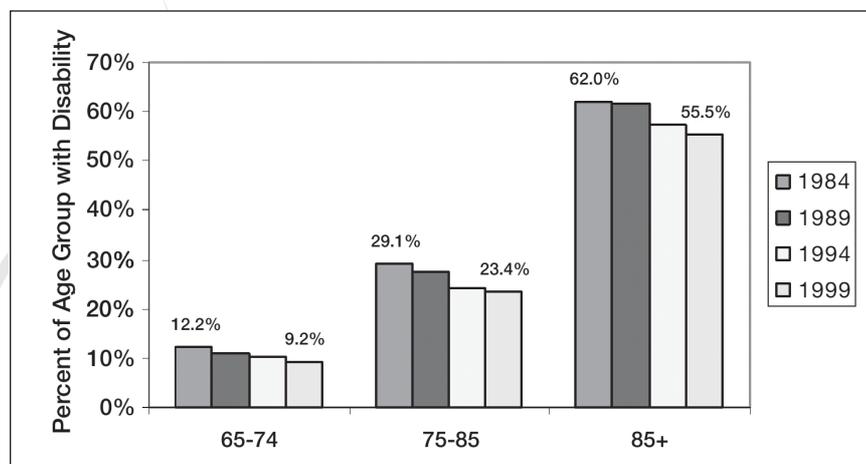
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Demographic Trends in the USA

Long-term care services for older people and people with disabilities in the United States have undergone dramatic changes during the last two decades. It is well-known that the elderly population in the U.S. is increasing rapidly, potentially increasing the demand for nursing facilities and other long-term care services. A less well-known trend is that the disability rate among older people is declining. Figure 1 shows that between 1984 and 1999 the disability rates of people between 65 years and 74 years old declined by 25% from 12.2% to 9.2%, those between 75 years and 85 years old declined by 20% from 29.1% to 23.4%, and those older than 85 years declined by 10.5% from 62.0% to 55.5%. The decline in disability rates among older people may reduce the demand for nursing facilities and other long-term care services.

Figure 1. Disability Rates among Individuals Age 65 and Over by Age

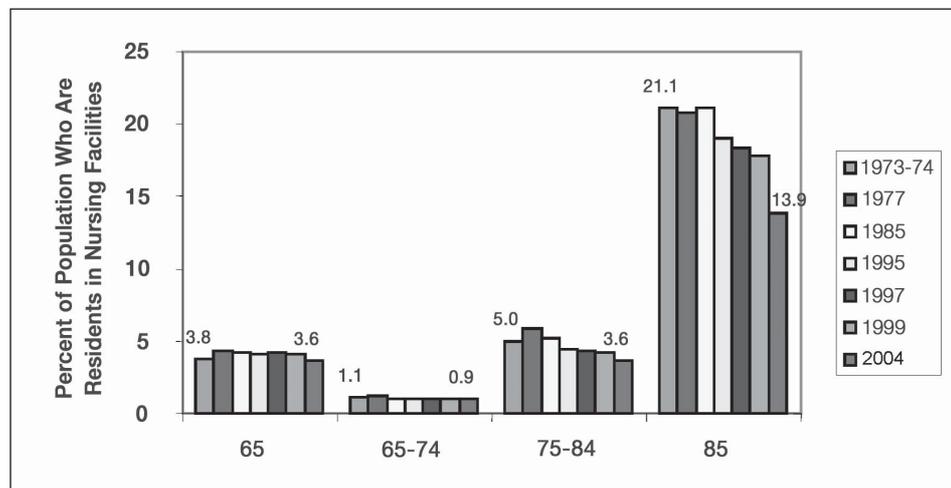


Source: Brenda C. Spillman (2003) *Changes in Elderly Disability Rates and the Implications for Health Care Utilization and Cost* for the Office of the Assistant Secretary for Planning and Evaluation at <http://aspe.hhs.gov/daltcp/reports/heutlest.htm>.

Delivery Trends of Long-Term Care Services in the USA

The ageing baby boomer generation is very different from their parents' cohort. They have a higher educational achievement, stronger non-agricultural work attachment, higher socioeconomic status, more independence, and at the same time, more buy-in to the idea of consumer choice and demand higher quality services. These factors have significantly affected the ways that long-term care services are delivered. Figure 2 shows that between 1973 and 2004, the nursing facilities utilization rate among the oldest old (people who were 85 years or older) dropped from 21.1% to 13.9%. Similarly, the utilization rate for those between 75 years and 84 years declined from 5.0% to 3.6% during the same time period.

Figure 2. Significant Decline in the Use of Nursing Facilities Among Oldest Old

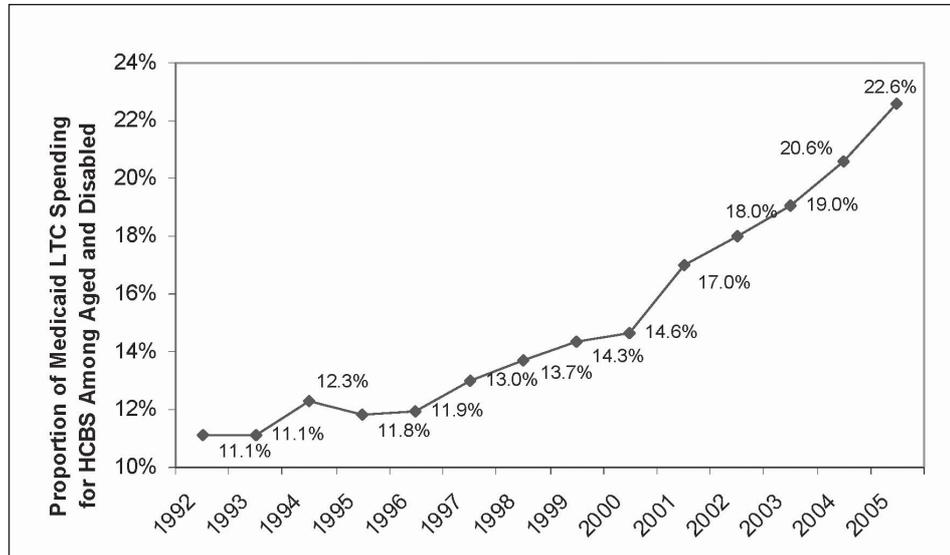


Source: 1973-4, 1997, 1985, 1995, 1997, 1999 and 2004 National Nursing Home Survey.

Financing Trends in the USA

As more elderly are staying or prefer to stay in the community, the demand for home and community based long-term care services (HCBS) has increased. HCBS refers to a range of compensatory or therapeutic support services delivered in a non-institutional setting that help maintain the independence of people with functional limitations in their own homes and communities. The Medicaid funding for long-term care services devoted to home and community based care for older adults and people with disabilities has grown significantly since 2000. Figure 3 shows that between 1992 and 2000, the percentage of Medicaid long term care funding devoted to HCBS increased by 3.2 percentage points, from 11.1% to 14.3%. However, between 2000 and 2005, the funding increased by 8.3 percentage points, from 14.3% to 22.6%.

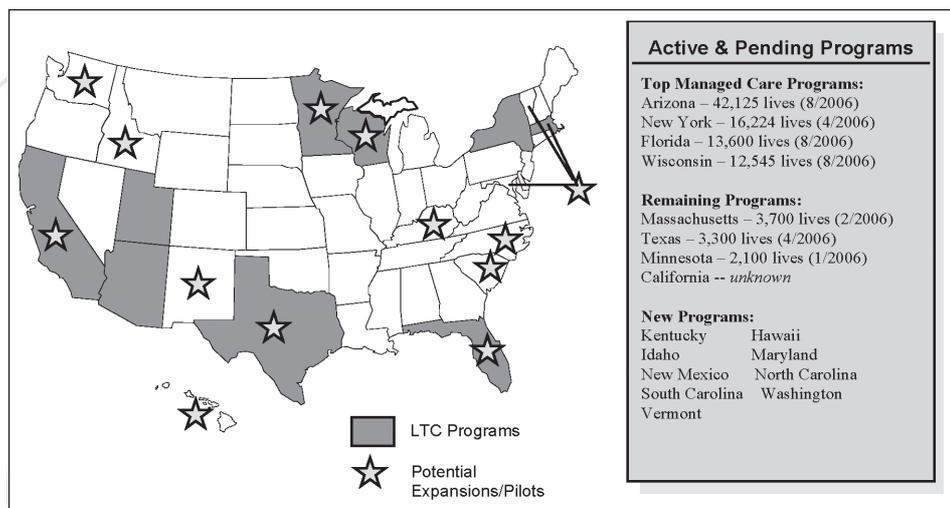
Figure 3. Percentage of Medicaid LTC Funding Devoted to HCBS for Older Adults and People with Disabilities Grew Significantly Since 2000



Source: 2005 MedStat LTC Data, Lewin Analysis. Long term care includes nursing facility, state plan personal care and home and community-based waivers for the aged and disabled.

Many states in the U.S. are looking to managed long-term care (LTC) as a way to rebalance Medicaid. While managed LTC can be mandatory or voluntary, many prefer the voluntary approach where managed care is one choice, but not the only choice. Studies on managed long-term care do indicate high consumer satisfaction, but the results on cost saving are mixed. Figure 4 shows the map of managed long-term care programs in the U.S.

Figure 4. A few well established programs and numerous start-ups



Preparing for the Future in the USA

Although the disability rates of older people are dropping, Figure 5 shows that the rapid increase in the elderly population will more than double the number of older adults aged 65 or above with disabilities between years 1996 and 2049. The demand for nursing facilities will also be affected by the lifestyle choice of the baby boomers. Figure 6 shows the relative risk for nursing home admission over the next 20 years at age 45-64 years. People who are inactive and diabetic are 4.55 times more likely to be admitted to nursing homes than active people who have normal blood pressure. People who have high blood pressure and are inactive are 1.89 time more likely to be admitted to a nursing home than those who are active and have normal blood pressure.

Few Americans plan ahead for their long-term care needs. Less than 10% of those age 65 years or older own a long-term care insurance policy. Long-term care insurance policies can be expensive and may be unaffordable for many middle-income Americans. Baby boomers had children later than any previous generation and worry more about college tuition than financing future LTC needs. Older adults own nearly \$3 trillion in home equity, yet few take advantage of methods to tap this resource.

Figure 5. Older People with Disability between 1996 and 2049

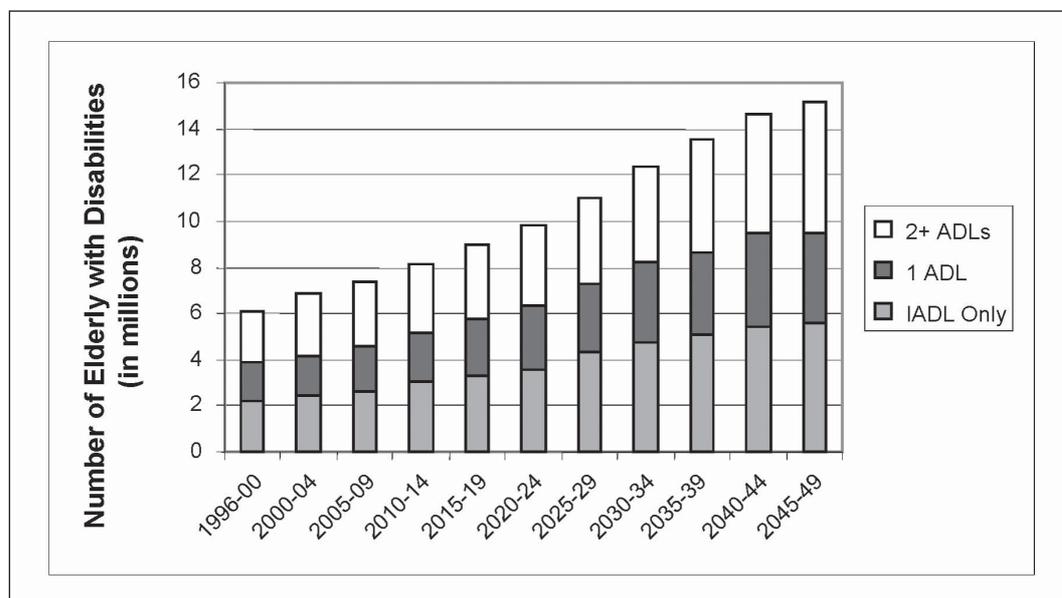
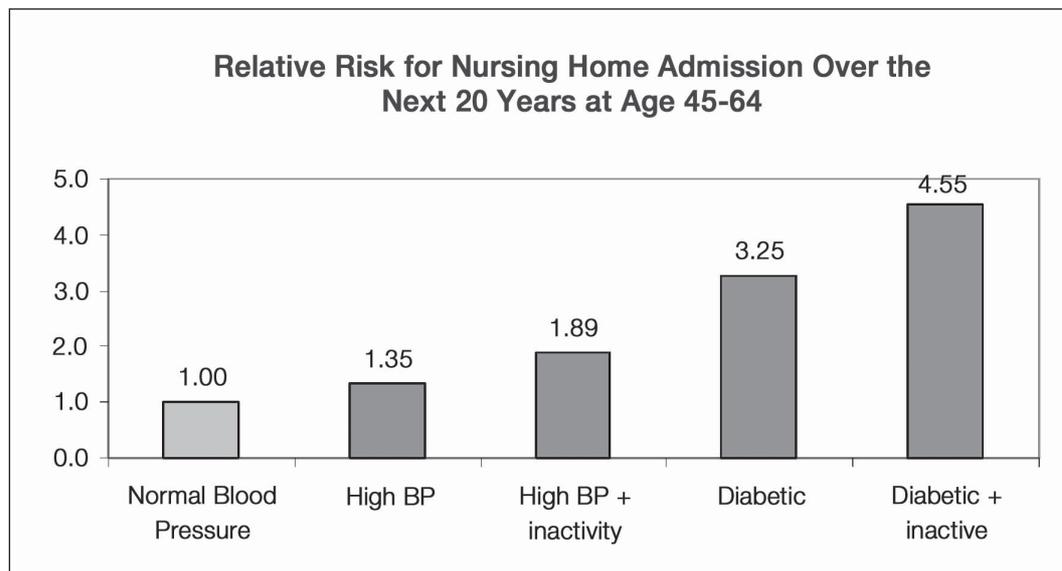


Figure 6. Lifestyle Choices Affect Nursing Home Use



Source: Valiyeva E, et al. Lifestyle-Related Risk Factors and Risk of Future Nursing Home Admission. Archives of Internal Medicine. 2006; 166:985-90. May 8, 2006.

Consumer-Directed Long-Term Care Programs

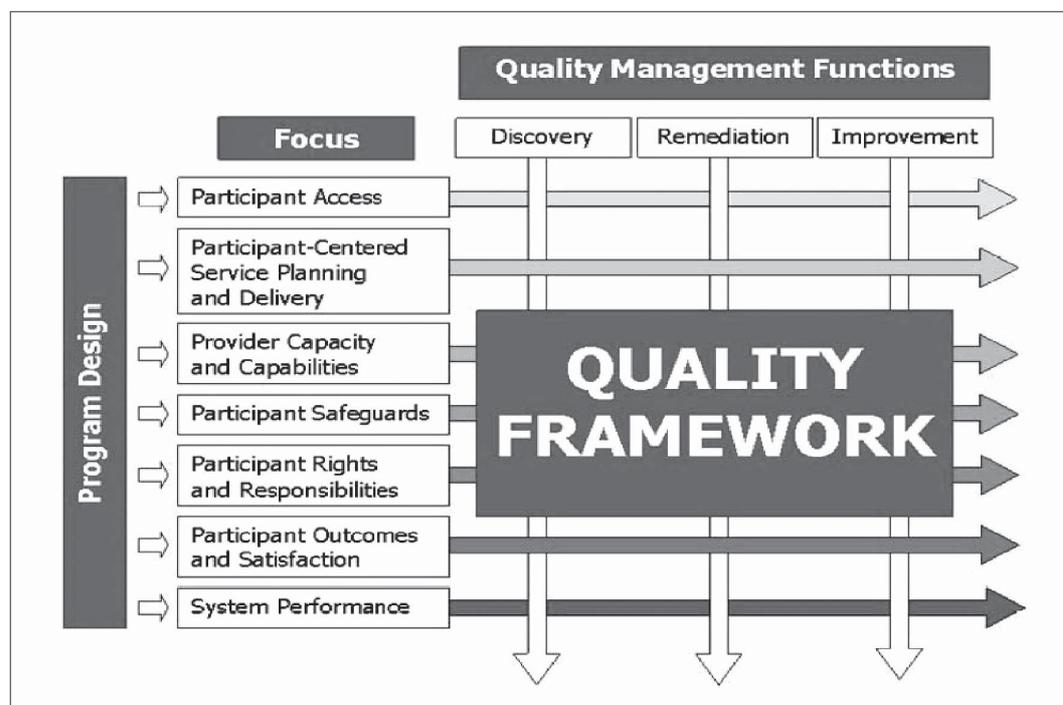
In the U.S., many states have been developing options for Medicaid beneficiaries with a disability to manage and direct their own home and community-based long-term care services. One of the more well-known of these consumer-directed programs is the Cash and Counseling Demonstration. Consumers or their representatives are allowed to hire their own providers as an alternative to a traditional model of using agency-based providers, with the assumption that consumers are able to determine what they require and can use good judgment in purchasing those services and overseeing their delivery. While many see consumer-directed programs as promising options for delivering long-term care services in a non-institutional setting, there are considerable debates on the needs for beneficiary protection and on how to ensure the quality of these consumer-directed services.

Current Quality Approaches in Consumer-Directed Approach in HCBS

Current quality approaches are dominated by health and safety values. There is an underlying assumption that service recipients are unable to assess or communicate about quality. In our search for measurable quality outcomes the United States has typically relied heavily on structural elements, such as resident to nursing staff ratios. The media, society in general, and politics all reinforce these beliefs.

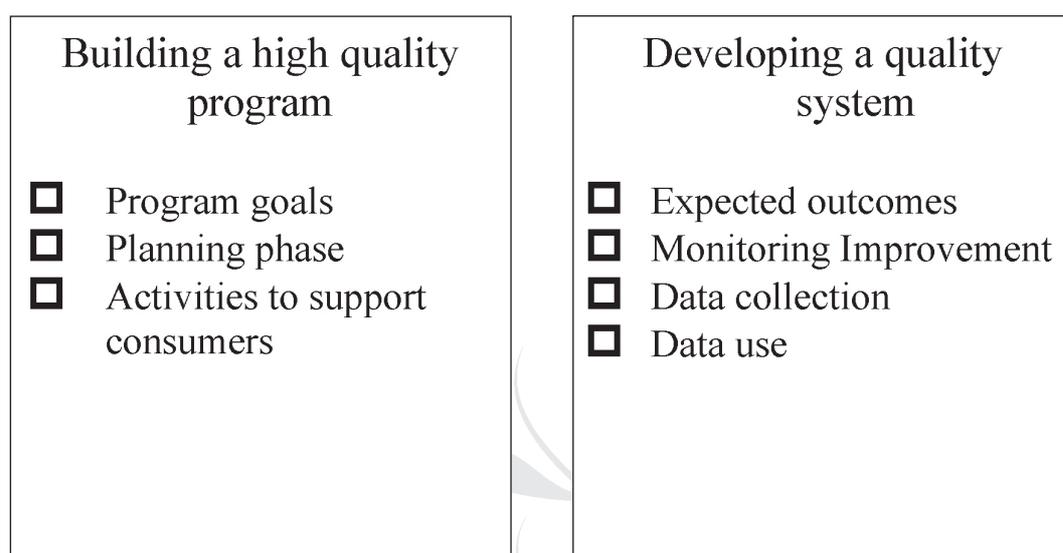
Figure 7 shows a quality framework for consumer-directed programs. Quality management is a continuous process and should be an integral part of program development. Consumer choice is a key element in high quality long-term care services. Quality is achieved because of choice not in spite of it. Consumers are the agents of quality. Programs can be designed to maximize consumers’ ability to achieve high quality. Accountability can coexist with consumer-centered programs.

Figure 7. A Quality Framework for Home and Community Based Long-Term Care Services



The first step in quality management is to begin by building a high quality consumer-directed program. Figure 8 shows the cross-walk of steps needed to build a high quality program and develop a quality system.

Figure 8. Relationship between building a high quality program and developing a quality system



Elements of High Quality Consumer-Directed Programs

A high quality consumer-directed program has several key elements. First, it must have training materials for consumers and family members. Most consumers are used to the traditional agency-directed service delivery model and do not have the knowledge about services available in their own communities. Training materials will empower them to become their own case manager. Second, the program should have training materials for support brokers. Similar to consumers, most support brokers are also accustomed to the traditional agency-directed model. They need to be trained to shift their role from case managers to support brokers. They also need to be trained to relate with consumers in the new consumer-directed model. Third, the program should have a process for participant goal setting. In the traditional agency-directed model, goals are typically set by professional care managers. In the new consumer-directed model, consumers set their own goals. Fourth, the program should have peer support. Peer learning is one of the best ways for consumers to learn how to manage their own care. It will also help consumers reduce the anxiety of managing their own care during the transition between the traditional agency-directed care model to the new consumer-directed care model. Fifth, the program should have emergency back-up/worker hiring. The safety and well-being of the consumer should be protected in case there is an emergency break down of the service arrangement under the consumer-directed care.

Once a high quality program is developed, the quality management system should include: establishing and using a quality improvement advisory group; developing tracking strategies to examine such areas as the lag time between when an individual enrolls and when they start to manage their own budget; incidents such as complaints or abuse; developing audit procedures to ensure that the individual budget is being spent according to plan; developing survey approaches to hear from consumers; and developing a plan for how data is used to improve quality.

Early Lessons from Cash and Counseling Program

States consistently recognize the importance of quality improvement committees. They have learned that the effective use of quality improvement committees requires considerable effort. They recognize the importance of hearing from consumers, but it is a challenge to collect and analyze data in a cost-effective way. They also recognize that it is important to link quality of consumer-directed programs to other HCBS efforts. Despite the importance of quality data and a quality improvement committee, states are less clear about how to use data to make improvements.

Top Ten Items for Quality

To conclude our discussion on consumer-directed care, we listed 10 items for you to consider when you are ready to develop your own consumer-directed services in Hong Kong:

1. Does the quality plan meet government assurances and allow you to say that you have the best program possible?
2. Do you have strategies in place so consumers can choose quality?
3. Do you have a plan for entering, analyzing, and using data?
4. Do you have a strategy for assuring and improving quality of financial intermediaries?
5. Do you have a strategy for assuring and improving quality of support brokers?
6. Do you have a system to track critical incidents?
7. Do you have a good system in place to track consumer processes?
8. Do you have a mechanism in place to test materials?
9. Do you have a Continuous Quality Improvement (CQI) Committee in place that includes consumers?
10. Do you have a good mechanism in place to hear the voices of consumers?

Consumer Direction in Providing Long-Term Care Services in Hong Kong

The late Nobel laureate economist Milton Friedman once said “if you want to see capitalism in action, go to Hong Kong”. The essence of a free market economy is the respect of consumer choice. It is true that in Hong Kong government regulation in the private sector has been minimal to facilitate the development of a market-driven economy and to protect consumer choices. Given choices, most people in Hong Kong believe that consumers will make their best decision when purchasing goods and services to maximize their own well-being under a limited budget. However, in the public sector, there is a general mistrust of consumers to either avoid abuse by the consumers or protect them from being harmed. In the health and welfare sector, service users are not being regarded as consumers and are given very few choices. The delivery of long-term care services in Hong Kong is driven by the agency-directed services model.

The heavy use of nursing facilities by older people in Hong Kong is a policy-driven behavior. Surveys by the Census Department found that given choices, most older people would prefer staying in their homes when they need support services to maintain independence. However, due to the current limited housing and health care options available to them, many older people or their family members may find that institutional care is the best “choice” for older people with disabilities.

We think Hong Kong is ready to add consumer direction as an option in providing long-term care services to its residents. Historically, Hong Kong people, regardless of age, are not strangers to a market-driven system. A consumer-directed approach in long-term care services also fits very well with the free-market ideology in the private sector. Socially, compared with the U.S. and many western countries, the family system in Hong Kong still remains intact. Geographically, Hong Kong is a very small city and older people usually live close to their adult children. Culturally, many non-elderly adults still see taking care of their ageing parents as their obligation.

Finally, we hope our discussion on the consumer-directed model will stimulate the discussion of developing a consumer-directed care option for older people in Hong Kong. The discussion on a quality approach should provide insight on ways to protect consumers and avoid abuse of the system. For more information, please consult the following websites:

Additional Resources:

The Community Living Exchange Collaborative Clearinghouse at: www.hcbs.org/

The Cash & Counseling National Program Office at: www.cashandcounseling.org

Chapter 4

**Consumer-directed Care
and Quality of Life of
Older People in the
Community: The Cash and
Counseling Experience**





Chapter 4

Consumer Directed Care and Quality of Life of Older People in the Community: The Cash & Counseling Experience

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Background of the Cash and Counseling Program

Cash & Counseling is a form of consumer directed care for Medicaid beneficiaries who are either elderly people or people with disabilities in the United States. Medicaid is a Federal-State funded health insurance program in the U.S. that provides health insurance coverage to certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law. Medicaid is the primary source of funding for long term care in the United States.

The Cash and Counseling program began in 1998 as a demonstration program in Arkansas, New Jersey and Florida. The Cash and Counseling demonstration was funded by the Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services, and the Administration on Ageing of the U.S. Federal Government. To implement the Cash and Counseling demonstration, states needed to obtain waiver approval from the Center for Medicare and Medicaid Services (CMS) of the U.S. Federal Government. The CMS reviewed states' waiver applications and provided continuing oversight and technical assistance in the waiver process.

The implementation and the outcomes of the demonstration were evaluated quantitatively by the Mathematica Policy Research, Inc. (MPR) and ethnographically by researchers at the University of Maryland, Baltimore County. The initial results found that Cash and Counseling participants were more satisfied with the quality of their overall care, had increased access to paid personal care, had fewer unmet service needs, and experienced an improved quality of life. Because of the promising outcomes, the program was expanded in 2005 to 12 new states, including Alabama, Illinois, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia. These replication projects are coordinated and directed by the National Program Office at the Boston College Graduate School of Social Work.

Basic Model of the Cash and Counseling Program

The Cash and Counseling model has several essential elements. First, consumers receive the traditional assessment and care plan; then a dollar value is assigned to the care plan that individual would have received from traditional agencies. States determine the amount of the budget. Second, consumers receive enough information to make an unbiased personal choice between managing an individualized budget and receiving traditional agency-delivered services. Third, the consumer with their counselor (and their family members if they so chose) develop a spending plan to meet the consumer's personal assistance needs. Consumers who cannot manage entirely on their own may designate a representative to help them. Anything can be included in the budget as long as it addresses the participant's personal assistance needs. Fourth, consumers managing their own budget are provided with financial management and counseling services. Fifth, participants must develop a back-up plan showing how their needs will be met if their usual worker is not available.

Original Cash and Counseling Demonstration Overview

The goal of the Cash and Counseling Program is to improve Medicaid beneficiaries' satisfaction and quality of life by increasing their control over their personal care services. The Cash and Counseling demonstration offered eligible Medicaid beneficiaries the opportunity to receive a monthly individualized budget to purchase supportive services that address their personal assistance needs. In the original demonstration the consumers could have received the actual cash (as long as they passed a skills test showing they could handle all the relevant employer functions), but the vast majority of participants preferred to have a bookkeeping/check writing/tax paying financial management service handle those concerns on their behalf. The five year demonstration was implemented in Arkansas, New Jersey and Florida in 1998, 1999, and 2000 respectively. Each state set its enrollment policy. Florida restricted enrollment to beneficiaries who were already using demonstration-covered services. New Jersey restricted enrollment to beneficiaries who had been assessed for such services. Arkansas enrolled existing beneficiaries and new applicants who were not already using personal care services, it did require such beneficiaries to agree to pursue personal care services from an agency in the event they were randomly assigned to the control group. These states' enrollment policies helped prevent the enrollment of beneficiaries who wished to receive the monthly cash allowance but would not otherwise use personal care services or home and community based services despite being eligible.

The enrollees of the Cash and Counseling demonstration included elders (ages 65+); adults with disabilities (ages 18-64) and, in Florida only, children with developmental disabilities. The targeted sample-sizes were 2,000 adults in each of these three states and 1,000 children with developmental disabilities in Florida. States were expected to meet the enrollment target within 12 months' time. All 3 states used existing programs as feeder programs for the Cash and Counseling demonstration. Both Arkansas and New Jersey used their Medicaid personal care option programs as the feeder programs. Florida used

the Medicaid 1915c Home and Community-based long term care waiver program as its feeder program. All three states took much longer than the 12 months' expected time to meet or nearly meet the sample-size targets: Arkansas enrolled 2,008 beneficiaries after 29 months; New Jersey enrolled 1,755 beneficiaries after 33 months; and Florida enrolled the targeted 1,000 children after 15 months and 2,820 adult beneficiaries after 26 months.

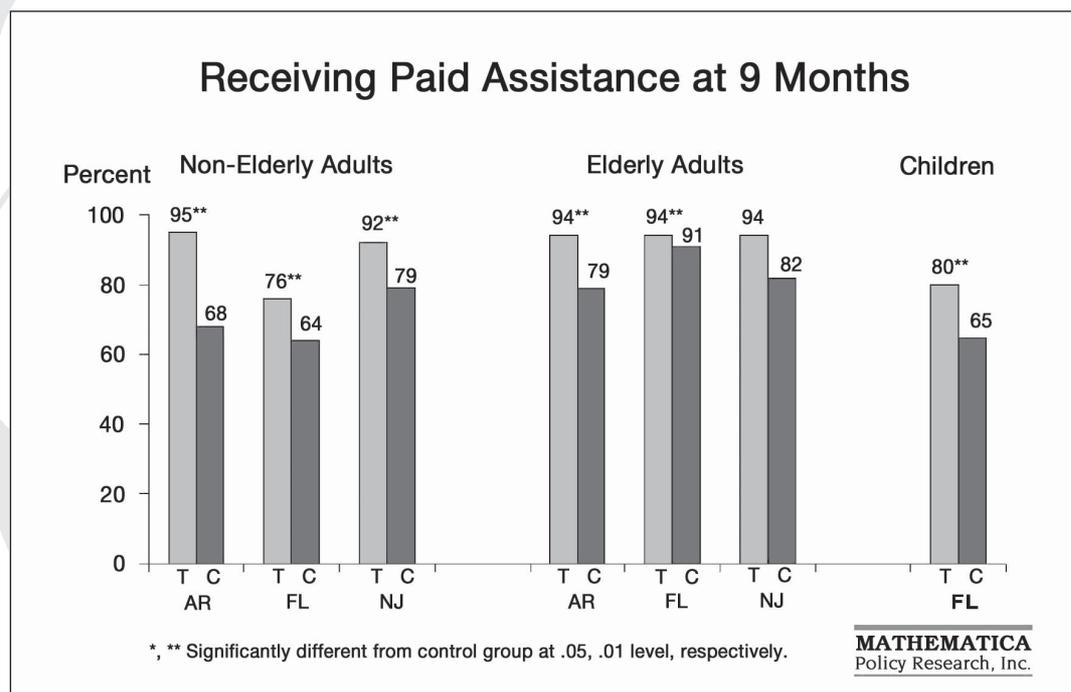
Enrollees in the Cash and Counseling demonstration were randomly assigned into either the demonstration group or the control group. Enrollees in the demonstration group received the cash allowance and the supportive services under the Cash and Counseling program while enrollees in the control group received their personal care services from traditional agency providers.

Results of the Cash and Counseling Demonstration

1. Enrollees in demonstration group received significantly more paid personal assistance than control group enrollees.

Figure 1 shows the differences in percentage of enrollees receiving paid personal assistance between the demonstration group and the control group at 9 months after enrollment. For non-elderly adults, Cash and Counseling enrollees received significantly more paid assistance than control group enrollees in all three states. For elderly adults, Cash and Counseling enrollees received significantly more paid personal assistance in two of the three states, Arkansas and Florida, but not in New Jersey. For children with developmental disabilities in Florida, Cash and Counseling enrollees received significantly more paid personal assistance than control group enrollees.

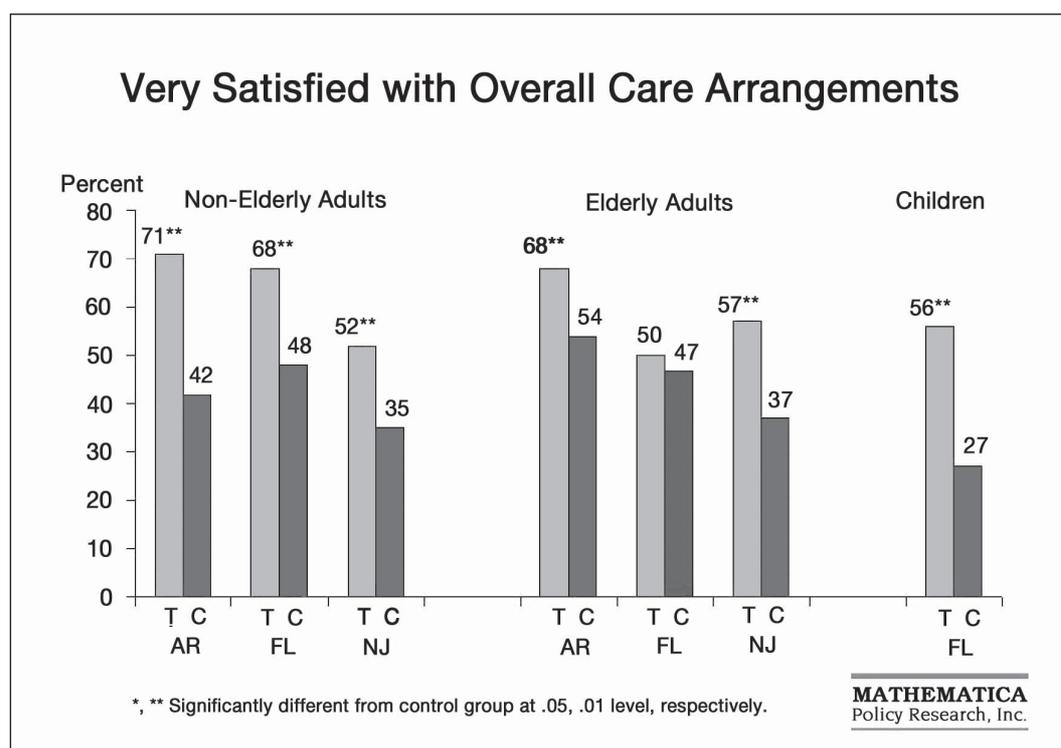
Figure 1. Differences in receiving paid assistance at 9 month between demonstration group enrollees and control group enrollees.



2. *More Cash and Counseling enrollees were very satisfied with overall care arrangements than control group enrollees.*

Figure 2 shows the percentage of enrollees who were very satisfied with overall care arrangements between the Cash and Counseling group and the control group across three states. For non-elderly adults with disabilities, significantly more demonstration group enrollees were very satisfied with their overall care arrangement than the control group enrollees in all 3 states. For elderly adults, significantly more demonstration group enrollees in Arkansas and New Jersey were very satisfied with overall care arrangement than the control group enrollees. For children with developmental disabilities in Florida, significantly more demonstration group enrollees were very satisfied with overall care arrangement than the control group enrollees.

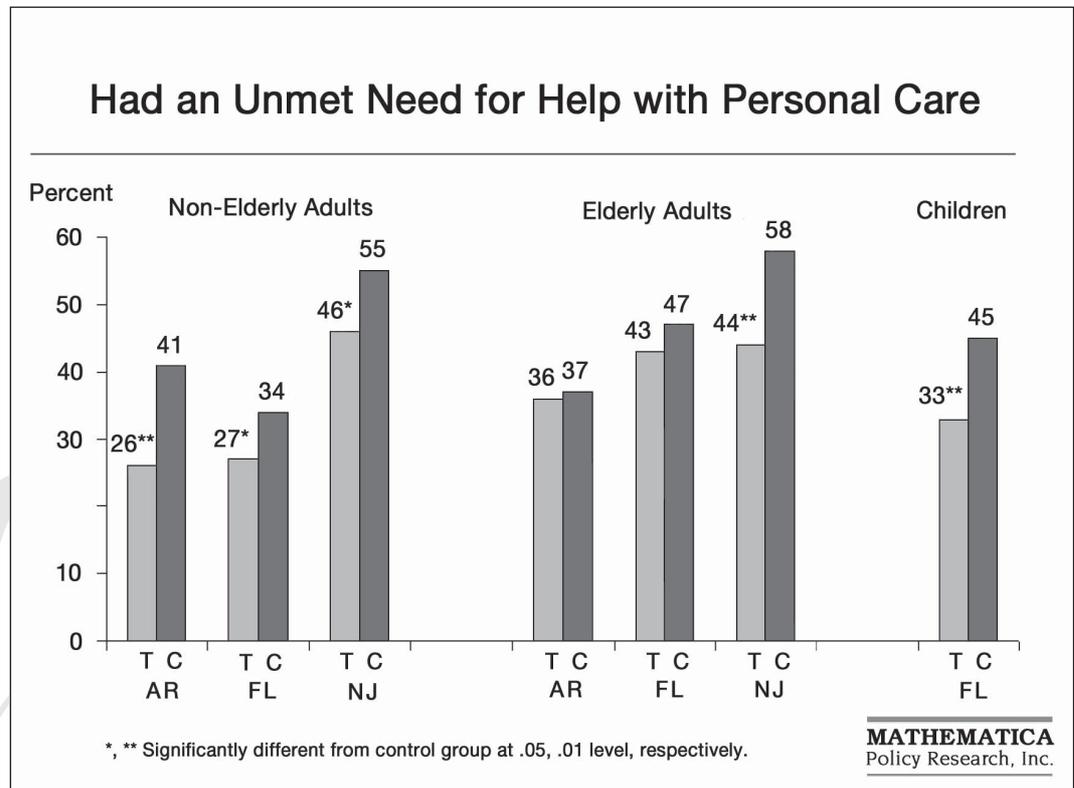
Figure 2. Satisfaction with Overall Care Arrangement between Cash and Counseling enrollees and control group enrollees.



3. *Fewer Cash and Counseling enrollees had unmet needs for help with Personal Care than the control group enrollees.*

Figure 3 shows the percentage of enrollees who had an unmet need for help with personal care for both the demonstration group and the control group. For non-elderly adults, significantly fewer Cash and Counseling enrollees had an unmet need than the control group enrollees in all 3 states. For elderly adults, significantly fewer elderly demonstration group enrollees had an unmet needs in New Jersey than the control group enrollees. For children in Florida, significantly fewer Cash and Counseling enrollees had an unmet need than the control group enrollees.

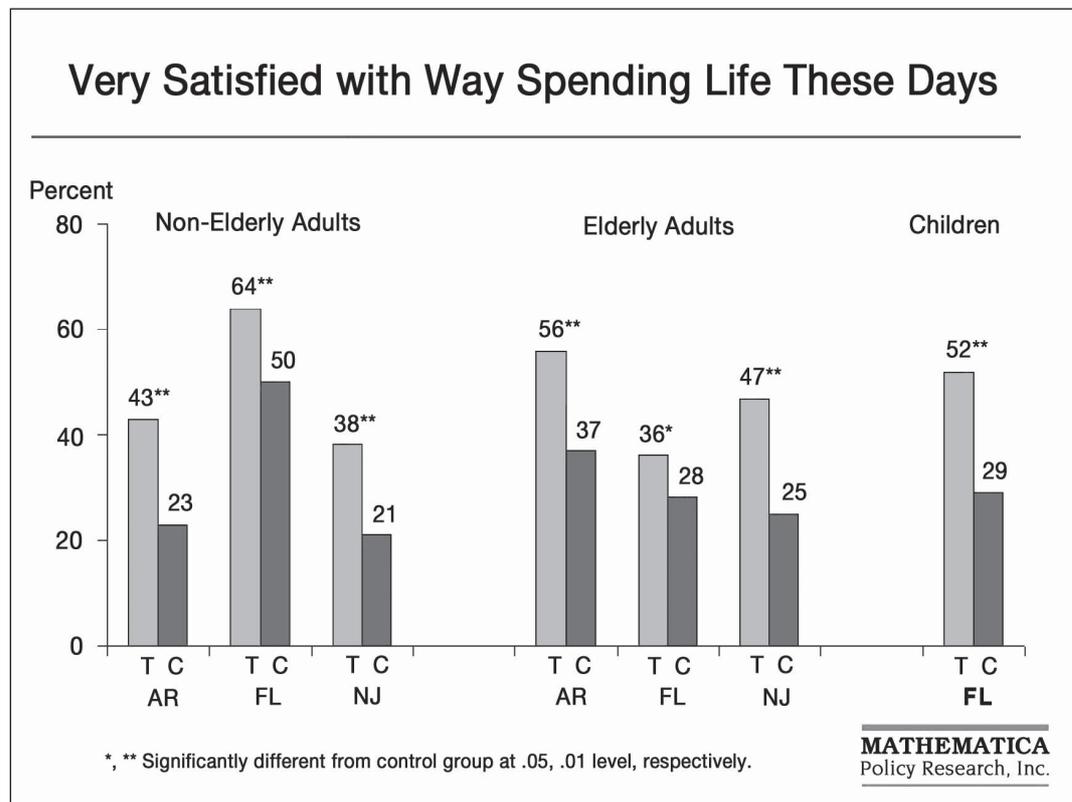
Figure 3. Unmet Needs for Help with Personal Care between demonstration group enrollees and control group enrollees.



4. More Cash and Counseling enrollees were very satisfied with “Way Spending Life These Days” than the control group enrollees in all 3 states

Figure 4 shows the differences in satisfaction with “ways spending life these days” between Cash and Counseling enrollees and control group enrollees. For non-elderly and elderly adults, significantly more demonstration group enrollees reported being very satisfied with “ways spending life these days” than the control group enrollees in all 3 states. For children with developmental disabilities in Florida, significantly more Cash and Counseling enrollees reported being very satisfied with “ways spending life these days” than the control group enrollees.

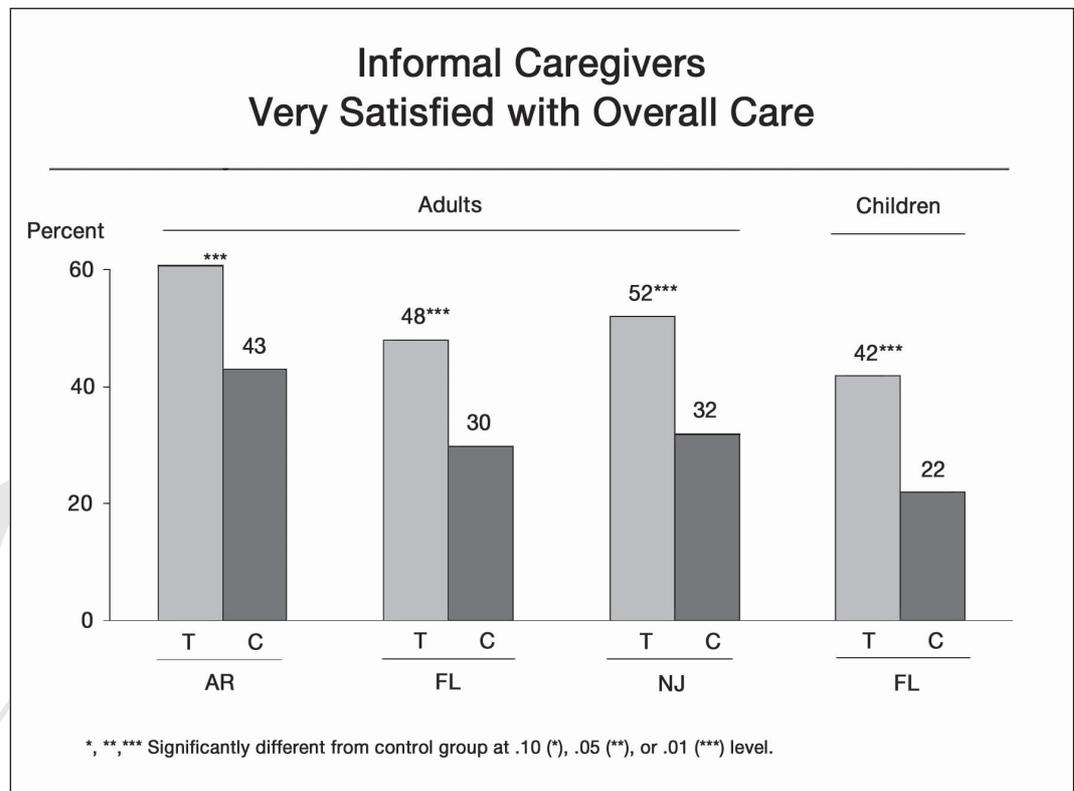
Figure 4. Satisfaction with Way Spending Life These Days between Cash and Counseling participants and control group participants.



5. Informal caregivers of Cash and Counseling enrollees were more apt to be very satisfied with overall care than the control group enrollees

Figure 5 shows the differences in informal caregivers' satisfaction with overall care between Cash and Counseling enrollees and control group enrollees. For adults, significantly more informal caregivers of Cash and Counseling enrollees reported very satisfied with overall care than the control group enrollees in all 3 states. For children with developmental disabilities in Florida, significantly more informal caregivers of Cash and Counseling enrollees reported being very satisfied with overall care compared to the informal caregivers of control group enrollees.

Figure 5. Informal Caregivers' Satisfaction with Overall Care between Cash and Counseling enrollees and control group enrollees.



6. *Cash and Counseling enrollees had better health outcomes than the control group enrollees*

The Cash and Counseling evaluation also looked at health outcomes, utilizing eleven measures including decubiti (bed sores), contractures, falls, etc. Looking at these eleven measures across the seven populations in the study, never did the traditional agency-delivered model show statistically more favorable results and in one-third of the measures the participants who managed their own budgets not only did better; they did 20 to 50 % better.

7. *The effect of the Cash and Counseling program on Medicaid costs was inconclusive.*

Cash and Counseling enrollees had a higher personal care service costs than the control group enrollees in all 3 states at the end of the first year. In Arkansas and New Jersey, the higher costs were mainly because control group enrollees received substantially less care than authorized. In Florida, the higher costs were mainly because children and adults with developmental disabilities got larger benefit increases after assigned to the demonstration group.

Other Medicaid non-personal care service costs were moderately lower for Cash and Counseling enrollees in all 3 states. For example, in Arkansas, demonstration group had 40% fewer admissions to nursing facilities in second year than the control group.

The effect on total Medicaid Costs were mixed. In Arkansas, there was no significant difference in total Medicaid costs between demonstration group and control group by the end of year two. The increase in personal care cost was off-set by the reduction in nursing facility use and other waiver costs. In New Jersey and Florida, the total Medicaid costs went up 8 to 12%. But these two states have learned how to control costs.

Policy Implications

Overall, the Cash and Counseling demonstration showed that this new consumer directed program can increase enrollees' access to care and also greatly improve their quality of life. Caregivers of these demonstration enrollees also benefited greatly. Although states may be concerned about costs, they have learned how to control them.

Expansion States

Because of the promising outcomes of the Cash & Counseling enrollees, the demonstration program was expanded in 2005 to twelve new states, including Alabama, Illinois, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia. Table 1 shows the details of the new Cash and Counseling expansion programs in these 12 states.

State (Start Date)	Participants (Target for October 2007)	Target Population	Lead Agency	Waiver
Alabama (early 2007)	90	Elderly/Adult Medicaid Recipients with disabilities	Department of Senior Services	1915j State Plan
Illinois (2006)	500	Elderly Community Care Program Participants	Illinois Department on Aging	
Iowa (2006)	400	Elderly with disabilities eligible for HCBS waivers	Iowa Department of Human Services	1915(c)
Kentucky (2006)	250	Individuals enrolled in waiver programs	Cabinet for Health and Family Services, Medicaid Services	1915(c)
Michigan (2006)	600	Elders/younger persons with physical disabilities	Long Term Care Supports and Services, Community Health	1915(c)
Minnesota (2004)	743	Older adults/adults with physical disabilities	Department of Human Services	1915(c)
New Mexico (2006)	400	Medicaid recipients and persons w/ brain injuries	New Mexico Aging and Long-Term Services Department	1915(c)
Pennsylvania (early 2007)	400	Elderly and persons with physical disabilities	Governor's Office of Health Care Reform	1915(c)
Rhode Island (2006)	400	Adults with disabilities and elders eligible for waivers	Department of Human Services, Center for Adult Health	1915(c)
Vermont (2006)	250	Elders and adults with disabilities	Department of Disabilities, Aging and Independent Living	1115
Washington (2006)	100	Adults with disabilities and elders requiring care	Department of Social and Health Sciences	1915(c)
West Virginia	400	Persons with mental and development disabilities	Bureau of Social Services	1915(c)

The Future of Consumer-Directed Programs

Cash and Counseling is a form of consumer directed care. According to Doty and Flanagan (2002), there were 139 consumer-directed home and community-based support services programs in 48 states in the United States. Most of these programs (58%) were relative small, serving less than 1,000 enrollees. Sixty-five percent of them were implemented since 1990. Most of them (88%) were permanent and only 22% were experimental. There were about 486,000 consumers in these consumer directed care programs and 51% were older adults.

Currently, there are 79 million Americans over the age of 65. Of those, approximately 5 million are Medicaid beneficiaries. 42 million older adults are covered by Medicare. According to a 1997 study released by the AARP Public Policy Institute, 76% of people over the age of 50 would prefer to manage their own home care services rather than receive services managed by an agency. As the baby boomers age, more elders will prefer to have the option of managing their own care when home care assistance is needed.

Consumer Directed Care in Hong Kong

Like the United States and other advanced industrial societies, Hong Kong is facing a rapidly ageing population. According to Hong Kong government data, the elderly population will increase to 24.3% of the total population by 2031. Traditionally, long term care in Hong Kong is heavily skewed toward institutional care. Currently, about 70,000 frail elders are living in about 880 residential homes. In a home and community care services setting, most, if not all, services are provided through the agency-delivered services model. Elders and their family members have very few choices on the services they needed and how these services are delivered. Given the lack of experience in consumer direction, some may argue that Hong Kong is not ready to develop its own model of consumer directed care. We will try to dispute this myth by addressing the following 3 questions:

1. Is consumer directed care good for Hong Kong elders?
2. Given the low educational level of elders in Hong Kong, are they ready to manage their own care?
3. Are the traditional service providers ready to provide needed support services for a new consumer-directed care model?

Is consumer directed care good for Hong Kong elders? Findings from the Cash and Counseling demonstration showed that enrollees and their family members were more satisfied when they managed their own care. With an emergency support system in place, the quality-of-care of the enrollees was not compromised. Once the government learned how to control the costs, consumer directed care did not increase the overall costs of long term care.

The experience from the U.S. suggests that the potential benefits of consumer directed care out-weight its potential costs. There is no reason to believe that Hong Kong cannot realize at least some of these benefits if it develops its own consumer directed long term care option. Given Hong Kong is one of the most market driven economies in the world, the city should allow elders and their family to have an option to manage their own care as an alternative to the existing agency-delivered services model. The new consumer directed model should be developed as an option to augment the existing agency-delivered model, not to replace it.

Are elders in Hong Kong capable of managing their own care? Given the relatively low educational level of Hong Kong elders, some may worry that Hong Kong elders are not capable of managing their own care. Findings from the Cash and Counseling demonstration showed that even for adults and children with developmental disabilities, with support from their family members and representatives, they could still manage their own care. Despite the relatively low educational level of many Hong Kong elders, they can still manage their own care with or without help from family members or representatives. It is true that consumer directed care may not be appropriate for everyone. If implemented as an option, those who can and are willing to manage their own care, with or without the help from others, should be allowed to do so. Consumer direction should be developed as an option to enhance the current agency-delivered care, not to replace it.

Are the traditional service providers ready for providing needed supportive services for a new consumer directed care model? The Cash and Counseling demonstration found that initial resistance to consumer direction came mostly from traditional service providers. However, under favorable market conditions and incentives, traditional providers would quickly transform themselves to provide supportive services for enrollees of consumer directed care. For-profit providers may also step in to fill the gap if traditional service providers fail to provide the needed supportive services. The increased market competition will potentially enhance the quality of care and lower the total costs.

We suggest that Hong Kong should consider developing its own model of consumer directed care. The consumer directed services model should be implemented as a new option to augment the existing agency-delivered service model. The new model should be evaluated to understand how different cultural, political, and socioeconomic characteristics affect the adoption of consumer direction in Hong Kong. With proper supportive services, consumer direction may increase the quality of life of elders in Hong Kong without increasing the costs or compromising the quality of care.

Useful Resources:

Pamela Doty and Susan Flanagan, "Inventory of Consumer-Directed Support Programs," Office of Disability, Ageing and Long-Term Care Policy, <http://aspe.hhs.gov/daltcp/reports/highlight.htm>, 2002.

Chapter 5

**Examples of How to
Enhance Quality of Life of
Older People in
Residential Facilities**





Chapter 5

Green House Nursing Homes as an Example of a Policy-Related Research Project in Residential Care

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This chapter describes the conceptualization and testing of a new model of nursing home known as a Green House. The Green House[®] is a trademarked concept that revolutionizes nursing home care in terms of its physical plant, its staff organization and roles, and the philosophy guiding care. This chapter has several goals. First, it describes the approach of the Green House and the results of the evaluation of the first Green House project in Tupelo, MS. Even more importantly, this research experience is used as an example of the importance and the challenges of building a research program into a closely-watched social experiment regarding residential care. It is a companion piece to a chapter by Kevin Mahoney in these proceedings that describes the carefully planned research into a cash allowance program to fund community care and the later dissemination of that research.

Background

When new ideas are conceptualized and tested for long-term care delivery, a related research agenda can be particularly helpful to study the effectiveness of the change in achieving intended outcomes, to identify any unintended positive or negative consequences, and to document issues and challenges in implementing and sustaining the change. Often such changes are small-scale and the provider organizations study the changes themselves as part of their ongoing monitoring of their own activities. If the ideas call for dramatic reorganization of the way a service is delivered, externally conducted research is needed. Typically, difficult decisions must be made about when in the course of implementing a service change, a full-blown evaluation is appropriate. Although a randomized design with random assignment to the experimental group experiencing the change may be the most convincing way of testing an innovation, such randomization is often politically or ethically impossible. That is particularly true when the test involves a new form of residential care; it is rarely appropriate to randomly assign applicants for housing and services to a particular place where they will live.

In the United States, several important demonstration projects have been implemented concerning long-term care services for older people in the last several decades of the 20th century and thereafter. In the 1970s and 1980s, numerous projects were undertaken in particular states to test whether provision of community services to low-income people prevented their need for nursing home care. The better designed studies with appropriate comparison groups seemed to suggest that community care did not have the desired effect, probably because of inadequate targeting of the intervention to those who would actually use nursing homes (Kemper, Applebaum, & Harrigan, 1987). Accordingly, a highly ambitious national demonstration project was launched, the Long-Term Care Channeling Demonstration, which used a randomized design to study the effects of providing case management and providing additional community services for people who were carefully assessed as functionally eligible for the nursing home level of care. The study entailed “Channeling projects” in 10 states. In 5 of the projects the consenting clients were randomly assigned to receive customary care or to receive intensive case management and to be eligible to receive gap-filling services from a pool of money; in the other 5 states the consenting clients were randomly assigned to receive customary care or to case management in a program where case managers could purchase community care up to a budget amount that did not exceed about 75% of the costs of nursing home care. This demonstration examined client outcomes such as functional status, health status, psychological well-being, satisfaction, death rates, and rates of moving to an institution. It also examined the extent to which family members continued to give help to channeling clients and the control group. Many outcomes related to utilization and costs of services were examined for both groups, including hospital costs. The channeling evaluation also contains qualitative components on the conduct of the case management, and the development of a service capacity. Analyses from this demonstration have informed long-term care in the United States for decades (Carcagno & Kemper, 1988; Kemper, 1988; Stephens & Christianson, 1986; Thornton, Miller-Dunston, & Kemper, 1988). Other community care projects that have had similarly large-scale evaluations include the Alzheimer’s Medicare Demonstration, which used a randomized trial to study the effects of adding case management and community care for people with Alzheimer’s disease (Fox, Yordi, & Newcomer, 2000); the national study of the Program of All-Inclusive Care for the Elderly (PACE), which integrated the acute-care and long-term care in a capitated program built around day-health care (Branch, Coulam, & Zimmerman, 1995; R. L. Kane, Homyak, Bershady, & Flood, 2006); and the national Cash and Counseling demonstration, a randomized study of using cash benefits in lieu of in-kind services to low-income people needing long-term care (Carlson et al., 2005).

In the residential care sector, we cannot point to large randomized trials of the type discussed above for community care. Nursing homes emerged in the 1950’s and 1960’s in the United States and by now are a well-defined and highly regulated entity. A huge research literature is available on the effects of various interventions in nursing homes, some of which we reviewed for a 1987 book (R. A. Kane & Kane, 1987). There is also a

large but uneven literature on assisted living programs, concentrating on the types of clientele served and the services received (R. A. Kane, Chan, & Kane, in press). This literature is highly descriptive and is rendered difficult to interpret because of the many different definitions of assisted living, lack of clarity about who it should serve, and uncertainty about its goals, including whether assisted living is meant to be a step on a continuum of intensity ending in nursing home care or a choice for people who might otherwise use nursing homes (Hawes & Phillip, in press; Stone & Reinhard, in press; Zimmerman & Sloane, in press). Outcomes for residents of various forms of assisted living, including adult foster homes, have sometimes been compared to outcomes for nursing home residents in large-scale studies, but careful analytic controls are needed to take account of likely differences in the characteristics of residents in each service sector (Frytak, Kane, Finch, Kane, & Maude-Griffin, 2001; R. A. Kane, Kane, Illston, Nyman, & Finch, 1991; Zimmerman et al., 2004).

The culture change movement in nursing homes described in Rosalie Kane's earlier chapter has not been characterized by a strong research base. The concept of a Green House type of nursing home was developed in its ideal outlines by William Thomas, who had previously identified boredom, loneliness and lack of meaning as key problems for nursing home residents and who had formulated a series of principles to empower both residents and frontline staff and produce habitats where seniors could flourish that became known as the Eden Alternative (Thomas, 1999; 2003; 2004). Thomas quickly became convinced that the formulations in the Eden Alternative could not be readily developed in the hierarchical structure of large United States nursing homes. At the same time, he aimed to develop a model that could largely be implemented within the regulatory structure of the United States nursing home and within the reimbursement levels of the various State Medicaid programs, which subsidize at least 50% of nursing home care in the United States. Those who developed the Green House as a concept, and later those who developed the first application, hoped for a strong research programme to be associated with the effort.

The Intervention

Green House as a Concept

The model sketched by William Thomas for a reformed nursing home entailed three major kinds of changes: changes in the physical environment for living and care both in scale and in details; changes in the organizational structure and deployment of staff; and philosophical changes in the orientation to elder development and quality of life that shaped all programmes and care routines. Each of the specific elements in the Green House concept can be justified by psychological and social research in areas of ageing, individual and group behavior, affects of environment on behavior, and similar topics (see Rabig, Thomas, Kane, Cutler, & McAlilly, 2006).

Physical environments. The median nursing home in the United States has about 100 beds though many are much larger; typically they are organized into nursing units of about 40 beds, the rooms are situated along double-loaded corridors, and typically bedrooms and lavatories are shared by one or more residents and showers and tubs are located on each unit for general use. Food is prepared in a central kitchen and consumed in large dining rooms (or delivered to rooms, if residents cannot go to the dining room). More recently food has been delivered to smaller dining areas in the units, but residents are far removed from the areas where food is prepared.

Green Houses, in contrast, were to be small self-contained houses for 7 to 10 residents. Each resident has a singly-occupied room with an attached bathroom and a full shower. The shared space in a Green House centers around a living area with a fireplace (the hearth), the dining area, and the large, residential style kitchen to which residents have access. Other Green House areas include a smaller sitting room that can hold a television, outdoor patio space, a den (which serves as an office for staff), a laundry with residential style washers and dryers, and a spa and beauty shop area. Although details or residential design may vary (and indeed must vary between urban and rural communities) and although many details have been worked out with the first iterations of Green Houses, the general principles for the space can readily be summarized. Green Houses were expected to be of residential scale, the space was to be inviting, opportunities were provided for privacy and interaction with family and for normal communal life, and furnishings were expected to be “non-institutional” and, where possible, provided by residents. Residents were welcomed into kitchens and laundry areas. One of the slogans early on was “if you would not have it in your own home, it should not be in a Green House”, which was to be a home with all the symbols of home. Ceiling lifts were built into residents’ rooms to enable easy one-person transfers from bed to chair or bathroom, and other forms of function-enhancing or life-enriching technology were envisaged.

Organizational and staff. A group of Green Houses would comprise a nursing home with its management holding a nursing-home license. They were originally envisaged as scattered in a residential neighborhood, perhaps with a radius of several miles. For example, 10 ten-person Green Houses would be licensed as an approximately 100-bed nursing home. The license-holder would have the responsibility to meet regulatory requirements and would be able to achieve some economies of scale for functions such as administration, human resources, training, purchasing and the like. The frontline staff in each Green House was to be dedicated to a particular Green House rather than rotate among multiple Green Houses. For the change to be affordable, this frontline staff was envisaged at the level of nurse’s aides, also known as certified nursing assistants (CNAs), who in the United States, receives 90 hours of pre-employment training and works under the supervision of nurses. They were to have a different designation to reflect their new role; Thomas suggested calling the new CNA a *shahbaz* (plural, *shahbazim*), a newly coined word without any previous connotations. Unlike CNAs, who ordinarily perform personal care and nursing

tasks only, the Shahbazim roles were broadened to include ordering, cooking, and serving meals; performing light housekeeping; and doing residents' personal laundry. They would also perform the usual personal care tasks (bathing, dressing, feeding, toileting assistance) and implement the care plan of the various professionals. Further, the shahbazim would serve as elder development specialists; they would come to know each elder under their care very well, and they would attempt to enable the quality of life the elder preferred. The usual dietary departments, housekeeping departments, and laundries in nursing homes would be eliminated or very much downsized (for example, a commercial laundry might be necessary for linens, and a housekeeping service for heavy cleaning such as ovens and windows).

Other clinical personnel, such as the medical director, the registered and licensed nurses, the physical therapists, occupational therapists, dietitians, pharmacist, social workers, and recreation therapists were all construed as part of a "*clinical support team*" who would visit the Green Houses and develop plans of care. Other supportive personnel such as medical records, maintenance, purchasing, and human resources personnel would work directly with the administrator to facilitate all the Green Houses. The administrator was to be called a "*guide*" and was meant to bring out the abilities of all personnel. The shahbazim were to report to a guide, in contrast to a traditional nursing home where the CNAs report to a supervising nurse, who ultimately reports to the Director of Nursing. Certain required personnel, such as Director of Nursing, Director of Social Work, and Activities Director would re-configure their roles to develop the policies, framework, and educational support to assist the shahbazim and the clinical support team.

Philosophy. Excellent health care was perceived as necessary as in any nursing home, but goals related to residents' quality of life predominated; residents' lives were not meant to be narrowly constrained by their need for health care. One emphasis was on ordinary life and interaction, where residents and their families were free to pursue individual interests and preferences with a minimum of fixed routines. In that sense, the philosophy was geared towards individualization of care and services. At the same time, the hope was to develop a nurturing community out of the "accidental community" of the Green House population, its shahbazim and its visitors. In his earliest formulations, Thomas envisaged a heavy presence of the larger community in the Green Houses, and that each Green House would have assigned to it a volunteer who would be a special resource to the elders and Shahbazim. This person, called a "*sage*," was envisaged as a personage with particular wisdom who functioned outside any of the formal supervisory relationships. Green Houses were encouraged to develop communal interests and projects and particular traditions. Original thoughts were that each Green House would establish its own menus and the residents and their family members would develop cookbooks based on family recipes, that meals would be leisurely events taking place around a single large table, and that a fireplace in each living area would exemplify warmth and homeiness. Trappings of a "medical model," such as medication carts, were to be avoided.

First Implementation

The idea of the Green House was discussed for a number of years before its first implementation. A National Green House Project was established in upstate New York under direction of William Thomas, committees were formed to discuss its ramifications, and national congressional hearings were conducted. Methodists Senior Services of Mississippi (MSSM), a non-profit non-governmental organization (NGO) that administered a group of 10 residential care communities, was the first organization to decide to implement a Green House. MSSM was a highly respected organization that had been operating residential communities for seniors since the 1960s. In its 10 locations, it developed independent housing (duplexes and houses available on life-time lease), low-income apartment housing, and assisted living. Only 3 of its campuses operated nursing homes. Its flagship campus in Tupelo, MS operated a 140-bed nursing home that was becoming out-dated as a physical plant and was in need of major renovations. MSSM's corporate office, also located in Tupelo, became intrigued by the Green House idea and abandoned its plans to renovate a section of the traditional nursing home in favor of building 4 10-person Green Houses in a residential section of campus. The money used for the initial construction was originally donated by Alzheimer's charities, and, therefore, two Green Houses were earmarked for the residents of the locked special dementia care unit in the traditional nursing home. A list was developed of residents who would like to move to the Green Houses, and the other 20 initial residents were selected in order of their length of time in the community. MSSM intended to expand the Green House model if it proved successful. Until that time, when vacancies occurred in a Green House, they were filled by residents of the existing nursing home or by residents in the community whose care needs had increased to the nursing home level.

Although the Green House Concept called for radical change in nursing homes and a complete transformation of existing arrangements, many of its details were left to be worked out in practice. During the time that MSSM was building its Green Houses, a philanthropic foundation, The Robert Wood Johnson Foundation, had awarded a grant to William Thomas and colleagues to encourage the development of Green Houses in general. An initial focus of the grant was to provide technical assistance to the Tupelo group. This included planning and conducting training for the first group of Shahbazim, and developing operational details, including the precise staffing pattern for each Green House and for the clinical support team. During this development stage, the concept of self-directed work teams was introduced; adapted from ideas developed for more traditional nursing homes (Yeatts & Seward, 2000), the self-directed teams were comprised of all the Shahbazim working on all shifts. Initially each team elected an overall team coordinator, a coordinator for scheduling, and a coordinator for food, a coordinator for cleaning, and a coordinator for care; all these were monthly roles, renewable once. The teams were responsible for their own scheduling; they planned their meeting agendas, and invited central personnel to the meetings as they thought needed. The technical assistance efforts were spearheaded by Judith Rabig, a nurse and gerontologist; she not only concerned herself with implementing the Green

House model, but also with the clinical programmes, such as the assessments, care planning, record-keeping, and communications. A number of changes were made that could not be said to be directly part of the Green House model, but rather designed to ensure good communication and regulatory compliance during a period of transition.

By May 2003 the first four Green Houses were ready to open; move-in was done in a phased manner over the next month. By this time, local and national media were intensely interested in this emerging social experiment, as were numerous professional and advocacy groups. With separate funding, a high-quality film was developed depicting the move to one of the Green Houses. Other organizations interested in developing Green Houses were particularly intent in observing the results at Tupelo.

Approach to Research

MSSM had committed to a research programme for the Green Houses, and funding for such research was granted by the Commonwealth Fund of New York City. The challenge was to determine how to best capture the development and effectiveness of these 4 Green Houses within a reasonable budget and as appropriate to its stage of development. The initial research effort was construed as related to feasibility as well as outcomes of the model, and included expectations that templates would be generated for further evolution of Green Houses should that seem justified by the outcomes. Phase 1 of the study lasted for 2 years; it was a mixed-method study using quantitative and qualitative methods, it was longitudinal, and it utilized comparison groups. Phase 2 of the study was a much smaller effort geared towards looking at the issues involved in expanding Green House to an additional 6 Green Houses on the Tupelo campus and the issues involved in evolving and sustaining the innovation over the first year that 10 Green Houses were operating on the campus and the traditional nursing home was reduced to 24 beds.

Phase 1. A longitudinal mixed-method evaluation of 4 Green Houses

Design A quasi-experimental design was used with two comparison groups: the traditional nursing home, and a nursing home on a different MSSM campus 70 miles away where no Green House was planned. Because randomization was not feasible, the two comparison groups each served a function. The traditional nursing home was the closest comparison because it had the identical management in the identical local community, but was open to be influenced by the Green House, either for better (because of spin-off changes) or for worse (because attention was drawn away from the traditional model). The second nursing home was a less precise comparison but did not have the potential contamination of being the organization sponsoring the experiment. Primary subjects for quantitative analyses were the residents in each of the 3 settings, their family members, and the frontline staff (that is, the Shahbazim in the Green Houses and the CNAs in the other two settings). Four waves of data collection were used: baseline just at the time of move-in to Green Houses, and at 36-month intervals thereafter.

Sample. All Green House residents, a family member for each, and all Shahbazim at baseline were part of the sample. At subsequent data collection times, anyone living or working as a Shahbaz in the Green Houses were in the sample. At the sponsoring nursing home (Cedars) and at the other comparison nursing home (Trinity), all line staff were in the sample at each time period, and a sample of 40 residents was drawn, increased to 70 residents at Cedars by the second wave. When residents died, they were replaced in the sample. At each time period, an attempt was made to identify a family member for interview.

Hypotheses. It was hypothesized that Green House residents would have better quality of life and satisfaction, that Green House residents' care outcomes would be at least equal to that of the comparison settings; that family members would be more engaged and better satisfied with their family member's care and their own treatment as family members; and that staff would be more confident, felt more empowered to change resident outcomes, would know the residents under their care better, would experience greater job satisfaction, and would be more willing to remain on the job and in the field.

Data collection and measures. We conducted individual in-person interviews with each resident in the sample and either in-person or telephone interviews with family members. For each resident in the sample, we also performed a brief interview with a Shahbaz to elicit information about the resident's functional status and administered a standardized Multidimensional Observational Tool for Elderly Subjects (MOSES) (Helmes, Csapo, & Short, 1987), which uses objective items administered to staff to measure resident anxiety, depression, social engagement, and social contact. If residents could not respond to the interview because of cognitive impairment, a family proxy was interviewed. Using established scales, we measured self-perceived health, 11 dimensions of resident quality of life (R. A. Kane et al., 2003), emotional state (Brod, Stewart, Sands, & Walton, 1999), and social involvement (R. L. Kane, Bell, Riegler, Wilson, & Kane, 1983). Information was abstracted from residents' records to generate the information needed for case mix adjustment of the outcomes and to construct the quality indicators that are used for all nursing homes in the United States. Front-line staff members were interviewed in-person during non-working hours; each staff member received a gift certificate in appreciation.

Analysis. We compared mean values for all the variables of interest across settings for each time period. Most of the analyses use multiple regression methods to compare change over time for the settings; to increase the power of the sample, we combined data from all waves and introduced wave of analysis as a control variable. We also controlled analyses for age, gender, length of nursing home stay, and prior functional and cognitive status. More details on analysis methods for the resident data have been published (R. A. Kane, Lum, Cutler, Degenholtz, & Yu, 2007)

Other Components of the Study

Qualitative components of interviews. We added open-ended questions to all resident, family, and staff interviews at each time period. We were particularly detailed in the staff interviews for Green Houses so as to explore how they reacted to all the new features of their work environment such as expanded roles, self-directed teams, doing cooking, and the like. Further, we conducted special exit interviews for any line staff that left employment at any of the sites for any reason, and relatives of residents who died at one of the settings. (Only 2 Green House residents left the Green Houses other than because of death, and we also interviewed those family members.)

Implementation history and context. We conducted open-ended semi-structured interviews at intervals with all staff leadership at the Green House, including administrative and clinical staff to identify issues in the implementation of the program. We also interviewed key stakeholders at the local and state level to identify the market reaction to the Green Houses and the views of public officials.

Environmental study. The changes in physical environment were a big component of the Green House, and the environmental component of the study was highly developed. Using established tools, we assessed the room and bath environments of all the residents in each setting (Cutler, Kane, Degenholtz, Miller, & Leslie., 2006). We also utilized the mixed-method approach known as post-occupancy evaluation (POE) to examine how the spaces were actually used in each Green House at each time period. POEs entail systematic structured observation of spaces at specified samples of time, and also interviews with those who use the space (residents, workers, visitors).

Costs and business case. We were eager to examine the costs of the Green Houses in terms of both capital construction costs and operational costs. We were successfully able to isolate the construction costs. We planned to look at operational costs once the Green Houses reached a steady state, but these proved difficult to monitor because of personnel changes at MSSM and lack of records that separated each Green House and the traditional nursing home as separate costs and revenue centers.

Phase 2: Expanding and sustaining the intervention

Before the results of this research were available, MSSM had decided to move ahead with the expansion of Green Houses as soon as possible, in part because the demonstration appeared successful and in part because of the difficulty in simultaneously operating a traditional nursing home and Green Houses. Accordingly, additional money was raised, and 6 new Green Houses constructed. The new Green Houses had some modifications and improvements in physical design based on the initial experience. They were also developed as 12-person Green Houses. By November 2005, all 10 Green Houses were in operation. We implemented a much smaller-scale study to examine how the organization as a whole adapted to being almost entirely comprised of Green Houses. Of particular interest were: how roles were configured, how admission to each Green House was handled,

how new staff and residents are introduced, how the market has responded now that admission are coming from the general community, and how the 12-person houses compare to the 10-person houses. The methods entailed two long site-visits, the first about 3 months after the 10 houses were in operation and the 2nd about 9 months after the 10 houses were in operation during which post-occupancy studies and qualitative interviews were conducted.

Findings in Brief

Phase 1 of the analysis is largely completed. The purpose of this chapter was not to describe the findings in any detail. The findings for the resident quantitative outcomes have been published (R. A. Kane et al., 2007) and other peer-reviewed publications are in process to describe findings for family and staff outcomes, and the results of environmental studies. Briefly, we can say that all the hypotheses were confirmed. The Green Houses had better results that were statistically significant on many measures compared to one or both comparison groups. The findings were robust; different approaches to analyses yielded similar results. We can assert with confidence that residents at the 4 Green Houses had better quality of life and greater satisfaction than the comparison groups, that there was no diminution of clinical or functional outcomes, the quality indicators typically measured for nursing homes were as good or in a few items (such as proportion of decline in functional abilities) or better than the comparison settings. We can assert that family members were better satisfied. Staff results very highly favored the Green House; frontline staff members were much more satisfied with intrinsic elements of their jobs and their overall satisfaction was higher. However, these results are somewhat confounded by the fact that Shahbazim received substantially higher salaries than their CNA counterparts.

From the qualitative components of the study, we learned the challenges of implementation and the gradual process of overcoming skepticism among professionals. We learned that the clinical support team members needed more attention in the introduction of the model, and that leadership also needed attention. The comments of the shahbazim suggested areas to emphasize in their training and retraining - teamwork and culinary areas were particularly challenging for the shahbazim but also rewarding when mastered.

- The environmental work suggested areas that needed improvement in future designs, as well as areas of vulnerability for maintenance and management. Through the environmental studies we learned to use photographs as a research tool; photographs describe better than words if institutional kinds of practices have recurred, and they can be used to stimulate reaction and discussion.

What Next?

Implications of the Study

This initial study had extremely positive results over a sustained period. Nonetheless, it refers only to the first 4 Green Houses in one setting, and generalization needed to be done with care. We were aware of the intensive attention lavished on these initial Green Houses by technical assistants, professional groups, and the media. It was always possible that this attention contributed to the positive results. Another issue concerns how to attribute the positive results. The intervention was a total package, and the study described does not clarify how the care model, the philosophy, or the environment contributed to results, or what aspects of the changes were most important to achieving various outcomes.

The overwhelmingly positive research results were helpful in the decision of The Robert Wood Johnson Foundation to create a national rapid replication project and to support technical assistance towards the development of 50 Green Houses in 5 years (with the intent of a Green House in almost every state). NGOs interested in adopting Green Houses have been extremely interested in applying the findings to their settings. As researchers, we are cautious about moving beyond the data to widespread generalization.

Future Studies

As of the Spring of 2007, we are completing our analysis of the full Green House implementation in Tupelo. Meanwhile 6 other Green House nursing homes have opened, some of which plan only a limited number of Green Houses as part of their overall offerings. Many other Green Houses are in the development stage. In addition, some NGOs are developing their own small-house nursing home projects that do not carry the Green House trademark. As the idea of small-house nursing homes expands and becomes elaborated, numerous other opportunities will arise for research.

In studying the future of Green Houses, we are studying a moving target. Replication is too precise a word for this phenomenon. The MSSM Green Houses were the first model, and the first 4 houses in Tupelo differ from the next 6. Similarly, the new developments in the National Green House project are not replicating MSSM in all details but are evolving their own variants of Green House, while attempting to identify and retain the key components of the model. There is danger in premature orthodoxy about such components, however. Next generation Green Houses are interested in the precise staffing patterns in the first Green House, yet there is no evidence that these are the only configurations or even the best configurations to achieve outcomes and remain compatible to the model.

Qualitative elements remain important in future Green House study so that the field can understand the issues in developing this kind of nursing home. The environmental components also remain very important. Financial studies are needed to make “the business case” for Green Houses and other small-house variants.

Small-house nursing homes are evolving in a political context. Although the idea behind the original concept was to deliver the services at the same price as a conventional nursing home, some NGOs are arguing to state agencies that the funding levels should be higher for a Green House or small-house model. Some may even aspire to offer Green Houses or small-house nursing homes for private-pay markets only. As small-house nursing homes become more numerous, their results may need to be compared not only to traditional nursing homes but to assisted living settings. It will be of interest, also, to monitor whether small-house nursing homes are seen as appropriate only for a particular kind of nursing home resident, and whether the residents get discharged to more conventional nursing homes. Further experience, if studied during the evolution of the model, will show the extent to which small-houses work as a setting for rehabilitation after hospitalization, how well they work for people with dementia, and a host of other questions.

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DISCUSSANT 1

Response to “New Ways of Thinking about Long-term Care”

Dr. LAM Ching-Choi

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Introduction

Hong Kong is going to be challenged by an ageing population in coming decades. Fortunately, Hong Kong has a strong social service infrastructure for the elderly well known for its wide coverage, sufficient service varieties and universal accessibility. Building on this platform, I have the following recommendations to prepare ourselves to face the challenge of an ageing population and these thoughts are mostly stimulated by Prof. Kane’s and Prof. Mahoney’s presentations.

1. Development of Assisted Living

Compared with Western Countries, the development of assisted living in Hong Kong is still in an infancy stage. Elders are left with little choice if they choose to meet their housing and care needs together under one roof, especially when they prefer to live in community instead of institutions. A conducive housing policy should be in place for our vibrant developers to venture into this area.

2. Specialization in professional development

While general care is provided in many of our LTC settings with reasonable standards, professional expertise on specialized areas such as dementia care, rehabilitation service, end-of-life care, sleep & pain management and chronic illness care should be developed. This specialization should be apparent in various disciplines, i.e., doctor, nurse, social worker, and para-medical professional.

3. Use of Technology

Since most of the service provided for the elderly are heavily subvented or subsidized by the Government, initiatives from the private sector are only exceptions. As a result, the

use of advanced technology in elderly care is very limited in Hong Kong. By bringing in the commercial sector and shifting the emphasis from output to outcome measurement by funding bodies, it is hoped that this can be reversed. The first signs have already been seen in the Silver Hair Market Fair held recently.

4. Staffing Supply and Capacity Building

Career paths should be built by establishing the Qualification Framework for care staff in various LTC settings. With this in place, the labour force will be stabilized and expertise can be retained in the field.

5. Architectural Design of the Elderly Residential Settings

With creativity, the functional needs of staff should blend in with the needs of the elders who live in RCHEs. Opportunities for cross fertilization between care professional and architects should be created in order to bring in new concepts of design for future RCHEs.

6. Prolonging Healthy Lives

Health promotion efforts have been questioned not only by prolonging life expectancy, but also disability. With the decline in disability rates in the US from 1984 to 1999, we witness the possibility of shortening the disabled years while prolonging life. It is good news for health promoters, and resources should be re-allocated from curative to preventive care.

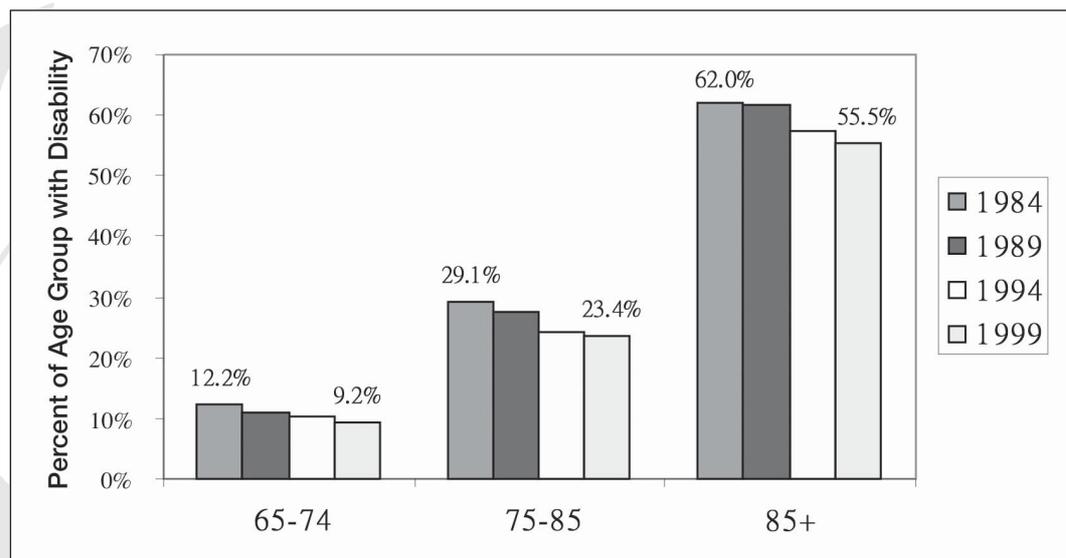


Chart 1: Disability Rates Among Individuals Aged 65 and Over by Age

Source: Brenda C. Spillman (2003) Changes in Elderly Disability Rates and the Implications for Health Care Utilization and Cost for the Office of the Assistant Secretary for Planning and Evaluation

7. Ageing in Community

A significant decrease in the use of nursing facilities among the oldest elders in the US was found in the recent two decades.

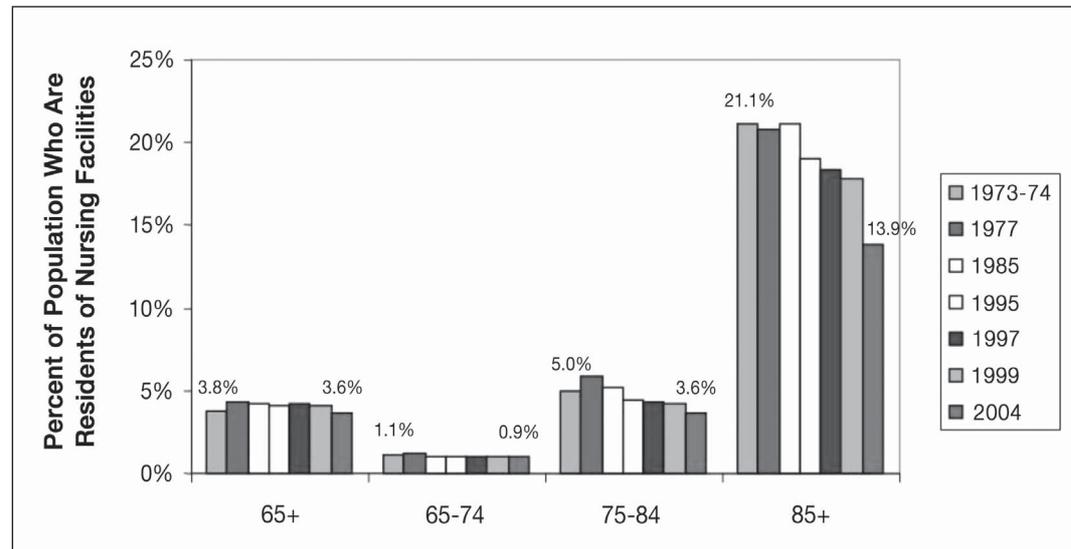


Chart 2: Significant Declines in the Use of Nursing Facilities Among Oldest Old

Source: 1973-74, 1997, 1988, 1995, 1997 and 2004 National Nursing Survey

It is only possible by providing choices for the elderly to stay in the community, shifting from provider-centered to client-centred service delivery philosophy, tapping the benefit of advanced technology and responding positively to the changes in societal values. Hong Kong should and is moving in this direction too.

8. Quality by enhancing Consumer Choice

Quality is achieved because of choice not in spite of it. A three-pronged approach should be used to enhance consumer choice in Hong Kong:

- i. Changing the delivery model: from service-based to individual-based by implementing a genuine case management system.
- ii. Changing the funding model: from per-facility to per-capita.
- iii. Creating a true market for consumers by encouraging investment from the private sector in the long-term care industry.

Conclusion

Some of these recommendations could be implemented in the near future and actual work has been commenced in many areas. However, some especially those with more far-fetched implications should be further discussed by the society in establishing directions.



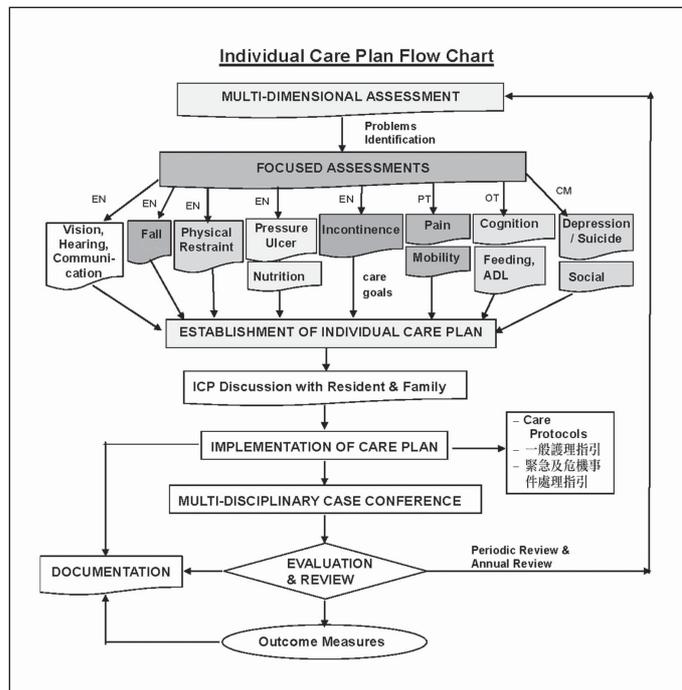
DISCUSSANT 2

Ms. Anita WONG

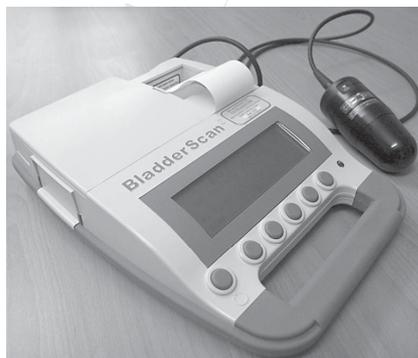
The Hong Kong Chinese Women's Club

Quality care for older individuals in long-term care residential facilities is for long a practice issue in Hong Kong. While we do have two quality assurance mechanisms in place, neither is effective in ensuring good quality service to older people. Our license regulation system is still struggling on basic low-level practice and inspections mainly focus on minor details. The accreditation certification system also has little impact as it is not related to government subsidies. On the other hand, consumer choice as a means to regulate service quality can hardly be exercised as quality subsidized residential places have a long waiting list and subsidized community care service is limited to one provider per service area. Thus maintaining quality care and enhancing the quality of life of people in residential facilities often depend on professional initiatives and ethical practice of individual service providers.

For the past two decades or so, our residential home has struggled hard to maintain quality care for our elderly residents. Since **clinical care** is the prominent service model in a long-term care setting, we have adopted both **continuous quality improvement (CQI)** and **quality assurance (QA)** in our clinical practice. Quality assurance involves looking for problems retrospectively by establishing an evaluation and monitoring system to detect errors and adverse outcomes. Continuous quality improvement is a data-driven process for seeking and assessing imperfections, responding to existing problems and preventing problems or uncovering opportunities for improving performance. The core of the CQI principle is a focus on the customer and thus the needs of the residents are our paramount concern. In doing so, we have established a comprehensive individual care planning mechanism including detailed focused assessments, multi-disciplinary case conferences, and care planning and evaluation with both residents and family members.



To ensure proper dispensing of daily clinical care by our multi-disciplinary staff team, we have established a series of **care protocols** including depression care, cognitive impairment care, fall management and prevention, incontinence care, pressure ulcer and wound care, drug management, infection control and others. In implementing these care protocols, we further collect clinical statistics on monthly or quarterly basis to monitor our service outcomes. These **quality statistics** include: prevalence of BPSD, cognitive impairment, depression, repeated fall, urinary incontinence, physical restraint, as well as incidence of new pain, fall, and skin breakdown, and numerous infectious diseases etc. Any abnormal occurrence would be handled immediately with caution by the multi-disciplinary staff team. In order to enhance care to needy residents, our facility has endeavoured to apply new and advanced equipment to provide appropriate care and assessment, such as the use of bladder scan for urinary incontinence care, and the installation of a Liko system to better manage new and repeated fall incidents.



Apart from clinical care, we believe that people who reside in a long-term care facility are entitled to the social and public services that are available to other older individuals residing in the community and that they should not be segregated from the rest of the society. We therefore have determined to operate the facility as a “**C&A Home without Walls**” by trying to integrate residential services with the community.

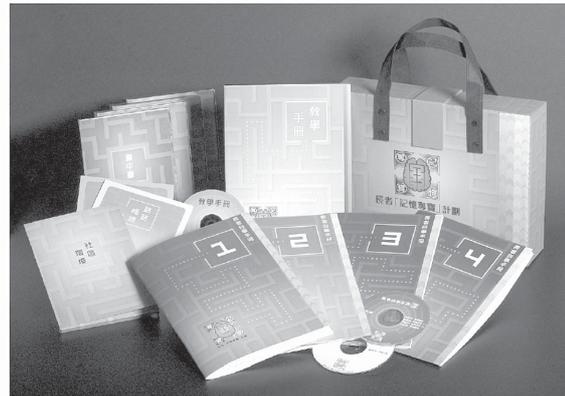
Elder learning has been proven to be effective in achieving positive effects on the elderly physical, psychological and social health, and our facility was the first service unit to provide and advocate elder learning programs for older individuals as early as in the mid-eighties. The program was later extended to older people living in the community. Recently, we have further adopted the University of the Third Age learning model to train third agers living in the community as advocates, managers and tutors to teach both third agers and fourth agers.

Owing to the changing family structure in Hong Kong and the increase of the nuclear family phenomenon, older grannies are often marginalized in a family system and there is a marked decrease of interaction between the older and younger generations in society. Older people living in care facilities need to have better communication and interaction with young people as much as their counterparts living in the community. In order to improve intergenerational solidarity, we launched an **Inter-generational Co-learning Program** 10 years ago, inviting students from secondary schools to serve as assistant tutors in the elder learning program during summer. Subsequent studies on the attitude and image of the students towards the older people confirmed that there were positive changes in both their attitude and image towards the elderly after participating in the program.

Older individuals admitted into a LTC facility wish to maintain kinship ties with their significant others more often than before out of fear of gradual abandonment. Many of them have chronic relationship problems with their family members, thus affecting their relationship building and adjustment to home life. **Working with families of older individuals** becomes a new challenge to staff in elderly settings who are concerned about quality of life of older adults. We have collaborated with the Hong Kong University Sau Po Center on Ageing to start a new clinical training program for our professional staff which is extended to other healthcare professionals in other service units. The training program has the special feature of live case demonstration aimed at exploring clinical skills in family-based work with older adults.

Dementia is a major mental health problem in the elderly population. LTC facilities are often the receivers of people suffering from dementia. As one of the residential homes that has participated in the 3-year pilot project on Dementia care in 1999, we often admit elders with dementia. Yet we often find that most of them have received no prior intervention program while living in the community. Since early detection and intervention is essential in delaying disease progression and enhancing the quality of life of dementia sufferers, we have initiated a project to develop a training kit for elders with early memory loss. The **Memory Training Kit** comprising two manuals for both the trainers and elders in the 5

areas of attention, registration & recall, problem solving, verbal fluency and perception, is the first of its kind ever developed for Chinese speaking older individuals. It is hoped that this newly developed kit will contribute to arousing the awareness of those working with elderly people suffering from early memory deficit and provide them with proper care and support.



Quality improvement is a never ending process. What we have pursued reminds us that this is a vast area for further exploration and that perseverance is needed by all those who care about the quality of life and well-being of our seniors.



Chapter 6

**Rebalancing Residential
Care to Community-based
Care: Possibilities &
Challenges**





Chapter 6

Rebalancing Long-term Care: Lessons from the United States Experience

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The term “rebalancing” implies an imbalance. Long-term care (LTC) can be said to be out of balance in the sense that care for older persons is heavily tilted towards institutions, primarily, the nursing home. LTC has historically been thought about primarily in terms of nursing home care. Even today, most lay people use these terms interchangeably. In fact, the vast majority of LTC is given and has historically always been given in the community. Depending on the source cited, estimates suggest that 90-95% of all LTC is provided by so-called informal caregivers. They are the backbone of the system and without their support the process would collapse.

Discussions about LTC are, however, directly mainly at paid care, and here the nursing home has held center stage. For many years we have tended to talk about alternatives to nursing home care, placing community care in the position of having to prove its worth against that implied standard. However, we may have the situation backwards. Community care is the preferred situation for most older people (and virtually all younger persons) with disabilities. Institutional care should be viewed as a sign of breakdown in the system.

Historically, in the United States, public expenditures for LTC have been largely for institutional care, but the last decade has seen a dramatic shift with increasingly more funding going to community-based care. However, the bulk of that transformation has been directed at younger persons with disabilities, whose strong advocacy has influenced policy decisions. Older persons have benefited to a much lesser extent.

Part of the explanation for this discrepancy may lie in the area of ageism. Older people are more likely to be protected and treated as vulnerable. Society is less willing to allow them to take risks, even when it means restricting their autonomy and denying them the opportunities they want to pursue. Older persons themselves may buy into this belief system and accept a more restricted life style.

The Basis of LTC

LTC consists of three major elements (personal care, housing, and medical care). All are important components of a good LTC program. It is rare that one can find a system that does a good job at all three. In a sense, balancing involves coordinating all three.

Nursing homes (NHs) do not typically offer a livable environment. Desired NH environments should include elements of both the physical environment and the social environment, including:

- Single rooms
- Control of entry into room
- Privacy
- Ability to set own life rhythms (e.g., getting up and going to bed)
- Choice of food

In the US, this coordination is impeded by funding practices. Personal care is paid for privately or by Medicaid, a welfare based program that serves all ages but is concentrated on poor mothers and children and poor older persons. Housing is paid for privately or through government subsidies. Pension and welfare payments may provide part of the private income for some housing and services. Medical care is paid for by Medicare, a universal health insurance program for older and disabled persons.

LTC services under Medicaid are provided in two ways: Services are provided as part of a state's Medicaid Plan. All Medicaid recipients are eligible to receive such services as they need them. Services are provided under special waiver arrangements, which waive aspects of the Medicaid law to allow broader use of funds and often a restriction in the service area to less than the entire state.

There is great variation across states in the way LTC is organized. The relative spending on NHs and home and community-based services (HCBS) varies widely. The use of NHs is partly driven by the availability of other means to provide LTC (like assisted living) and partly by policy. It is misleading to imagine some automatic displacement effect whereby HCBS will immediately reduce the use of NHs. Figure 1 shows the relationships between changes in HCBS use and expenditures and NH use and expenditures for eight states. It also tracks the changes in activities of daily living (ADL) and cognitive dependencies for NH residents across the same time span. An increase, even a dramatic increase in HCBS over a five year period is not associated with a change in NH case mix. Although one expects that increasing the supply of HCBS would mean that many people, especially those with less ADL or cognitive needs, would be served in the community instead of entering a NH, the actual pattern is different. There is no commensurate increase in NH case mix with greater HCBS. Changing the relative composition requires political will. The availability of HCBS can facilitate efforts to reduce NH use.

In fact, HCBS does not serve the same distribution of clients as the NH. Figure 2 shows the difference in the distributions by ADL dependency between LTC waiver programs and NH at admission and at 3 months after admission. Although the full spectrum of disability can be found among HCBS clients, more of them are likely to be less disabled than is the case with NH residents. This observation suggests that HCBS does not displace NH admissions. Indeed, at least some of the HCBS effort comes in addition to NH care. Presumably the more desired community services encourage some people who had not previously used LT services to take advantage of them. Thus although more people can be served by HCBS at a lower price, not all of them would necessarily have been admitted to a NH.

Many people need housing and care. Providing care may involve some economies of scale. Although people like the idea of having care brought into their homes, at some point, that arrangement becomes quite expensive. In order to afford such home care, some compromises may be necessary. Congregate living, by which we mean any way in which people live in the same geographic area (e.g., the same building or same neighborhood), eliminates the home care workers' travel time and thus makes such care more efficient.

However, getting personal care need not mean forcing people to live in inadequate housing or to give up their autonomy. The living circumstances represented by many NHs (often sharing a room with strangers, having no privacy, living according to a daily regimen established by your caregivers) need not be that way. It is feasible to provide needed services in a livable environment. Getting care should not require surrendering your dignity. At the same time, the importance of privacy and autonomy may vary across cultures. Whereas Americans place great store by autonomy and independence, not all cultures feel this way.

Even within LTC institutions there are some success stories. Some NHs have created "communities" within the institutions that include new designs that use smaller living spaces to be used for private rooms. This individualized living is reflected in more individualized care. Residents can set their own schedules and do the things that please them.

The Evercare program offers a model for how to organize better medical care model of medical for NH residents. It uses nurse practitioners (NPs) as front line primary care providers. These NPs are in the NHs regularly working with staff and residents and are in regular contact with residents' family members. They coordinate actively with NH staff providing training and direction.

Many people need housing and care. Although most older people prefer to stay in their own homes, providing care may involve some economies of scale. Congregate living can eliminate travel time for workers delivering periodic services at home. It is feasible to provide reasonable housing and adequate services. The old institutional models like the NH should not prevail. At the same time, we should acknowledge cultural differences. The importance of privacy and autonomy may vary across cultures.

Chronic Disease Care

Many older people who need LTC also need chronic disease care. Good chronic disease care means good primary medical care. The essential components of effective chronic care are proactive monitoring (coupled with effective early intervention and early treatment) to prevent catastrophes.

Thus, LTC should include active monitoring of clients' condition. Change in status can be monitored and compared to expected clinical courses. Clinicians need to be alerted as soon as the patient's clinical trajectory begins to deviate from what has been plotted. Two types of tracking systems are currently in use. All NHs are required to complete standardized form, the Minimum Data Set (MDS) on each resident at predetermined intervals (every three months or when a person's status changes). This data will track major changes over long intervals. Hence, it is not very useful for clinical management.

Clinical care requires using clinical information systems that monitor patients' status daily and generate information that can be used for active intervention to address problems before they become catastrophes. One approach to tracking clinical problems is the clinical glidepath.¹ This chronic care information system encourages patients to make systematic observations on their clinical status using relevant parameters determined jointly with their physicians. Deviations from expected clinical courses trigger immediate warnings using pre-programmed trigger thresholds.

Active chronic care can save money in two ways: substitution and efficiency. The latter implies treating patients for problems that have already occurred in less expensive sites. For example, the Evercare program showed it was possible to care for many nursing home residents who would otherwise have been sent to the hospital in the nursing home. Efficiency implies that more aggressive chronic care will actually prevent the complications of a chronic disease that would lead to the event that triggers a hospitalization. It is highly desired, but the empirical evidence to demonstrate such successes is still scant.

Both substitution and efficiency require good coordination between the medical team and those providing LTC. Unfortunately too often such coordination is weak. There must be shared values and goals. Although there should be good communication, the two groups effectively speak different languages. They have different goals. The medical practitioners expect to see some effect from their care, even if only to slow the patient's rate of decline. By contrast, many LTC providers see their role as simply compensating for functional losses already sustained. They do not look for change as a result of their efforts. Caregivers are the eyes on the ground. They are well positioned to detect early changes in client. To be effective, they must know what to look for. Information systems can guide them and make it easy to notify clinicians when there is a change in a client's condition.

Dual Eligible Programs

In the US, the group that poses the greatest costs and care issues is the group that is eligible for both Medicare and Medicaid. They tend to be on Medicaid because they have incurred substantial medical costs that have exhausted their financial resources. The problems that led to this situation mean they are expensive to care for. Because these two programs have different eligibility and benefit structures there is difficulty in coordinating them. One approach is to merge the funds from both into a single capitated payment to a managed care company, thereby placing responsibility for medical and LTC in one place. Such an arrangement should stimulate coordination.

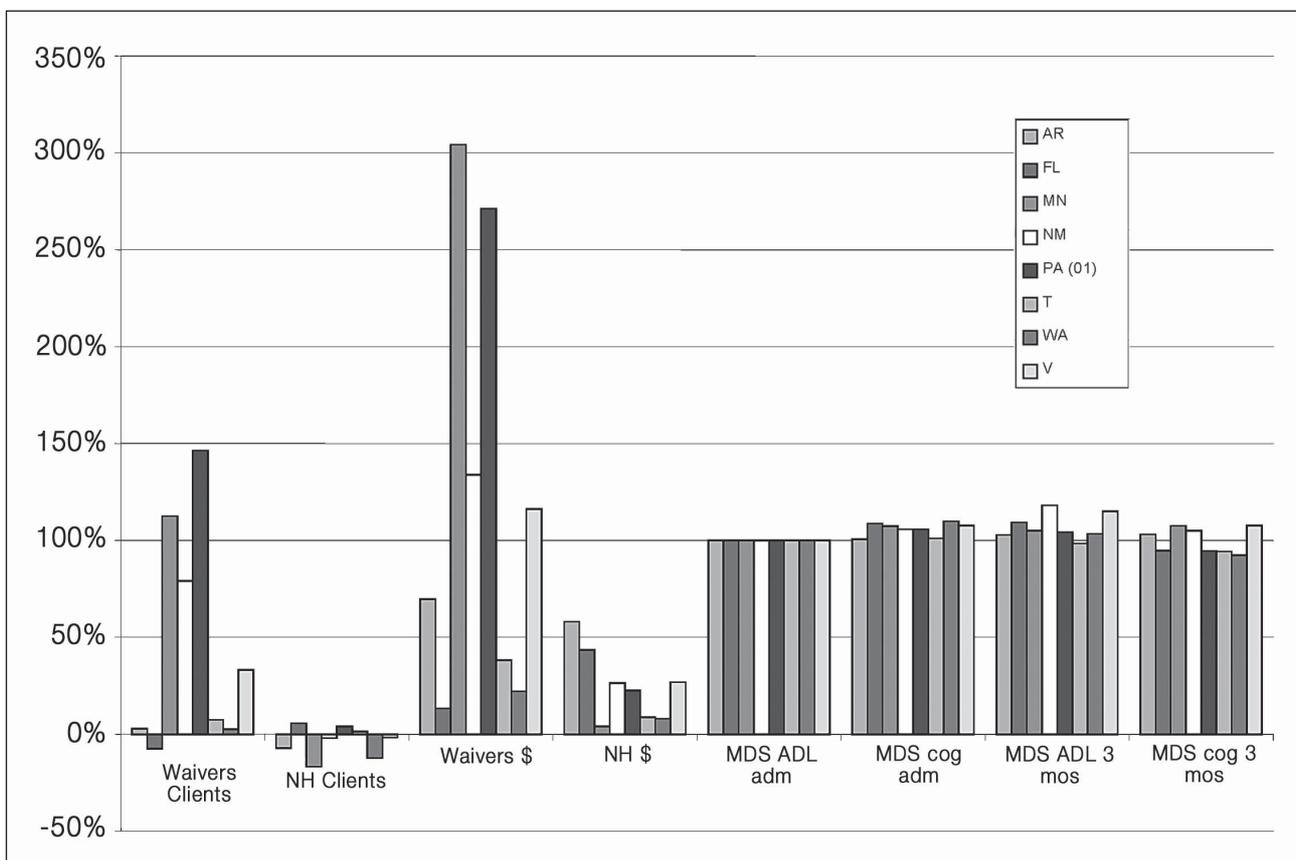
A few programs have emerged to use managed care in this way. The best known is the Program of All-inclusive Care for Elderly (PACE), which cares for a very select group of persons who are eligible for NH care but are still living in the community. PACE has been shown to reduce the use of hospitals and nursing homes but not to improve health outcomes.²⁻⁵ Another program that treats a broader range of clients is MSHO (Minnesota Senior Health Options). It covers older people who are in NHs and in the community. It too has been shown to reduce hospital use (especially among NH residents) without changing outcomes.⁶⁻⁹ A variant of PACE is WPP (Wisconsin Partnership Program). It allows clients to keep their own doctor, whereas PACE uses a limited set of contracted doctors.⁷⁻¹⁰⁻¹² Another model, SCO (Senior Care Organization) in Massachusetts more dramatically restricts the types of organizations that can contract and places heavier emphasis on using geriatricians.

Another model of managed care is Evercare, which was developed to provide Medicare-covered services to long-stay NH residents. Indeed, it covers little of the NH costs per se. Evercare has been shown to dramatically reduce hospital use, largely by caring for NH residents in the NH and not hospitalizing them. It makes active use of NPs to supplement (not supplant) physician care.¹³⁻¹⁶

Lessons

- Defining LTC as merger of personal care, housing and medical care allows much greater flexibility.
- If you pay for services and not for housing, the concept of a NH becomes now unnecessary.
- Various means to provide housing with services will be needed, but the housing costs should come from other sources.
- Policies are needed to sustain informal care. Informal caregivers need financial and practical assistance to remain active. Caregiving is very draining.
- LTC financing works with narrow margins. Payment systems should specifically encourage good outcomes, which may be assessed as slowing the rate of decline.

- Savings from more effective medical care could be invested in LTC.
- Extent of savings depends on how payment is organized. Under fee-for-service the payers must be willing to invest in one area with a reasonable hope of offsetting savings in another. Under capitation savings for the government occur only if the negotiated payment rate is sufficiently low; all internal savings benefit the managed care organization, not the consumers or the government.
- We need to re-examine attitudes towards older people. Current policies are overly protective, thereby reducing autonomy and choice. Older people should be allowed to take risks once they appreciate the potential consequences. Concerns about safety should be balanced against concerns about autonomy.



MDS ADL adm / 3 mos: MDS ADL assessment at admission / 3 months after admission;
MDS cog adm / 3 mos: MDS cognitive assessment at admission and at 3 months after admission.

Figure 1: Changes in Utilization, Expenditures and Nursing Home Case Mix, 2000 to 2005

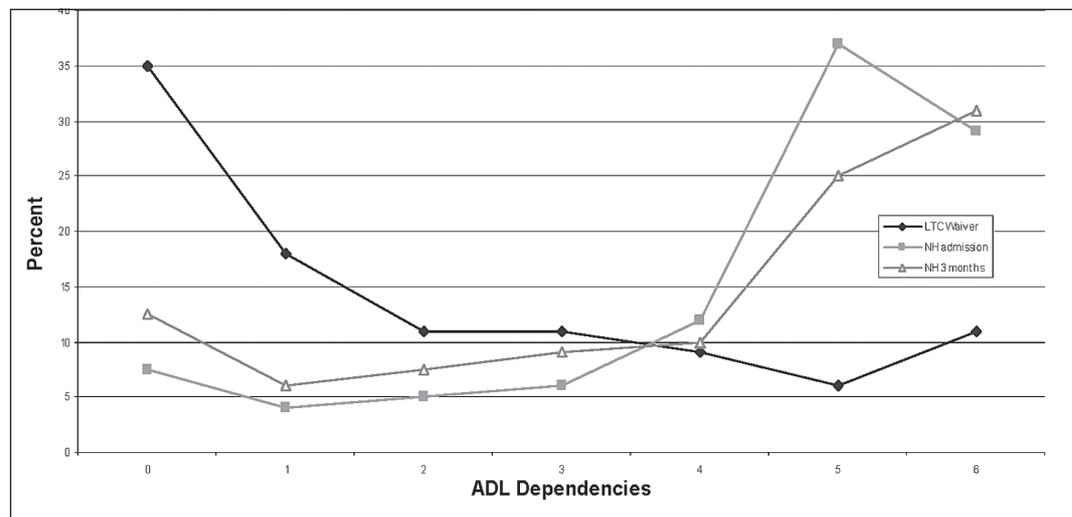


Figure 2: Comparison of Distribution of ADL Dependency Scores in HCBS Waiver Participants and Nursing home Residents on Admission and at Three Months

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DISCUSSANT 1

Response to Dr. Robert Kane's presentation: Re-balancing long-term care

Professor Jean WOO, MD, FRCP, FRACP, FFPH

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The Chinese University of Hong Kong

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Dr. Kane reminds us to re-focus on the fundamental starting point in long term care: from the perspective of the user. My response is divided into three parts: perspectives from the user; current developments in Hong Kong to address issues in long term care; possible future improvements-more efficient use of resources or additional resources.

The user's perspective

On the first day the value of stories was emphasized. I shall also illustrate the two key principles of long term care from the user's perspective: that of easy accessibility and seamless co-ordination, with real stories.

Geriatric Day Hospitals have been developed in Hong Kong, as an interface between hospital and community care, where multidisciplinary geriatric assessments, adjustment of medication, investigations, and rehabilitation can take place. This service enables early discharge back to the community as well as provides support for those remaining in the community. However, transport depends on taxis, apart from minibuses for the disabled. For some hospitals, rural taxis are not allowed, so that those attending the Day Hospitals may have to change taxis before reaching the Day Hospital. This provides an additional burden, since taxis are reluctant to pick up passengers who are dependent, and the need to change would add to this obstacle. It can be seen that policies are sometimes conflicting: encouraging people to return home earlier, yet not facilitating continuing care.

Barriers to community care as a result of poor coordination is not an uncommon experience, a situation occurring where there are multiple service providers from different organizations. The following story is a case in point:

A 70 year old resident of a residential care institution presented to the Geriatric Clinic with depressive symptoms, elicited during a falls screening assessment. She originally entered the facility with a group of friends, thinking that she would have a good social life in a place where she will be looked after. However, with the passage of years, all her friends died. In the meantime there was a change in policy such that only very dependent people were admitted, and she could not talk to any of them. Furthermore, the rules of the institution were very restrictive, so that she could not go out at night for social activities. She wanted to be re-housed but did not know to whom to turn to for help. In this case she did not need medication or psychiatrist's consultation, as the solution to her depression is a social one.

Local initiatives in Hong Kong

There has been sustained development in various community services by multiple organizations involved in elderly care: the Hospital Authority, Department of Health, Social Welfare Department and non-governmental organizations, the Housing Society etc. However, these have been developed from the individual organization's perspective. There has been no systematic documentation of what people really need, and to what extent the needs are met. For example, the intake rate of community cardiac rehabilitation and falls prevention programmes is very low. It is uncertain whether better public education or a change in paradigm is needed.

Possible future improvement

It would be challenging to see if the various community resources available can be used in a more efficient way, through better coordination using a comprehensive case management model. The latter could be part of a new primary care system that is being advocated in Hong Kong, and which could include a fee paying element. Such a model would require evaluation, including a cost-benefit analysis. Recent studies suggest that models developed in one country may not achieve the same results in another country. Thus the Evercare model developed in the US, when transposed to the UK, resulted in improved quality of life for users but produced no impact on hospital admissions. In parallel, there would need to be a move away from the concept of the patient playing a passive recipient role, and a move towards improving health literacy and empowering the management of chronic diseases.



DISCUSSANT 2

Thinking about Long-term Care: Reflection on Hong Kong Context

Mr. KWOK Lit-Tung

Christian Family Service Center

Hong Kong has a well developed comprehensive long term care system. The system embraces a range of services and facilities which could be broadly classified into 1) Residential Care services which include care and attention home, nursing home etc.; and 2) Community Care services which include enhanced home and community care, integrated home care, day care center etc...

The system controls entry through a Standard Care Needs Assessment Mechanism (SCNAM), introduced in 2002-03. For elders served in community long term care settings, a case management component is embedded in the system to ensure better coordination of care. These are the system knowledge we learnt from the Western world and we are doing good as well and the service is comprehensive. To view the system on its own, it is rather perfect. What can be added to improve the situation?

When we widen our vision to see a bigger picture, we might be able to see what can be further improved. I have two observations to share.

1. In reviewing the profile of residential placements, around two-fifths (29,000+) fall into the subvented portion, while three-fifths (45,000+) fall into the private sector. The private portion has already out-numbered the conventional placements managed by NGOs. Though these privately-run residential homes are monitored by a licensing system, there is no guarantee for quality service, as it lacks comprehensive assessment and care planing. On the SWD web-site, the private sector placement is not even included under the heading of long term care, and reflects the Government's mind-set. As the elderly living in private homes cannot benefit from the long term care system. CADENZA could further explore possibilities of improving the current situation.

2. The situation of another group of elders not included by our long term care system deserves even deeper concern. Some elders I know, live alone, do not like to live with their families, have enough savings and suffer from chronic illness. They are often admitted to hospital due to the lack of security and proper home support. This group of elder however does not meet the criteria for long term care but creates a great burden on hospitals. If the criteria of home help service could be relaxed and more inclusive to serve this group of people, or a private market developed, the burden on hospitals could, to a certain extent, be alleviated.

To go a step further, our long term care system is not seen by other departments as good as it sees itself. In 2005, the Government issued a report “Building a Healthy Tomorrow” in which long term care was commented as not being adequately provided and the burden shifted to hospitals. The report suggested two pieces of evidence to support their claim.

1. Statistics in 2004 indicated that follow up cases in SOPD increased by 50%, most of them comprising of elderly with chronic illnesses. The result led to long queues for new cases and delayed treatment for urgent cases.
2. The long term care system had no medical component and all medical support relied heavily on the Hospital Authority. The report suggested employing doctors in elderly residential homes to improve the situation.

In short, the Report recommended strengthening and enhancing our long term care and primary care so that hospital resources can be better used for acute care purposes. As a suggestion, transit care for the short-stay needs of elderly could enhance the effectiveness of community care, and alleviate heavy unplanned admissions and re-admissions of elderly patients. The task, as recommended, should be the joint effort of NGOs and private hospitals.

In concluding the speech, further integration of medical and social interfacing and the development of primary care should be the prospect of CADENZA in the near future.



Chapter 7

Implications for
Hong Kong





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Implications for Hong Kong

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In recent years in Hong Kong, much attention has been drawn to the ageing population and its consequences, the focus being largely placed on the health, social and financial implications for our society. There has been an undercurrent of rather negative sentiments, along the themes of escalating health and social care costs to the government. It is timely that this issue should be placed in its proper perspective in this symposium explaining the positive aspects along the Cadenza themes. Speakers from overseas and Hong Kong in their presentations and Roundtable discussions covered the use of life stories, positive attitudes and image, mainstreaming, coping and empowerment issues, health literacy, choice in care, and creative and social engagement. Several lessons may be drawn with regards to the Hong Kong context.

The use of life stories discussed on the first day raises two issues. Firstly, through narratives, one has a good example of how ageing can be positive in spite of health and social problems. It is a common perception that one can age successfully or positively only in the absence of health, social or financial problems. The concept of positive ageing in spite of progressive loss of function or disease through empowerment and self-management is vital to our ageing population, and much needs to be done to raise the health literacy level through public education. Secondly, the role of narrative medicine is gathering importance among the medical profession in the US and UK, as an important tool in understanding problems from the patient's perspective. Without this understanding there may be problems in subsequent management plans, particularly of clinical conditions. This aspect of care needs to be highlighted more among health care professionals in Hong Kong.

The promotion of positive or successful ageing, is an ongoing objective of the Elderly Commission in Hong Kong, a three year campaign having been carried out to promote this message in 2001. The City University of Hong Kong subsequently funded a study to develop a positive ageing index, led by Professor S.H. Ng. Currently the Elderly Commission has

an Active Ageing subgroup, led by Professor Alfred Chan, which has carried out various initiatives to counter the negative perception of ageing at all levels in society, particularly among the younger generations. Much work remains to be done, as there still exists an undue level of pessimism with respect to ageing issues.

Speakers emphasized the role of meaningful social engagement in contributing to positive or creative ageing, as well as countering the negative image of ageing. What is meaningful has to be from the elder person's perspective, and currently there is little data regarding this issue for the diverse older Hong Kong population. Many different initiatives organized by non-governmental organizations were described. However the sector of the older population participating likely only represents a small percentage of the older population and may not represent the soon to be old population. A broader issue that is of relevance relating to efforts to promote social inclusion, is that attention must be paid to the reverse process; that of social exclusion, or ageism. This has not been systematically studied in our society, but in other developed countries, would cover work place and healthcare settings. It is pertinent to note that between 1991 and 2005, the percentage of people aged 65 and over still participating in the work force fell from 12.8% to 5.4%. If older people perceive that they are of no use to society and feel marginalized, it would be difficult to achieve the aim of positive ageing or create a positive image. Research findings of Professor Ng's group clearly showed that social engagement is a key factor contributing to positive ageing (1). Much work needs to be done in this area in terms of research and public education.

The second major theme of the Symposium is long term care, whether in the community or in residential care homes for the elderly. Current models of care in Hong Kong are largely dictated by government social welfare policies, health care financing system and other health policies, and radical changes are unlikely to be achieved. Nevertheless, within the existing framework, it may be possible to achieve quality improvement in care, by using clients' needs as a starting point to achieve seamless interfaces between medical and social care, between different organizations, and mobilizing untapped community resources. Key to continued community living is easy access to services that are user friendly, coordinated and responsive to changing needs. In the absence of this, those who depend on carers will, out of necessity, enter long term residential care. There is a need to define what the needs are from the users' perspective; to experiment with newer models of care with evaluation as well as evaluate existing diverse models of care, in terms of cost benefit and cost effectiveness studies.

The quality of long term residential care is of concern, in view of the rising percentage of the older population living in these settings. Crowded living environments, limitations on long term care costs and the current health care financing system likely preclude the setting up of models such as the Green House Project, although this philosophy of care could be widely promulgated. Increasingly, efforts could be directed more to outcomes, rather than structure and processes. Further research needs to be carried out to provide

data for evidence-based practice and policy. Promulgating policies in residential care homes driven by political (rather than evidence have unintended based) considerations that are difficult to carry out may have unintended consequences, such as encouraging hospital admissions.

Finally, patient choice necessarily accompanies the empowerment process. In this regard, the US experience of cash and counseling described by Professor Mahoney may be relevant to Hong Kong by allowing users to use the existing social welfare allowances in a flexible way to purchase the service they need.

Following on this Symposium, the CADENZA project will continue to work on the above themes through public education, training, research and evaluation, and pilots of community care projects.

Reference:

- 1) Ng SH, Woo J, Kwan A, Cheng A, Lai S. (2005). A positive ageing index of Hong Kong: its development and some preliminary findings.

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