BUILDING INCLUSIVE LIFELONG COMMUNITIES ACROSS THE GLOBE: CHALLENGES AND OPTIMISM FOR THE 21ST CENTURY

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The goal of SYSTED calls us to think about and analyze our current complex social challenges from a systems perspective – choosing to use and integrate multiple approaches to understand our complex social and personal and community lives and how to improve them so that all members of our local and global communities can live lives of dignity, worth, engagement and empowerment across the lifespan. I’d like to share one example of how this can work that is very personal to me – the story of my parents, who are both 89 years of age, and how they have been able to stay living independently in their lifelong community, even though my father has dementia and my mother has high blood pressure and heart problems. There are a variety of factors that have contributed to their continued independence – they live in a neighborhood where they can walk to many shops and services, they have access to public transportation to get to stores for food and medications, beauty salons, mail and library services, vision, hearing and other medical services. They can have meals delivered to their apartment, which is a secure place for them to live. It also provides an immediate community for them connect with each day, as they see and talk to their neighbors in the building. They have served as the managers of the building for many years and so many of the older people rely upon them for help, even as they have become more frail themselves. This meaningful and contributing role has helped my father maintain his sense of dignity and worth, even as his ability to fulfill his responsibilities has declined. But because of his personal relationships with other residents, the owner of the building allows him to continue to help to the degree that he is able. Other residents also support my parents by sharing food and cooking for them sometimes. My parents continue to be involved in not only their apartment community, but also in the larger community, including their church which is a few blocks away. They also go to visit other elderly people who live in nursing homes nearby to give them some social support. They also continue to be engaged in community service organizations. My father also has his favorite ice cream shop nearby to take his grandchildren to when they visit.

Due to the integrated system of services and support they have access to in their current living circumstances, they have been able to continue living by themselves, and so I see their situation as a great example of how, if we can design neighborhoods to provide these kinds of support for older persons, those with disabilities, and all people across the lifespan, we can fulfill our goal of building inclusive communities – where all can thrive, contribute to and benefit from a vibrant and supportive environment.

So, how can we approach this goal of inclusive lifelong communities? We need to consider the critical factors in how societies function. A group of international researchers, including Dr. Anne and myself, have been thinking about this issue from a systems perspective: examining the roles of government, private markets, and civil society – including individuals, families and non-profit/volunteer organizations – in providing adequate policies and programs to support older persons in different countries. We introduce an analytic framework using cultural values as its base, that we believe can assist in understanding the difficult choices that nations face as their populations age. Many nations are experiencing the common prospect of rapidly aging populations; but they also encounter unique circumstances in their specific societies that provide the context in which social programs and policies must try to meet the needs of not just older citizens, but all members of society. This context includes changing demographics, political structures, economic systems, social resources, and, perhaps most importantly, underlying cultural values. Specifically, we have looked at the impact of some of these factors on long-term care (LTC) policies in four countries – Sweden, Japan, Israel, and the United States. These countries were chosen because they represent different mixes (both historically and currently) of government programs, private market options, and constellations of civil society (families, neighborhoods, community agencies, etc.) in relation to LTC policies. They also represent countries with a diversity of basic cultural values, varying rates of change in their aging populations, as well as different political structures that impact the ways in which social policies are developed and enacted.

We have been trying to examine whether LTC policies and practices appear to be moving towards a more balanced mix of these three components (called a "convergence" model), or whether traditional social and cultural values continue to drive each society’s approach to meeting the LTC needs of its population, resulting in relatively small changes in policy and practice, in spite of similar economic and demographic pressures – called the "divergence" model.

For example, Sweden was the first country to grow old and so has long experience in planning for the integration of elder care into the community in terms of designing and organizing home care. Sweden is characterized as a "strong welfare state" country with high levels of taxation and a social policy system of universal welfare programs. The goal is to help all people to maintain independence and integration in the community. An overall aim is that ALL people should have equal access to care and services despite age, sex, ethnicity, or financial situation.

As a "strong welfare state," the responsibility for old-age care is divided between Swedish national, regional and local levels. The Parliament and central government set out their goals through laws and national policy declarations. According to law, the municipalities or provinces are obliged to meet the needs of older people at the local level; however, the Swedish municipalities have substantial autonomy concerning standards for services and care provided. This tradition of local independence, which applies to all the Scandinavian countries, is somewhat similar to the U.S., although central policy remains stronger in Sweden than in the U.S.

In Sweden, the role of the government in maintaining the cultural value of egalitarianism has been challenged by
rapid aging and has resulted in a need to tighten eligibility criteria for support services. Thus, the shift from institutional care to community-based care may lead to some potential vulnerability if the critical role of voluntary civil society is underestimated and not acknowledged and supported, and if the government continues to constrain the role of the private market. Research has found that there is a large and active volunteer group in Sweden, even though the government has traditionally provided care. We all know that there is something IMPORTANT that comes from social interaction with peers and with neighbors or family, rather than the interaction with professional caregivers. In Sweden, some feel that there may be a risk that aging in place may lead to loneliness and safety concerns. As we move through the 21st century, there are concerns about the diminishing role of government, and how to manage a growing private market without constraining it, while also acknowledging and supporting the critical role of volunteers. Across the European Union “social cohesion” is the new term used for future community development, including planning for an “aging-friendly” community and we hope this will be the direction of 21st century societies.

Japan’s system of care reflects its history of Confucianism, with very strong values of filial piety and family responsibility, similar to other northeast Asian countries. In such a relatively small, close and homogeneous society, with a central government structure, cultural norms are tightly bound. For example, beyond the family, according to the historical ideal of mura (a village-based society), all community members help each other meet their needs, with pressure from both regional and national levels (thus, both a bottom-up and top-down system). However, this complete mutual interdependence was never really developed, and the concept of mura declined after World War II. Since then, the younger generations of Japanese adults have been moving to big cities and rural areas have remained a relatively stable but closed section of Japanese society, with large proportions of older residents. Japanese people have the greatest longevity in their nation. Japan is becoming more familial and the elderly are expected to care for their family, even with very little immigration from outside. With younger generations becoming more “westernized” and individualistic, Japan faces a turning point in changing societal values from a group orientation to an individual orientation. In addition, with a lower fertility rate than in the past, the country will continue to age at a rapid rate. Yet, Japanese are motivated to try and maintain as many of their traditional values as possible in the 21st century. Thus, evoking the historical concept of mura, today community empowerment has become one of the key terms used in Japan to signify this challenge. This term implies empowerment for both the individual and the community, and the belief is that it is crucial to maintain a sense of social solidarity in this potentially fragile situation. This is similar to the notion of social integration in the European Union.

To this end, the Japanese government began to enact a series of policies aimed at supporting the country’s growing elderly population. In this way, Japan has now moved from a traditional “civil society”-focused nation to a relatively greater “welfare state,” similar in some ways to Sweden.

In Japan, we see the possibility of a culture making major changes in its balance of care, as it has moved from a family-based model of care to a government-focused model of support. Yet, if we look closely at the types of programs that the government has implemented, we can see the cultural values still being supported – through universal participation in contributions to the national health insurance plan – and through the tax incentives and support of community-based programs. We also see an increase in the number of local neighborhood organizations where older persons can volunteer and stay active in their own communities. Families, too, continue to play an important role in the emotional and moral support of older persons, even if they are no longer providing physical care. Similarly to Sweden, there is a small private market of services available in Japan. However, Japan has a more centralized political structure than Sweden that can enact and enforce national laws – while Sweden, has the more decentralized system and more local control and variations in services.

Some of the challenges for Japan in the 21st century include: Developing a workforce for taking care of older persons, with smaller younger generations; maintaining traditional values in the midst of major socio-cultural change; and continued financing of public long-term care insurance.

Somewhat similar to Japan, Israel has long-standing social values that guide its policies and programs for LTC: first, Jewish values, religious laws, traditions, and ethics emphasize social and family responsibility; second, unlimited immigration for all Jews is a central determinant of Israel’s existence and clearly impacts the needs of its citizenry for care of all types; and, third, the principle of cultural and ethnic pluralism stemming from ongoing waves of immigration creates a diverse, pluralistic, and democratic society which seeks to support all its residents. In the Israeli cultural context, then, the two basic goals of service delivery to the elderly and disabled are: (1) to enable them to maintain maximum self-sufficiency to live in the community as long as possible; and (2) to allow them to participate actively in society, while considering their diversity and heterogeneity. Even LTC of the frail elderly focuses on continuity in lifestyle, attempting to avoid premature institutionalization.

Reflecting this strong culturally cohesive value of family obligation of care, the Family Law of 1958 obligates adult offspring to financially support parents and grandparents if they are unable to provide for themselves. Thus, the two major sources of funding of institutional long-term care are the elderly and their families, and the government. Israel could be described as an urbanized welfare state that relies on a mixture of governmental, private market, and civil society forces that shape its policies. As such, Israel has well-developed systems of special services for those who need them. The role of civil society in Israel is a strong one, including trade unions for workers, non-governmental voluntary organizations such as those for immigrants, and a cultural focus on community support for individuals and families. All of these play important roles in providing support.

In terms of concerns for the 21st century, Israel will have to deal with a changing family structure, leading to the question of who will care for whom and who will be available? In addition, longest lives means young-old adult children caring for old-old parents, so the same family will need multiple support programs. And, how much unlimited immigration can be absorbed with current support laws? Can the traditional cultural values of openness and inclusion continue? In addition, as many countries are now grappling with - how will Israel deal with growing gap between rich and poor?
In contrast to Israel’s focus on community, the U.S. focuses on individual responsibility which reflects underlying American cultural values emphasizing individual autonomy and self-sufficiency, dating back to the "Declaration of Independence." A central component of this emphasis on independence is the notion of "privacy," including control of, and responsibility for, one’s personal affairs, including any type of supportive care. Individuals and families are expected to solve their own problems, principally by individual efforts or by purchasing products and services (including LTC) through the free market. One of the government’s primary LTC efforts has consisted of a publicity campaign exhorting individuals to “own your own future” rather than depend upon the government to assist with LTC needs. LTC is provided through a mixed economy of care, with a diverse array of payors and providers. Nonetheless, citizens in the U.S. consistently state a preference for aging at home when they can and desire home care services to enable them to remain as independent as possible in their own residences. Public LTC policies, however, have historically not focused on home care. Long-term care policy in the United States is based on a residual or “safety-net” model, whereby individuals and their families are given full risk and responsibility for providing, managing, and paying for LTC until their resources (human as well as economic) are exhausted. Only after individuals reach poverty level does public support become available, providing full coverage for nursing home (NH) and only partial coverage for non-NH care. More than two-thirds of older adults lack any protection against LTC costs, resulting in high rates of individual vulnerability and often impoverishment. And while the U.S. has an active and wide range of volunteer organizations and civil society, the burden remains on the individual and their family.

For the 21st century, the country continues to struggle with the concept and implementation of universal health care that the other three nations discussed here already have. The U.S. has recently passed the CLASS Act – the Community Living and Support Services Act which is supposed to provide more home care options for older persons and those with disabilities, but it is still a voluntary program, not a universal one. The U.S. has higher immigration rates than other countries, with those immigrants being relatively young, so there may not be the same concern over a workforce challenge as other countries have. Yet, as the income divide continues to grow between those who have resources and those who don’t, the future is uncertain concerning LTC for those who need it the most.

So, we might ask if there is an “ideal” balance of the roles of government, market, and civil society. There are different theories about this balance- first is the “substitution approach” that is used by the Scandinavian countries – where the government substitutes for traditional family roles and provides expansive public support programs. Second, we could consider the “conservative approach” used by many European countries, which relies on social insurance programs where all contribute to them through taxes. In the U.S. we see the “liberal” model where the government plays the residual, not central role, in long-term care. Yet, we’ve also seen models of the “complementary approach” such as those in Israel and Japan – where the government provides much support, but the types of support given don’t substitute for the important social and emotional roles of the family and community.

So, what might the “ideal” balance be? We have seen that where government plays a fundamental role of collector of revenues for and provision of basic and adequate services (above the impoverishment model of the U.S.), and where government can provide quality control of services paid for by them, citizens can rely on a basic level of care, regardless of their personal resources. In Japan’s case, the role of government has transitioned to a new role that almost supplants the traditional family physical care and yet works to sustain cultural values. For those with additional personal resources, the private market can provide supplemental options which people might want to purchase with their own money. The private market can also provide options for government-funded programs, though the government should be sure to provide oversight and monitoring. We believe civil society is critical in providing complementary social and emotional care and support to elders, and also in creating opportunities for meaningful social integration and contribution to community. We can see this evidenced in Sweden and Japan, where physical and/or medical care is easily found in governmental programs, but that care in no way substitutes for the emotional support from family. And we see this also reported in Israel, where even after family support policies were enacted, the role of emotional support remains the responsibility of family members.

As we become more of a global village and the boundaries between public and private and civil aspects of society become blurred, will we even be able to ask such questions in another 50 years? Perhaps we will move in the direction of care as a public good: one that all facets of society – public, private and civil – will agree on. Perhaps countries such as the U.S., where care is an issue of entitlement (e.g., through Medicare) or legal right (e.g., through Medicaid when one becomes poor), will move toward seeing care as a fundamental social good that every citizen both contributes to and benefits from (as in Japan, Israel and Sweden). Yet, we may also ask whether the efforts of the central government in Japan and Sweden to sustain traditional cultural values of community through policies will stand up to ongoing social change over time, as younger generations may opt out of the long-existing social contract between family members of different generations. It seems that at this point, we are observing a continued divergence of approaches to long-term care rather than a convergence of values and approaches. It may be that, even with similar challenges due to aging societies, the fundamental role of cultural values will continue to guide the balance of state, market, and civil society in the provision of long-term care through the 21st century.

One element, though, that is becoming more common in countries across the globe who are trying to meet the needs of their citizens is the concept of empowerment, as we learned about Japan and the European union idea of social cohesion. Empowerment is a term that has becoming increasingly applied in various human service fields to efforts aimed at both giving power to individuals, and to removing obstacles that people may face in attempting to make decisions for themselves. As the number of frail older persons and persons with disabilities continue to increase in industrialized countries around the world, the need for sustaining the rights of such persons to make decisions for themselves is more critical than ever. Understanding the myriad mechanisms and constraints on people’s empowerment will help us identify ways in which we unwittingly contribute to stripping people of the power and dignity that all persons deserve to retain. Properly identified and understood, we can then make our best efforts to both remove barriers to, and increase opportunities for, true empowerment of all persons, across the lifespan.
If we think about empowerment at the societal level, Moody talks about stages of societal development and values around older persons and, we could include, those with disabilities, as well: The first stage is rejection, where people seen as "dependent" or "non-contributors" are rejected by society – placed in isolated circumstances – like senior housing or supportive housing, away from the rest of society. They are not asked to participate in or contribute to society. The next stage Moody describes is referred to as the "social service" approach – where experts are the focus and it is they who determine what services are most appropriate for different groups of people – again either the elderly or those with disabilities. But this approach is fundamentally a patriarchal system – whereby the person themselves does not have a say in what they need or want, but the professionals are the ones who determine types of policies and programs that will be put in place. In the third stage, according to Moody, "participation" by clients and patients and a focus on consumer rights is most common, allowing individuals to have an actual and empowering role in their own care and a say in how their needs and desires are met. In the fourth stage, where no society is currently able to function, self-actualization reflects a strengths approach – recognizing that each individual, no matter their age or ability status, has strengths that they can bring to not just their own care situation, but to society in general. In this kind of utopian situation, people across the lifespan would have multiple opportunities to engage in activities that both meet their own needs, but also contribute in a meaningful way to their communities.

The next question, then, may be how we accomplish moving from one stage to the next – whatever stage our society might be at right now. For that process, we can look to a model of community empowerment that was developed here in Japan by Dr. Tokie Anme, called the CASE Model. In this model, there are 4 stages: Creation, Adaptation, Sustenance, and Evaluation/Expansion. In each of these stages, there are multiple systems that need to be involved and engaged for the final goal: empowering all citizens and giving the community. These include activities that are community level, and the societal level. For example, imagine a village where it is mostly older persons who live there. The goal is to help them maintain their health and vitality for as long as possible... Or imagine working mothers in a city that need quality day care for their children. Initially, you would want to create a program to meet those needs and ideally, the older persons and mothers would be involved in the development of the program so they have a chance to voice their needs and desires. Once you put that new program into practice, you will have to adjust it to what works, and also face new and unexpected challenges. As you deal with those challenges, you will reach a stage of Sustenance, where things seem to be working pretty well. To assess that functioning and your progress towards your goals, you will want to evaluate your program and then again either adapt it or perhaps expand it as you learn more about what makes it successful.

Innes and Booher (2010) talk about three trends in the evolution of planning and policy making that are important to understand: first: the traditional linear methods relying primarily on formal expertise (the "social service" stage described by Moody) are being replaced by nonlinear socially constructed processes engaging both experts and stakeholders, in the way that the CASE Model describes. In traditional processes, decision proceeded from goals provided by elected officials, to data collection, analysis, and formulation of plans and policies by experts, to implementation by elected officials and bureaucrats. In the practices we see emerging, many actors – experts, stakeholders, elected officials and the public – are engaging jointly to address planning and policy problems. Together they collect information about a situation and consider what it might mean. They may start with some general shared concerns, but collectively they do not start with specific goals. They do not operate on the assumption that there is an optimal solution. They formulate options and consider what the consequences of those options might be. Implementation is always contingent and evolving, such as in stage 4 of the CASE Model – evaluation and expansion. There may not be a universal truth to be discovered, but a shared understanding of reality that can be a basis for action. The second trend is a move away from "expert scientific" knowledge to include knowledge and experience of those who live with and through decisions that have been made, such as caregiving arrangements. The successful processes we have observed included methods in which experts, lay people, and people with unique local knowledge engaged to jointly create an understanding of the challenges they faced and the potential of the options they considered.

Such collaborative processes can lead to changes in the larger systems that help make our institutions more effective and adaptive and make the system itself more resilient. These processes do not just produce immediate outcomes like agreements and joint activities, but with the people engaged, they can extend collaboration to other contexts. Participants learn more deeply about issues and other interests which they can then transfer to other situations. They develop new skills. They build new networks that they use to get new sorts of things done that they could not have otherwise considered. Collaborative planning however is well adapted to dealing with a complex, changing and fragmented system.

Over the next two days, we will hear from Holger Stolarz who will give us specific examples of what this looks like in Europe in terms of planning new senior housing, involving many key players and stakeholders. He will share with us why it has become true that neither specialist housing excluding older people from society nor care relying only on professional support can be the answer to the demographic aging of society. So we can see now that they are trying to move from one stage of societal development according to Moody, as I described earlier, to a higher one, where the elders themselves are involved in the planning. He tells us that the older people themselves have asked for a different kind of role. What they increasingly wish for is to continue a self-reliant life and be included in society, even if they are in a severe need of care. The basic idea for structural changes was that the growing care needs cannot be met by a mere increase of professional care provisions but by getting older and younger citizens involved – and also create a new system of care where the choice and need of care is based on the preferences of the caregivers and the older people. This change should be a change from a "provision oriented" to a more "participation oriented" approach. To encourage this, housing and care for older people and those with disabilities must be organized where old and young live together and social networks can function, i.e., in ordinary residential areas.

The focus on local areas is necessary for a further reason. Since there will not be enough professional caregivers in the future for the growing number of older people needing care, more participation on the part of regular citizens will be
required. A big challenge to the future structure of welfare for the elderly lies in the ability to strengthen the potential for individual initiatives and mutual help. This will likely develop best in places where the young and old already live together, and where relationships have developed over many years – in other words, in “normal” residential areas. Only here one can succeed in building up and strengthening social networks. Proximity of these services will not be enough, however; individual initiatives and mutual help must also be actively targeted and encouraged. Again, we know that in Sweden, Israel, the U.S. and in Japan, the role of individuals and mutual aid organizations is critical to meeting the needs of all citizens. In this way, all countries can begin to move towards a self-validating society.

We will also be hearing from Dr. Duncan Boldy from Australia, in his talk about ‘Aging in place’, which is about enabling people to maximise self-fulfilment and preferred lifestyle, either in familiar surrounds or elsewhere. He’ll talk about how, based on research, a holistic or ‘systems’ approach was taken in that ageing in place was considered in a wider context than is often the case. Remaining ‘independent’ is a key aim as people age. This is now more clearly articulated by older people than in earlier times. The study has demonstrated the importance, both for older people and policy makers, of different dimensions related to needs to be taken into account in planning and implementation.

From the U.S. experience, which I will be sharing from the work that Dr. Leonard Huumann has done, we know that national and state funds will be necessary for senior housing and community based services. But the planning must be local to address population diversity, unique local economies, and unique local physical and social environments. In addition, Dr. Ele-Marie Anbacken from Sweden will share her insights on the similarities and differences between Sweden and Japan in terms of civil society involvement. Then she, along with Dr. Matsuura from Japan and Mr. Amarsanaa Gan-Yadam from Mongolia will speak to us about caregiving and support services across the lifespan. Understanding the needs of all people, at all stages of life is critical to systems sciences and true inclusive communities. To this end, we shall also hear from some local researchers, here at Tsukuba University, who will share their research on early childhood development and how it leads to life satisfaction in adulthood. We shall learn how early praise from mothers to infants can positively impact child development. Across the globe, the needs of people at every stage of life are important to consider, and thinking about different models to help us achieve that goal is one of the aims of SYSTED.

Technology is also something that many countries are trying to incorporate into a broader systemic approach to supporting older persons. Boston Life Labs in the U.S. has developed a home monitoring system that securely and reliably transmits vital signs from patients at home to health care providers and family members, including blood pressure, temperature, pulse rate and blood oxygen levels, as well as a smart scale that measures weight, body mass, body fat, and body water. All these devices are wire-less and designed to be simple to use. Individuals can also utilize a glucometer to monitor blood sugar levels if necessary. Other technologies include motion sensors and bed sensors so that others can learn if someone has fallen and hasn’t moved for a period of time, or if someone has remained in bed for an abnormal amount of time. A similar system, called the Mobile Link Service has been developed in Hong Kong. Mobile health units, for rural areas and areas where little or no health care is available are also becoming more common in the U.S. Even mental health has entered into the technology arena – both the U.S. and the U.K. have developed a web-based cognitive behavioral therapy system which is just this month available in the U.S., but has been used in the U.K. for several years now and data from randomized controlled trials has demonstrated the program’s effectiveness for many people with common mental health issues. Currently, the program has been made available to more than 300,000 people there. This system is also being used in Scotland, Northern Ireland, Canada, New Zealand, and the Netherlands. It is also available for individual purchase.

The European commission has made 2011 the European Year of Volunteering. The aim is to exchange best practices between member states and to establish new Europe-wide networking initiatives that encourage cooperation, exchange and synergies between volunteering and other sectors, especially the corporate sector. This is another way to build a systemic approach to communities and individuals and the ability to thrive. This can help pave the way to next year’s European theme of Active Ageing and Intergenerational Solidarity.

Volunteering has also been associated with physical and psychological health advantages, which are particularly important for older persons (and can also save health costs). The Netherlands estimates that they have saving 2.3 billion Euros through volunteer activities, just at minimum wage! Volunteering also supports the value of the social contract, as volunteers function within social networks, exchanging skills and knowledge and transferring them to others. The bonding and bridging social capital that is created and maintained in the process is clearly advantageous to older citizens after retirement.

In Denmark, they are talking about the appropriate role for volunteers and the tendency for some governments to want volunteers to take over public services that governments have traditionally provided but can’t any more at previous levels due to financial pressures and constraints. It is an important question – what is the most appropriate role for volunteers and how do we balance that with what are truly larger social concerns that only governments can address.

As the world becomes smaller and the notion of global villages becomes more familiar to us, the goal of creating and sustaining communities that include and support all, throughout the lifespan, is an admirable one. When we, as professionals learn about innovative endeavors around the world, there are increasing opportunities for creating best practices in planning, policies, and programs. Calling all of us to focus on fundamental human values and realities such as interdependence, dignity, choice and autonomy, we must strive to work collaboratively to meet our common aims. Thus, optimism on many intellectual and practical levels needs to be the driver of our work, which is long-term, complicated and yet, ultimately rewarding.