CONNECTING THE DOTS: FORMAL AND INFORMAL CARE

2014 Senior Government Officials Meeting – 10th of June 2014, Hyderabad
Connecting the Dots: Informal and Formal Care

INFORMAL AND FORMAL CARE EXPLAINED

The “textbook” definition of informal care is “a nonmarket composite commodity consisting of heterogeneous parts produced by one or more members of the social environment of the care recipient as a result of the care demands of the care recipient.” Simply put, informal care is unpaid care provided by family, friends and volunteers based on a complex social relationship between the carer and the supported person. Some definitions specifically state informal caregivers do not receive any payment for their caregiver duties while others state that as long as they receive less than market wage they are still informal carers. For the purpose of this report informal caregivers include those who receive minimal payments with no payment being at or more than market value and where the caregiver would not want to do the task outside of their social circle for the same wage.

The United States estimated the economic value of informal caregivers at about $350 billion in 2006. In 2006 between 30 million and 38 million adult caregivers provided both activity of daily living (ADL) and instrumental activity of daily living (IADL) supports to older adults. In France two thirds to three quarters of care provided to older people is informal. More than 80% of long-term care assistance by older adults is provided by exclusively by family members, typically by women. In China informal care is even more prevalent as more than 95% of long-term care assistance is provided by family members.

Women account for about 90% of all care workers, 61% of all informal care workers, and are also the majority of beneficiaries of informal care. This presents a challenge because the average level of pensions is lower for women meaning they have less financial security as they age. Even with increasing male longevity it is unlike this will change as men are more likely to seek formal care as opposed to providing informal care. With the changing societal structure more women work out of the home and the availability of informal care is dissipating.

Formal care refers to paid care services by a healthcare institution or individual for a person in need. Formal care is available in most countries privately and publically although public formal care is significantly more limited than private options. It is widely recognised that formal care is often a last case resort which is only chosen by family members or friends who can no longer provide the necessary care to their loved one.

Integrating formal and informal care is a substantive option to mitigate the effects of the ageing population on the formal healthcare system and improve the lifestyle of the ageing population.
Currently many families use a combination of informal and formal care to prolong an older person’s ability to live well at home as opposed to a long-term care facility or nursing home. This integration is essential when moving a senior from a hospital or care facility back into the home after an illness or injury. Informal care is expected to influence demand for formal care, especially low residential care. Therefore, caregiving for seniors is a joint function between informal and formal systems.

BACKGROUND AND OVERVIEW

Since 1999, coinciding with the IFA bi-annual international conferences, the IFA has placed significant importance in providing a platform for senior government officials and Ministers to meet to examine current trends in policy and practice on specific areas of interest in light of increasing population ageing.

Recent areas of interest have included Long-Term Care and Technology, Ageing in Place, and Social Inclusion, subjects that have been based on mutual interest of the participants, and designed to promote dialogue and interaction among officials. Senior Government Officials Meetings provide the opportunity for government officials to showcase programs, policy, leading practice and to hear firsthand how other governments are responding to similar issues.

The current global economy has required the implementation of tight budgetary restrictions in states worldwide. The current financial environment makes it all the more important for every sector to work together to connect formal and informal healthcare systems to ensure the ageing population has access to all necessary care. Currently one in nine people are over the age of sixty (60). In 2050 this number will grow to one in five people over the age of sixty worldwide to a total population of two (2) billion over 60 years old.

With demographic changes come societal changes as well. In the past informal care was replaced by formal care in what is referred to as the ‘substitution effect’. This resulted in
cultural institutionalization and a new balance of responsibility between individuals, government, formal care providers and the social environment. In Western Europe people have a ‘right to care’ and the expectation that they will be healed of any disease or illness. The social welfare costs that have resulted from this expectation have put significant pressure on the financial system and are no longer affordable. Furthermore this medical system of diagnosis and treatment is no longer believed to guarantee improved quality of life.

Societal changes such as declining family size, rising childlessness, changing living arrangement coupled with a growing ageing population will also result in an increased demand for long-term care services and a deficit of informal carers. In Canada nuclear families have decreased by 18%. viii As the world’s ageing population continues to grow while birth rates decline healthcare service challenges will continue to grow.

Solidarity has also dropped in several European countries because there is not a balance between giving, taking and paying for formal and informal caring services. Strong cultural differences impact the kind of care those in need receive as well as the quality of care. Cultural aspects of care need to change; a new balance needs to be found.

After the age of 65 years the prevalence of disability increases about 1.5 times every five years.ix As a result the demands for care will rapidly increase in the future as the ageing population increases. Certain states face larger challenges than others. Canada, Japan and Australia are expected to age at a greater rate than other OECD countries.x OECD’s “Help Wanted: Providing and Paying for Long-Term Care” states most OECD countries currently spend between 0.5-1.5% of their GDP on long term care however in 2050 estimated expenditures rise to 2.2-2.9%. Whether privately or publicly financed, total home care expenditures reached $3.4 billion dollars in 2001 in Canada and continue to grow.xi With these demographic and societal transformations the creation of effective infrastructure that supports informal care givers while regulating formal care is essential for countries everywhere to thrive.

It is critical informal and formal care providers work in tandem to ensure all people can age in the best possible health and with dignity. Societies are becoming wealthier and individuals demand higher quality and more responsive social-care systems. With technological advances the possibilities for long-term care services at home are greater. However it requires reorganization of care and to connect the dots between formal and informal care. Enabling and encouraging families and older people to integrate both informal and formal care services to maximize care efficiency will be critical to deal with these demographic changes and prevent flooding healthcare systems worldwide in the decades to come.
**CHALLENGES FOR INFORMAL CAREGIVERS**

Whilst the informal care system has obvious benefits informal caregivers themselves face serious challenges as a result of their duties. It is important to recognize these challenges when developing and implementing policy that will affect them.

One of the challenges faced by informal caregivers is balancing employment obligations with caregiving duties. Workplaces provide little support for caregivers and this significantly impacts their ability to work and their ability to provide quality care. Some employers offer short-term leaves or allow for flexible work hours to accommodate some of the challenges caregivers face. However, these programs are not sufficient to deal with growing numbers of informal caregivers in the workplace. Very few programs exist in workplaces that provide working caregivers with training opportunities and strategies to care for loved ones. There is currently a disconnect between what employees, who are caregivers, need from their employers to succeed professionally and personally, and the programs and opportunities employers provide.

While men and women both struggle with reconciling work and caregiving women in particular are more affected as they constitute the majority of caregivers worldwide. The MetLife Study of Working Caregivers and Employer Health Care Costs demonstrates the disparity in wage loss between men and women in the United States:

### Impact of Parental Caregiving on Lost Wages and Social Security: Women

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<th>Reduced Hours Working</th>
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<td>Lost Social Security Benefits</td>
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<td><strong>Total Impact</strong></td>
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Source: MetLife Mature Market Institute, *The MetLife Study of Caregiving Costs to Working Caregivers*, Table 2, 2011

### Impact of Parental Caregiving on Lost Wages and Social Security: Men

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<td>$89,107</td>
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<tr>
<td>Lost Social Security Benefits</td>
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<tr>
<td><strong>Total Impact</strong></td>
<td><strong>$164,857</strong></td>
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Other long-term effects specifically affecting women are increased risk of poverty and receiving public assistance later in life. In France, 15% of women carers in employment resort to part-time work to meet care requirements. xiii
On a more general scale 12% of informal caregivers in the United States choose early retirement as a result of their duties and 41% report having to take a leave of absence. Other common changes in working patterns worldwide are arriving late/leaving early, going from full time work to part time, losing job benefits and turning down a promotion. With a decreasing labor force and increased spending on long-term care for the ageing population including options such as early retirement a shortage in the labor force is imminent.

The second challenge is the inability to complete all the necessary caregiving tasks whether as a result of a lack of knowledge of caring techniques or physical limitations. One of the dominant reasons informal caregivers seek formal services, especially long-term care is their inability to perform the necessary tasks the supported person requires. While this cannot always be prevented training and support can mitigate this to an extent.

Third, caregivers often incur financial strain because they spend their own money to support the care recipient. It is commonly known informal caregivers incur many costs as a result of their caregiving activities. Transportation, medicine, supplies and even some in-home formal care services are often paid for by the carer. In the United States caregivers contributed $200 a month on average financially to the care recipient totalling $2,400 a year. Those with the greatest caregiver burden reported spending $324 per month out of pocket on care-related expenses. In Canada, 25% of informal caregivers report out-of-pocket expenses of $407 a month. This, coupled with changing employment patterns, has the potential to financially incapacitate informal carers.

It is also challenging for informal caregivers to navigate the current formal service system. The existing service system is a confusing network to navigate due to a lack of integration and collaboration between service providers. As a result caregivers are unable to identify the best service for their loved one and service providers are not adequately prepared to address the needs of the supported person.

Another challenge is the age of informal carers. The mean age for informal carers is quite high at fifty-five (55) years of age and ranges from fifteen (15) to ninety-six (96) years of age in Europe. The following chart shows the trend in caregiver age:
This graph shows that the majority of caregivers are forty-five years and older and the percentage of those over this age continues to grow. In ten years the number of caregivers under the age of forty-five decreased by three percent and continues to grow.

A growing trend shows women postponing birth for career advancement as well. This trend will result in older primary informal caregivers supporting their parent(s) in addition to a young child creating many multigenerational homes. This is known as the ‘sandwich generation’ and researchers question the effects of the potential burden they face caring for a child and an ageing parent simultaneously.

As the average age of informal caregivers increases it gives rise to another challenge, lack of technological expertise. Many potential support and information platforms are not accessible to these caregivers because these platforms use technology such as social media sites, online marketplaces or websites to disseminate information and connect people. Therefore older caregivers do not have access to many tools that may help them offer better support and receive support themselves.

Finally, the culmination of the primary obstacles results in caregiver exhaustion, physical and mental ailments. These illnesses seriously affect their ability to work and thrive in their day-to-day lives. The health costs incurred by the caregiver as a result of their informal care duties often result in sharp drops in income, totaling huge losses in wages, Social Security benefits and pension benefits.
CHALLENGES IN THE FORMAL CARE SECTOR

As previously mentioned women make up the majority of care workers in both the informal and formal sectors. The major challenge faced by the current formal care sector is high turnover because of low wages, high physical and emotional demands, and poor working conditions. The result is an inconsistent sector where the quality of care is significantly impaired. The Netherlands, Italy, Austria, Poland and the UK have the highest turnover rate in Europe with an average 13% turnover rate in nursing and caring homes and a 17% turnover rate in home care positions. Unfortunately no countries have identified the issue or made any significant effort to improve it with the exception of Germany who identified the wage crisis in the care field and implemented a minimum wage in the sector.

BARRIERS TO INTEGRATING FORMAL AND INFORMAL CARE

A culmination of research suggests there are five main challenges that affect the informal care sector and the ability to connect it successfully with the formal care sector. Cost, current infrastructure, lack of awareness, public policy, and public perception are all challenges impeding the integration of the two systems.

1. Cost

The cost of formal healthcare for the ageing population is expected to reach up to 2.9% of each state’s GDP by 2050. Despite many governments reliance on informal caregiving they will still have to invest significant sums of money to create the necessary infrastructure and provide the formal care their ageing populations will require while balancing support payments to informal caregivers.

There are also many hidden healthcare costs as a result of informal care. 45% of caregivers have chronic illnesses twice the rate of noncaregivers (24%) most resulting from the ailments informal caregivers suffer as a result of their caring duties. Caregivers often suffer from mental and physical ailments that require treatment such as depression, arthritis, back and other musculoskeletal conditions. It is important to recognise the cost saving benefits of informal care on government spending however, it is also important to acknowledge the indirect expense of informal caregiving.

2. Institutional Infrastructure

Current institutional infrastructure is another barrier to maximizing both informal and formal caregiving. There is no institutional infrastructure that exists to educate informal caregivers and many program structures focus only on the client or care recipients needs and undervalue the caregiver. The current public view of institutions such as long-term care facilities and the interactions between family and staff at times hinder the potential for a positive and beneficial
relationship. Current institutional structures are not sufficient to manage the new ageing population.

The current healthcare system infrastructure is another barrier to coordinating effective care. The de-institutionalization of care in countries such as Canada has further increased the challenge. The European Commission found relationships between informal carers and professional formal carers were substitutive as opposed to complimentary. There are two reasons they identified for this: 1) unequal sharing of care duties and 2) unequal caring status of informal carers and professionals. The infrastructure of the health system is designed in such a way that it separates informal and formal caregivers as opposed to bringing them together to provided higher levels of care. The solutions they suggested are: 1) information and education of cared-for and caring people, and 2) use of home care services. These solutions would increase the value of informal caregivers and create a more equal and balanced relationship between healthcare professions and informal carers.

3. Public Policy

The lack of public policy supporting informal caregivers is a barrier to the full integration of informal and formal caregiving systems. On macro (policy) and meso (provision) levels policy makers often overlook the complexities of the informal carers and those they support. Conflicts and challenging dynamics between the carer and the supported person are only evident at the micro (delivery) level. Acknowledging these complex relationships and building policy to support both the carer and the person supported is critical to successfully helping the ageing population. Lack of cohesion in current public policy where usually only the carer or the supported person are targeted creates disconnect and results in inefficient and ineffective policies.

Long-term care insurance policies are another barrier to connecting informal and formal care as they often place limitations on who can provide long-term care in the home to the care recipient. Usually only licensed healthcare professions or certified home healthcare professions are covered under the insurance thereby creating formal employment opportunities and undermining the role on informal caregiving. Some long-term care insurance policies do not even cover in-home care.

4. Awareness and Accessibility

Another hindrance to formal carers and informal carers working as a connected team is a lack of awareness surrounding formal care options. Oftentimes informal caregivers are unaware of local services available to aid them in caring for their loved one. Long-term care facilities and hospitals are the most recognized form of formal care amongst caregivers despite many other formal care options that may be more useful such as community respite services.
In addition to a lack of awareness, accessing caregivers is also a struggle. Many caregivers do their work privately and are only visible after problems arise in care or with their health. While municipalities are more capable of identifying and supporting these hidden caregivers they do not have the financial resources or expertise to provide adequate support systems.

The accessibility of these services is the second part of this barrier. While some carers may be aware of services in their communities, long wait lists or costs impede their accessibility to these services when they are most needed.

5. Public Perception

The public perception of formal healthcare and societal expectations are both challenges to connecting informal and formal care. Negative press surrounding long-term care facilities and nursing homes, and elder abuse make informal caregivers less likely to seek out helpful formal services. Those who seek formal services are occasionally viewed as lazy or selfish. This coupled with many society’s expectations that aged care is a family obligation is a definite barrier to improving the connection of informal and formal care.

Current Trends in Informal Caregiver Support

There are numerous programs and initiatives in many countries that attempt to combat the challenges facing the informal care sector. The two basic systems of support are cash supports and in-kind support. Cash supports include:

1) Cash-for-care
2) Care allowances
3) Attendance allowances

Cash supports are a common form of government supports for informal caregivers especially in Europe. These programs are usually either targeted to the carer or the supported person. Care allowances are paid to the family carer or older person as compensation for the carer’s services and are paid by municipal or regional authorities. Attendance allowance, on the other hand, is paid to the older person for him or her to purchase services and is tax-financed. It is granted on certification of severe disability. Attendance allowances are more common than care allowances in Europe and tend to be higher in amount ranging from 90% to just below 50% of the reference income. Some claim cash supports blur the line between a formal and informal caregiver and put older people at risk for financial abuse.

In-kind supports include:
1) Home based professional formal services
2) Respite care
3) Monitoring technologies such as movement sensors, automatic medication dispensers and tracking devices
4) Home support devices and home adaptations
5) Counselling
6) Training/Education
7) Information in paper form and using online resources
8) Self-help and peer support groups
9) Employment support
10) Advocacy groups and informal carers’ associations

The effectiveness of these programs is much more difficult to measure and hence they are less frequently found as supports for informal carers. Often in-kind supports are available for a fee and subsidized by the government or through insurance.

These types of solutions create stronger relationships between the family, practitioners and organizations, and improve communication and quality of care. This relationship ensures the medical practitioner and other service organizations receive essential information about the care recipient through informal reports from the informal caregiver, which improves the effectiveness of early detection systems for falls and memory loss.

Other supports include tax credits and mandatory and voluntary long-term care insurance found in such places as Germany. Short-term job secured leaves are also common in many countries and typically last between ten days and one month. However, whether they are paid or unpaid leaves varies. Long-term leaves are also available in some countries but conditions are more restrictive and are usually unpaid. Flexible time is another option being utilized in the workforce, which allows carers to modify their working hours to be able to provide necessary care. It can significantly help carers cope with care obligations especially during early stages of disability.

**CONNECTING THE DOTS**

The return on investing in the coordination of formal and informal care is excellent. Newhouse and McAuley provide four policy suggestions to encourage and support informal caregivers with the aid of the formal care sector.

1. Offer training in basic skills necessary to manage the care of elders in-home.
2. Address the physical and emotional strain and potential isolation that in-home caregiving might cause.
3. Consider direct financial compensation for informal caregiving.
4. Develop lines of communication between formal organizations and agencies and informal caregivers.

These suggestions may potentially combat most of the challenges that limit the connection on formal and informal care. Both direct and indirect supports need to be provided to informal caregivers. Direct supports such as information, training, education, care allowances and accident insurances are critical. Indirect supports however, are also vital to connect the two sectors. Indirect measures include training for formal carers to show them how to support and include informal carers.

CONCLUSION

In order to maximise the health and well being of the ageing population there has to be a better allocation of resources to improve health and social care and an openness to having community members involved in the decision making process. Using formal and informal care in tandem will sustain healthcare systems around the world. By enabling family members, neighbours and other volunteers to create an environment and support network that allows ageing people the opportunity to stay at home longer it will ease the financial burden on the state and informal caregivers. However, if states fail to adequately encourage and support informal caregivers the influx of older people will continue to grow and have no one to them to care for them. Connecting informal and formal healthcare alternatives will benefit both sectors and improve the quality of life of people as they age. It will also help governments deal with the new challenge of care provision resulting from societal changes in classical family organization.

Currently women are the dominant informal care providers. However, this is not sustainable over the long-term. No country has adopted any policy to encourage men to enter the sector despite inevitable growth of the care sector in the future and the increased life expectancy of men. Improving gender diversity in informal care is essential to the future success of informal caregiving.

Communication and coordination between formal providers and informal caregivers is also essential to provide effective care at home. Informal and formal carers need to build shared goals and shared knowledge in addition to dedicated resources and supports in which providers deliver care. Not only does the relational coordination between formal and informal caregivers improve the efficiency of service it also improves the physical and mental health of the supported person. Flexible education systems for informal caregivers with the help of formal care givers will ensure care recipients receive the best possible care available. In order to provide safe informal care in the home there has to be better connection between informal and formal care.
**SOM Meeting Purpose**

The purpose of the Senior Officials Meeting is to provide a forum for senior government officials, Ministers and Secretaries of State to examine current trends in policy and practice as they relate to connecting formal and informal care in the face of increasing population ageing. The meeting programme will be based on mutual interest of the participants, and designed to promote dialogue and interaction among delegates, some of whom may represent countries who are well advanced, others from countries who have not yet been able to tackle the problem. The planned Senior Government Officials meeting will provide the opportunity for government officials to showcase leading practice in their respective countries and to hear firsthand how other governments and the industry sectors are creating policy to improve the connections between formal and informal care, the quality of life of older people and improve cost effectiveness.

**It will enable them to:**

- **Review** key aspects of formal and informal care policy and practice that for some countries have advanced significantly in recent years; to confirm successes, failures and learning; and to explore the challenges they and their governments face, both now and into the future.
- **Hear, question and challenge** acknowledged informal and formal care experts on key policy and program design developments that enable care providers and older people to improve efficiencies and client outcomes.

Senior officials attending this event will also have the opportunity to register and fully participate in the IFA’s 12th Global Conference on Ageing by contributing to a number of symposia and paper sessions designed to appeal to all conference delegates, covering issues central to the theme of the SOM. The conference website is: [www.ifa2014.org](http://www.ifa2014.org)

**Meeting Outcomes**

By the end of the Senior Officials Meeting, delegates will have:

- **met colleagues from around the world**, exchanging views and experiences in developing policy and programs relating to connecting informal and formal care;
- a greater awareness and **understanding of the key factors** that underpin successes;
- identified some of the **challenges and obstacles** to connecting formal and informal care from different countries;
- greater **transfer of knowledge and expertise** through potential partnering relationships;
- established a **global network** of colleagues and experts from whom to obtain advice;
- **created knowledge and skills export opportunities** across borders.
DELEGATE/GOVERNMENT REQUIREMENTS PRIOR TO MEETING

Additionally Officials are asked to respond to a short series of questions through an online survey response process. It is through these responses that the interactive elements of the days meeting will be scheduled. The draft final program will be circulated to attending delegates in the first week of March 2014. The Qualtrix survey, which will go live September 2013, focuses on the following questions:

1. Please mention one or more best practice(s) regarding long term care and technology developed and implemented successfully in your country.
2. Please indicate the most important barriers you perceived to successfully implement technological solutions in long-term care.
3. Please think of key-conditions that are relevant for sustainable solutions in long term care enabled by means of technology.
4. What are financial requirements or incentives to scale-up the technological innovations?
5. What should be the role of the national governments and the EU in stimulating the use of technology in long-term care?

SOM PROGRAM FORMAT

The meeting will be structured around a number of key presentations from the technology sector, a 1.5 hour interactive workshop and presentations from selected governments who have submitted abstracts for inclusion in the program. A complete program will be forwarded to Officials after 15th March 2014, the deadline for government submissions for program inclusion.

IFA 12TH GLOBAL CONFERENCE ON AGEING

If you are planning to also attend the IFA 12th Global Conference on Ageing that commences at the close of the SOM please go to the conference website www.ifa2014.com to register your attendance.
SOM VENUE - NOVOTEL HYDERABAD CONVENTION CENTRE

HICC is the first purpose-built and state-of-the-art convention facility, the first of its kind in South Asia. HICC in every aspect, be it infrastructure, services or technology, compares with the best in the world. It has an internal hall measuring 6,480 square meters, which can be partitioned into six small halls. The pre-function foyer area itself exceeds 6,400 square meters. Novotel Hyderabad Convention Centre adjacent to HICC is a 5-star 287 room hotel, built to suit the requirements of the discerning business traveler. HICC is a Green Globe certified convention centre.

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iv Ibid.


vii Ibid, pp 5.

viii NATSEM. “Projecting the need for formal and informal aged care in Australia: A dynamic microsimulation approach.” June 2011, pp 19.


xi NATSEM, 5.


xiii Ibid, pp 5.

xiv Ibid, pp 2.
xvi European Commission, pp 126.
xvii AARP, pp 2.
xx European Commission, 9.