

Unpaid Health Care: An Indicator of Equity

Prepared by Pat Armstrong



Office of Gender, Diversity and Human Rights

Unpaid Health Care Work: An Indicator of Equity. Summary

Pat Armstrong, PhD. DRP, FRSC
York University, Toronto, Canada

Unpaid health care is a gender issue, an equity issue and a human rights issue. It is a gender issue because women and girls throughout the world do the overwhelming majority of unpaid health care. It's an equity issue not only because women do much more of this labour and more of the labour that is most demanding and daily. It is also an equity issue because women with the fewest economic resources are the most likely to do the heaviest work and because those who need care experience inequities in the amount and quality of care they receive as a result. Recognizing, as the *Universal Declaration of Human Rights* (1948) does, that everyone has the right to health means recognizing that unpaid health care is a human rights issue because those who provide unpaid care too often suffer disproportionately from ill health as a consequence of this work and are thus denied the highest attainable physical and mental health.

The right to health includes the right to provide or not provide unpaid health care, and thus access to the conditions that support this right. Yet the demand for unpaid care is growing while the alternatives and supports to unpaid health care are not. Across countries in the Organization for Economic Cooperation and Development, more than one in ten adults does unpaid care work and this is the case for one in three adults over age 50. Two thirds of the care workers over age 50 are women.¹ Half a million Canadian women compared to a quarter million men, spent 10 or more hours a week providing unpaid care or assistance to seniors.²

This paper makes the case for unpaid health care labour as an indicator of equity in health services, and identifies strategies for addressing the inequities that result from the nature and distribution of unpaid care work. It recognizes the tensions that need to be balanced when developing strategies and argues that contexts must be taken into account in determining the most appropriate ones. It is a policy paper intended to provide an integrated picture of the factors shaping changes in unpaid health care work, in the nature, extent and distribution of this work, and of the consequences not only for individuals doing the work but also for the labour force, for those with care needs and for societies in general. It is designed for a broad audience, including policymakers, health care workers, health care advocates and members of the general public. It seeks to contribute not only to analysis of health policies but also to the development of new approaches to equity in the health field.

Contexts: There are political, economic, technological, demographic, health and value factors shaping the changing demand for and nature of unpaid health care. While the impact of any specific factor varies not only among countries but within them and while the various factors interact in different ways, there are some common patterns. The aging of the population, declining fertility and smaller households, technological advances that allow more care outside hospitals as well as longer survival for those with disabilities, the growing demand for female labour force participation combined with new managerial practices, and new policies emphasizing free markets and free market strategies together contribute to a growing demand for unpaid health care work that is combined with a decreasing number of people available to provide the labour. These developments are shaped by new values stressing individual responsibility and old ones assuming women naturally do such work willing and well.

Unpaid Health Care Activities: Unpaid health care involves a host of overlapping and increasingly complex activities. The six identified here cover broad categories that are involved to varying degrees depending on the country, the location within the country and the person with care needs. They include Instrumental Activities of Daily Living which are for healthy people usually provided in and by household members and mostly by women; Activities of Daily Living which involve those things such as bathing which we most commonly do for ourselves; nursing care which is mainly about medical care formerly provided primarily in institutions; health care management which has become increasingly important as care is fragmented through privatization; advocacy, which has also become more necessary as governments cut back services; and finally the social and emotional support which, although often provided in households, has altered significantly as more people are sent home quicker and sicker. These various aspects of care may be provided by the same person, by different people or by more than one person at a time and for more than one person. The location of the unpaid work also varies. Not everyone has a home and not everyone in a health care facility receives the full range of support, creating the need within these facilities for various forms of unpaid health care.

Unpaid Care Workers. The daily work of providing unpaid health care and especially the personal care is disproportionately done by women in every country for which we have data. Men not only do less; they are also more likely to do the work that is more flexible in terms of when and where it can be done. Children, too, provide care and so do neighbours, volunteers and some workers otherwise paid to do the work. However, there are differences within these patterns depending on location, culture and economic status, with poorer women doing more

and heavier care labour with fewer supports. Although some women have the resources to pay others to do the work and some countries provide paid care at home, the overwhelming majority of health care work in the home is unpaid and that even when some paid care is provided, unpaid work is still required and is still done. Equally important, those paid to provide the care are frequently low-paid workers who have migrated across and within national boundaries to do the care labour while leaving a care deficit at home.

Consequences: Unpaid health care has consequences for both the individuals who need care and those who provide it. It has an impact on families and on the next generation as well as on social relationship between families and others. Governments too are affected, as are employers and the labour force. Unpaid health care has an impact on health and costs, on social solidarity and on equity. It may be

done willing and well and it may be rewarding for both those who need the services and those who provide them. However, this is most likely to be

In Argentina, more than nine out of ten unpaid care workers are women and women account for more than four out of five providing care in Chile, Cuba and Uruguay.

Canadian research found that, among those providing four or more hours of care a week, approximately two-thirds of the women and nearly half of the men experienced significant job-related consequences.¹

the case when alternatives and supports are in place. Otherwise, the consequences are more likely to be negative. Given that women bear the primary responsibility for the most intense and long-term unpaid health care, it is women's health and future that is most at risk as the pressure to do the work and the work itself increases. In addition, the unpaid work limits women's labour force participation in ways that can make them more economically dependent on men, limiting their power in the household and beyond. It can also mean they cannot do their best at their paid job. It is not only the women doing the unpaid work who are at risk however. Men who take the primary responsibility for providing intensive care also experience negative consequences. Employers and governments can also face rising costs as a result, and so can the next generation. What suffers as well is equity, with women who are poor in particular losing out and differences among women increasing.

Strategies for Equity: Assessing the strategies for equity in unpaid health care work involves both an analytical framework and an ethical one, as well as an evaluation of impact. A useful analysis of unpaid health care takes context into account, recognizing both overall patterns within and across countries as well as differences among them. It recognizes not only the developments but also the forces and power differentials at play, along with their consequences. In that play, the female unpaid care provider is often the least powerful and the most vulnerable and it is the poorest women, regardless of location or culture, who are most likely to provide the daily, heavy unpaid health care and who have the fewest options. While ideas about women play a role, they are far from the only factor contributing to the increase in the demand for unpaid health care work or to women's responsibility for that work. Thus strategies that focus primarily on values rather than on the structures and institutions that enforce women's work are bound to fail, as are strategies that focus on men doing more of the unpaid health care labour. As the World Health Organization report on ethical choices in long-term care makes clear, "putting respect for human dignity at the centre of the social paradigm means accepting laws and social practices that protect the weak and vulnerable from domination, exploitation and neglect".³ Both the unpaid health care provider and the person or persons for whom they provide care are weak and vulnerable in many cases. Their relationships, as well as their health, are too often at risk and inequities grow. Governments have an interest and the leading responsibility in ensuring people are treated equitably, and with dignity and respect. To do so means avoiding the assumption that unpaid health care is provided willingly and well by women; that health care needs are the same for everyone or that households have the time or membership to provide care. The goal must be the right to care, which implies the right not to provide and not to rely on unpaid health care.⁴

There is an array of tensions in policy options, tensions that are often the result of assumptions and values rather than of evidence. These tensions, which combine and balance in different ways in different places, need to be made explicit and taken into account in developing strategies for equity. These include tensions between affection and obligation; between rights of the workers and rights of the person requiring care; between decision-making at the care place and outside it; between paid and unpaid workers; between levels of responsibility; between the short and long terms and between support that encourages women's unpaid health care work and those that allow women real options.

The most important supports are related to basic rights, including appropriate housing, a guaranteed minimum income as well as decent wages, and health services. These are the

most fundamental to human rights but they also have a profound impact on what unpaid care is required, on how it is provided and on whether those who willingly do the unpaid care work can reach the highest attainable physical and mental health. Respite services and adult day care can relieve some of the workload but may also serve to reinforce women's responsibility for the rest of care. Training and appropriate, accessible information can improve the quality of care and relieve some of the anxiety involved in the work but it too may primarily serve to ensure this is women's work. Employment supports such as flexible work hours, care leaves and carer pensions can make it easier to combine paid and unpaid care work but can also ensure women take on double workloads. Cash and tax supports, while some help, too often reinforce the low value attached to the work and limit options. Developing any of these strategies requires the measurement and valuing of unpaid health care work, although this too must be undertaken with care to ensure the data are an accurate reflection of what women and men, as well as boys and girls, actually do and what is required. Developing these strategies also requires an assessment of the impact on equity not only between women and men but also among women and for children.

It is clear that, regardless of location, the right to care for both providers and recipients requires structural supports from governments, employers and communities and real alternatives to unpaid health care work for those who now provide or are pushed to provide the labour and for those who need the care. It is also clear that the demand for unpaid care cannot continue to grow without profound negative consequences for individuals, families, communities, employers and governments. Indeed, the demand needs to shrink. Without such strategies, inequalities will increase not only between women and men but also among women and among men. It will also increase among countries, which is one reason why unpaid health care work provides an indicator of equity.

¹ Organization for Economic Cooperation and Development (2011) *Help Wanted? Providing and Paying for Long-Term Care* Geneva: OECD www.oecd.org/.../0,3746,en_2649_37407_47659479_1_1_1_37407.

² Statistics Canada (2011) *2006 Census of Canada. Topic-based Calculations Unpaid Work*. <http://www12.statcan.gc.ca/census-recensement/2006/dp-pd/tbt/Rp-eng.cfm?LANG=E&APATH=3&DETAIL=0&DIM=0&FL=A&FREE=0&GC=0&GID=0&GK=0&GRP=1&PID=92100&PRID=0&PTYPE=88971,97154&S=0&SHOWALL=0&SUB=0&Temporal=2006&THEME=74&VID=0&VNAMEE=&VNAMEF=>.

³ World Health Organization (2002) *Ethical Choices in Long-Term Care: What Does Justice Require?* Geneva: WHO, p.vii.

⁴ Armstrong, Pat et al. (2012) *The Charlottetown Declaration on the Right to Care*. Appendix in *Thinking Women and Health Care Reform* Toronto: Women's Press.

Unpaid Health Care: An Indicator of Equity

March 21, 2012

Pat Armstrong, PhD, DRP, FRSC

York University, Toronto, Canada

Unpaid health care is a gender issue, an equity issue and a human rights issue. It is a gender issue because women and girls throughout the world do the overwhelming majority of unpaid health care. It's an equity issue not only because women do much more of this labour and more of the labour that is most demanding and daily. It is also an equity issue because women with the fewest economic resources are the most likely to do the heaviest work and because those who need care experience inequities in the amount and quality of care they receive as a result. For example, in 2006, half a million women compared to a quarter million men, spent 10 or more hours a week providing unpaid care or assistance to seniors, with half those women putting in 20 or more hours.¹ If we are to recognize, as the *Universal Declaration of Human Rights* (1948) does, that everyone has the right to health, then unpaid health care is a human rights issue because those who provide unpaid care too often suffer disproportionately from ill health as a consequence of this work and are thus denied the highest attainable physical and mental health. This includes the many children, and especially girls, who also do such work.

The right to health requires the right to provide or not provide unpaid health care, and thus access to the conditions that support this right. Yet the demand for unpaid care is growing while the alternatives and supports to unpaid health care are not. Across countries in the Organization for Economic Cooperation and Development, more than one in ten adults does unpaid care work and this is the case for one in three adults over age 50. Two thirds of the care workers over age 50 are women.² Half a million Canadian women compared to a quarter million men, spent 10 or more hours a week providing unpaid care or assistance to seniors.³

This paper makes the case for unpaid health care labour as an indicator of equity in health services, and identifies strategies for addressing the inequities that result from

the nature and distribution of unpaid care work. It recognizes the tensions that need to be balanced when developing strategies and argues that contexts must be taken into account in determining the most appropriate ones. It is a policy paper intended to provide an integrated picture of the factors shaping changes in unpaid health care work, in the nature, extent and distribution of this work, and of the consequences not only for individuals doing the work but also for the labour force, for those with care needs and for societies in general. It is designed for a broad audience, including policymakers, health care workers, health care advocates and members of the general public. It seeks to contribute not only to analysis of health policies but also to the development of new approaches to equity in the health field.

Unpaid health care is complex in terms of the contexts, the activities, the actors, and the issues. It is becoming increasingly complex as demand for such care grows alongside fundamental alterations in the nature of the care required. Although it is difficult to capture unpaid health care in all its complexity –in part because unpaid care has not been a top priority of governments-, there is more than enough evidence to identify the main factors that are shaping unpaid health care, the consequences for different populations, and the urgency of developing policies in this field. As the *Human Development Report 2010* makes clear, “people are the real wealth of a nation”. Assessing “whether people can lead long and healthy lives, whether they have the opportunity to be educated and whether they are free to use their knowledge and talents to shape their own destinies” is a critical measure of a country’s success.⁴ Unpaid health care serves as both a reflection and a gauge of a nation’s human development. It provides an indicator of the growing inequalities between women and men as well as among them that are the subject of increasing concern throughout the world. It is a means of addressing inequities for both those who need such care and those who provide it. Unpaid health care also has consequences for the formal economy, as well as for the future of women, of families and of the next generation. As a result, governments everywhere have a responsibility to take action.

The Contexts Shaping Unpaid Health Care

There are political, economic, technological, demographic, health and value factors shaping the changing demand for and nature of unpaid health care. While the impact of any specific factor

varies not only among countries but within them and the various factors interact in different ways, there are some common patterns.

Demographic changes are both the most discussed and the most obvious factor influencing demand for unpaid care. Although life expectancy has declined in former Soviet Union countries and in nations where HIV or armed conflict have had a heavy impact, people are living longer in most countries. “Life expectancy is expected to rise across all categories of countries and is projected to increase from 68 years to 81 by the years 2095 to 2100”.⁵ In Latin America and the Caribbean, for example, life expectancy has increased by 24 per cent since 1970.⁶ As of 2011, life expectancy in all countries included in the Pan American Health Organization is at least 70 and women can expect to live longer than that.⁷ Living to be over 70, as more people now do, does not necessarily mean health care dependency or even significant care needs but even if the proportion of the older population requiring care remains the same, the actual numbers will increase significantly.

Whether the aging population will need care and of what kind is partly shaped by the kinds of lives these older people have experienced and both the nature and the range of alternative supports available. Data from PAHO countries indicate considerable variation in the need for care, with for example one in five Argentinean older women experiencing limitations in coping with daily living in ways that mean they require assistance, compared to a quarter of Chilean women.⁸ Older men are considerably less likely than women to experience such limitations in part because they have shorter life spans, although the gap between women and men also varies by country. For example, a quarter of older Cuban women experience limitations in relation to the carrying out essential tasks for themselves on a daily basis while this is the case for 14 per cent of the men.⁹ These gender differences have important implications, given that women are likely to need care and for a longer time period at the same time as they are expected to do the care work. Income is a critical factor in all countries in the need for unpaid health services, with higher socio-economic status associated with better health as well as with more opportunities to hire health services. Because women are more likely than men to be poor, they are less likely to be able to either pay for care or hire substitutes for their labour.

Households are also changing in ways that have profound implications for unpaid care provision. Although it is important to avoid assuming that all families, and especially the women and girls within them, have traditionally provided unpaid health care willing and well, it can be

assumed that most of the unpaid care provided in households has in the past been provided by the females within them. And although it is also important to avoid assuming that traditionally all households had an earning husband and a wife and/or daughters –as well as other extended family members- available to provide care, it can be assumed that new patterns in household formations alter who is available or able to provide care. These patterns vary across and within countries. For example, fertility rates are still quite high in some countries in the Central American Isthmus,¹⁰ but there are some clear overall demographic trends. “The projections also indicate that population ageing is the fastest in low-fertility countries. Today, 11 per cent of the population in low-fertility countries is 65 years or over. In 2050, the percentage is expected to be 26 per cent for this age group.”¹¹ In 2011, fertility rates throughout the region were very close to those in the United States and some were lower.¹² Fertility decline means there will be fewer children around to do care work for aging parents or other siblings with disabilities, even assuming children did so in the past and would or could do so now.¹³

Moreover, children and even spouses are increasingly likely to seek employment far from their family of origin, making unpaid care difficult if not impossible to perform. Urbanization has also disturbed family and neighbor connections. Extended families have become less common, with fewer people per household, while same-sex marriages that tend to involve few children have become more common¹⁴. Because women tend to marry men older than them and to live longer than men, they tend to be without a partner in old age even if they stayed married. Meanwhile, the number of divorces is rising, and more never-married women are parenting alone. “One-parent families are soaring in Latin America and, in particular, in Brazil”,¹⁵ while lone-parent families accounted for one out of four Canadian families with children.¹⁶ One-parent families have fewer resources and the majority are headed by women with low incomes. Remarriage after divorce may create larger households but reconstituted families can bring more people requiring care. HIV and armed conflict in particular have devastated households, often removing those most likely to provide care. In addition, a growing number of women are migrating within and across national boundaries to do care work, in the process leaving their own families without access to any unpaid care contribution from them. The growing numbers of homeless are usually without family or estranged from them, and thus are unlikely to have family willing or able to provide care.

Neighbourhoods and other social networks are also changing. If you google social engagement, the most common sites talk about social media and the ways people connect over the web. While such technologies expand acquaintance networks and may link families, there is little

indication that they could or would provide a source of unpaid health care. Canadian data show that half the respondents did not know their neighbours and only a minority belong to the kinds of community and religious organizations that provide volunteer health care services, including the kinds of social support networks essential to health.¹⁷

With the exception of changes in women's economic activity, **economic factors** shaping the growing demand for unpaid have received less attention. The focus women's paid work is not surprising given the assumption that women are able and willing to do the unpaid care work. A growing number of women are counted among those who supply labour for the production of goods and services in virtually all countries. With the exception of the middle east, Pakistan and a few other, mainly very small countries, significant portions of the female populations over age 15 are now active in the formal labour force and many are active in the informal one.¹⁸ Among member countries in PAHO, the majority has 50 percent or more of the women defined as part of the formal labour force. While women's increasing education levels play a role in motivating them to seek paid work in the formal economy, the overwhelming majority of these women enter the labour force because they need the money.¹⁹ In spite of the continuing labour force segregation that keeps many women in the lowest paid jobs, women's income has helped reduced inequalities in Latin America.²⁰ However, even with rising female labour force participation inequality has been growing among households in the wake of the most recent economic crisis²¹. Moreover increasing numbers of women are the sole economic support, because either they do not have a partner or their partner is unemployed. It is difficult to tell how many are involved for how many hours in the informal economy but this work too has an impact on the time available for unpaid health care. In Latin America, for example, it is estimated that 58 per cent of women workers are in the informal sector.²²

But the economic issues shaping unpaid health care are about more than women's growing labour force participation. With the emergence of managerial practices justified in terms of global competition and flexibility, the work itself is changing. As a result, women and men are working longer hours in their paid jobs and they move from job to job more frequently. Women especially often work irregular hours that make it difficult for them to take on regular and unpaid healthcare work involving heavy time commitments.²³ Indeed, with employment becoming more precarious for women and men, few may be willing to leave work or refuse overtime in order to provide care because they may fear losing their jobs. For many, technology and pressures to

compete combine to extend the paid work day into the home. Moreover, some paid work has been moved into the home, which may make it possible for women to combine it with unpaid health care but may also make it difficult to do either job well. Moreover, this intensification of work can mean neither women nor men have energy left to take on unpaid care work at home. This is especially the case for the women who make up the majority of the paid health care labour force and of those in precarious employment.²⁴

The rate of economic growth, as measured by Gross Domestic Product (GDP), also varies considerably among countries in the Americas.²⁵ A significant number have registered a decline in recent years and

this decline shapes ideas about the possibilities for supports for unpaid and paid health care by governments. Some aspects of the informal economy that produce goods are captured in this indicator but these measures of GDP exclude unpaid care work. As a report prepared for the United Nations Research Institute for Social Development points out, this approach to measuring economic output “could well result in ill-thought-out policies if they do not take into account unpaid care work and its interaction with SNA [System of National Accounts] production as well as its impact on the general well-being of the population”.²⁶ The result is that much of women’s work remains invisible in the economic accounting and the accounting itself provides an inaccurate basis for planning. In addition, lack of investment in supporting paid and unpaid health care now could mean higher costs in the future in terms of the labour force supply as well as in terms of medical costs.

“Ninety per cent of HIV/AIDS care-giving takes place outside of hospitals”.¹

Technological advances, including mechanical, medical and therapeutic ones, also contribute not only to the growing demand for unpaid health care but also to its changing nature. New technologies have made it possible to do more day surgeries, sending people home for their recovery while still in need of considerable and complicated care. Technologies have also been critical in allowing people to live after severe injuries or with chronic illnesses, often at home. Those with HIV, for example, are living longer and living outside facilities. “Ninety per cent of HIV/AIDS care-giving takes place outside of hospitals”.²⁷ Although the prevalence of other communicable diseases has been declining in PAHO member countries, chronic illnesses have become more prevalent.²⁸ Such conditions often require extensive and daily support. Equally important, technologies have made it possible to send home the kind of care previously only possible in hospitals. People now go home with catheters, monitoring devices and oxygen

masks, have dialysis and a wide range of injections, and frequently require a variety of therapies and complex equipment. Technologies can be used as well to link patients at home with professionals outside it or to family members, reducing the need for transport to services while increasing the amount of care left to be done at home. “For example, for seniors receiving home care services, a medication monitoring system equipped with a sensor-trigger system allows family members to monitor which medications were taken when from anywhere in the world.”²⁹ This is not sending care back home but rather using technologies to relocate care, mostly to unpaid providers who are usually unqualified for the increasingly complicated care work required.

More babies are surviving with disabilities, thanks in part to new technologies and health services for pregnant women. Others become disabled in later years as a result of injury or illness, malnutrition, lack of health services, abuse and alcohol or drug addiction, to name only some of the major causes. War is also a significant factor in the growing number of disabled. All these developments mean there are a growing number of young people who need care on a daily basis.³⁰ Current estimates indicate that 10 per cent of the world’s population lives with a disability and most of them are in low-income countries. According to the World Bank, between 80 and 90 per cent of people in Latin America and the Caribbean with disabilities do not have paid jobs.³¹ They are less likely than others in the population to have higher education or paid jobs that would allow them to purchase care.³² In the majority of nations women are more likely than men to live with disabilities,³³ often making it more difficult for them to provide care for others.

Political developments influence the demographic, economic and technological factors shaping demand for unpaid health care. The decades-old emphasis on market strategies has had a profound impact. Tax cuts intended to promote competition, combined with an emphasis on smaller government and concern over rising government debt, have resulted in smaller and fewer public health and social services. The imposition of structural adjustment policies have also meant a significant reduction in public services, including health services and a range of social supports that had helped both those who need health services and those who provide unpaid health care. Most of those who provide these public services and of those who use them are women. Meanwhile, the market strategies applied to the public services that remain have resulted in women especially losing paid work in the public sector at the same time as they have been pressured to take on more unpaid health care work that has been sent home. As a report

for the World Health Organization puts it, “Under the guise of health reform, some societies are offloading responsibility from the central government to the least capable and most vulnerable local authorities and family units, without a concomitant decentralization of resources.”³⁴ And ‘family unit’ usually means women. Similarly, a report for the United Nations identifies the “ever growing gap in services and safety nets on the part of governments associated with health sector reforms, decentralization, privatization and cuts to social spending” as critical factors in the increase in demands for unpaid care work.³⁵ Governments to varying degrees have promoted responsabilization, encouraging the voluntary sector, families and individuals to take responsibility for their own care in ways that increase the amount of unpaid care required.³⁶ The extent to which countries have privatized or failed to develop public services varies significantly by country, however. “In Latin America and the Caribbean, health financing schemes differed according to the income level of the country”, with the poorest countries offering the least public support and services.³⁷

Values also have an impact on the demand for unpaid care. There are a host of often contradictory developments in expressed and assumed values that influence the demand for unpaid health care. While there are significant differences among countries in terms of values, there is increasing emphasis placed by governments and economic leaders on individual and family responsibility for care. This responsabilization³⁸ is often characterized as choice but without options this choice may reflect “compulsory altruism”³⁹ or “conscriptio” into unpaid health care work, especially for the women and girls who are assumed to be natural caregivers.⁴⁰ Furthermore, choice is often equated with having services available for hire and thus with the ability to purchase—an ability many, and especially many women, do not have. At the same time, women are described as choosing to take on paid work, even though economic need is the primary motivation for women’s paid employment. Increasingly, governments have been promoting a restriction of services to their ‘core business’ and the transfer of services to the private, often for-profit, sector where costs are higher and access more limited. This emphasis has coincided with a strong critique of institutionalization as oppressive and hospitals as dangerous places in terms of infections, malnutrition and loss of mobility. The critique is linked in turn to stress on independent living for those with disabilities.

There is as well a widespread belief that the best and preferred care is at home, assuming there is a home, and that families or more particularly the women within them, want to and can provide quality care. And there is also an assumption that most want to die at home. Yet

Canadian research “offers little empirical evidence that the first choice of most frail elderly is to depend on family for hands-on caregiving, nor that most family members would freely and willingly choose to do so”.⁴¹ Indeed, North American research suggests that income and education matter at least as much as culture in terms of the kinds and amounts of unpaid health care women provide. Those who can afford to buy services or can access public services do so.⁴² Similarly, research in Nicaragua shows that although for both women and men there is a “clear pattern of diminishing participation rates” in unpaid care work with rising income and of fewer hours put into such work, this is especially the case for women.⁴³ In contrast, a Mexican study of parents providing care for children with multiple sclerosis concluded that their relatively high level of satisfaction could be attributed to “familism” values and high respect for people with disabilities.⁴⁴ However, this care was provided more often by low-income families with little access to alternative services and the values were used to explain data and were not measured in the data. Caution is needed in assuming not only that some cultures or genders naturally want to provide unpaid care or that providing care means it is a choice but also in assuming that stated values match practices or that practices result in quality care.

In addition, there has been a growing conviction that markets and for-profit practices provide the most effective and efficient services and supports. This is combined with the assumption that private delivery and the right to buy allows more choice. However, like the belief that all women can and want to provide unpaid, appropriate care, it is a value that tends to be based on belief rather than evidence. Unquestionably, when services must be bought there are those who cannot afford to buy. Moreover, there is little evidence to demonstrate that the quality is better when access declines as a result or that the for-profit sector provides better care. As markets increasingly dominate in health services, they become luxury, private goods rather than accessible public ones and access to health care is no longer a human right or even understood as such.

At the same time, there is demand for more and better services or supports of various kinds from governments. According to a European Commission report, “the number and influence of vocal patient groups and self-help groups is likely to increase and the trend towards internationalizing health interest groups is set to grow.”⁴⁵ Alongside these value shifts is the continuing belief in the importance of encouraging the education and labour force participation of women and a commitment to equity, both of which depend to some extent on government intervention and which cannot be easily combined with more unpaid health care. This contrasts

with the persistent idea that care is women's responsibility and that care is about "love, attachment, duty and reciprocity" and not about work.⁴⁶ Without pay in a world where more and more services are valued in monetary terms, the unpaid labour in health care has less value than other work. Without supports, those who do want to provide care find it difficult to do and to do well.

In sum, a growing number of people require unpaid health care and the care they require is more complex than in the past, even though few have the necessary training to do the work effectively. At the same time, fewer women or other family members are available to provide unpaid care and governments have not only failed to fill the gap; they have cut back on services and introduced reforms in ways that increase demand. Meanwhile, shifting values simultaneously promote individual responsibility for economic survival and health care while emphasizing women's place in the home providing unpaid health care.

Unpaid Health Care Activities

Unpaid health care involves a host of overlapping and increasingly complex activities. The six identified here cover broad categories that are involved to varying degrees depending on the country, the location within the country and the person with care needs.⁴⁷ They are briefly described in order to provide a basis for understanding the scope of what needs to be done, who does it and what is required to promote equity.

The most common form of care work required is what in the literature is called **Instrumental Activities of Daily Living (IADL)**. These activities primarily involve those usually provided in and by households. They include cooking, shopping, cleaning and laundry as well as home maintenance tasks and any other work frequently done in and around the home. In some countries or households it may also include work such as feeding and tending to animals, carrying water or other forms of household production. Some of these tasks must be done on a daily basis and at specific times but many of them are more flexible, allowing care providers to undertake them when their schedules allow. Many mean adding to the usual daily tasks, although the workload is often more intense and the task frequently take more time. If the person providing care does not live in the household, traveling is added to the work time. Equally important, the tasks may have a significantly different form and even dangerous consequences for both worker and the person needing care when they are provided for

someone who is ill or disabled. For example, clothes from those with infectious diseases may have to be washed separately and in particular ways and diets may require special preparation, as is the case with diabetics. As a result, the quality and the risk of care become the responsibility of the person-usually a female- doing the tasks rather of the health system.

A growing number of people require more than assistance with these instrumental activities however. What are termed **Activities of Daily Living** (ADL) refer to much more personal and increasingly medical aspects of health care work. These include assistance with dressing, bathing, eating, using the toilet, brushing teeth and combing hair. Incontinence care is increasingly common, as is the need to lift and move people in and out of bed. In short, this work involves the direct, personal care that individuals who are able usually do for themselves. Those who return from day surgery, have disabilities, or have become frail in old age may also require assistance getting around the house, or moving outside it. Most of these tasks must be done on a daily basis and many must be done according to a strict schedule. Some must be done around the clock and may be made more difficult by the need to travel to provide care. All require extra effort and some skill when they are done for others and when those others are frail, disoriented or disabled.

There is a third set of tasks that are also becoming more visible as health reforms and new technologies are put in place. They include giving medications, inserting needles, changing dressings, monitoring temperature or blood pressure and using a variety of equipment such as catheters, oxygen masks and feeding tubes. These tasks could be defined as **nursing care**, even though they are seldom carried out by people with formal nursing credentials. Nurses not only have the education to ensure they know how to do the work but they also have a professional code of ethics covering their practices and often some form of collective organization to protect their rights while those doing unpaid health care work seldom have any of these.

A fourth, less visible but increasingly important form is **health care management**. While most care providers do some care management, some are primarily managers and care navigators. They investigate and arrange for more formal care services, as well as ensure such services are provided. In effect, unpaid providers act as what in the formal system are called case managers, determining hours of service and eligibility, making appointments and convincing care recipients to participate. They mediate between the formal and informal system, as well as between the

system and the person with care needs. Managing money, completing forms, assembling documents, investigating options, and tracking tests results are all part of care management. Some aspects of care management are possible to do from a distance and offer considerable flexibility in terms of when they must be done. However, other aspects can only be done at the convenience of the formal system. The program and office support provided by volunteers in hospitals and other health care facilities could also be classified as management work. Similarly, the fundraising done for various health care services could also fit in this category.⁴⁸ It is work that requires both knowledge of the system and equipment such as computers in order to do some of the tasks.

A fifth form of care work has to do with associated activities done in relation to those outside the home. Care providers often have to spend considerable time and energy **advocating**, individually and through organizations, for care and supports. They frequently have to educate others about the particular health issues faced by their disabled children or older relatives.⁴⁹ This advocacy work is time consuming and, like other aspects of unpaid health care work, requires considerable knowledge and time to do effectively.

Finally, there is a form of unpaid health care work that should pervade all other forms but may constitute the primary aspect. Everyone requires **social and emotional support**. But those who have undergone surgery, live with disabilities or live into frail old age have particular needs for companionship, for touch, for listeners and talkers. This is especially the case if they are not able to leave their beds or their homes. The need is particularly great for those requiring palliative care. Such support may be combined with other tasks; it may be done from a distance and does not necessarily have to be done at specific times. It is work that is often assumed to come naturally to women but it is a skill taught to formal care providers because it is both an essential and learned capacity for health care work.

These various aspects of care may be provided by the same person, by different people or by more than one person at a time and for more than one person. The location of the unpaid work also varies. It is not necessarily provided in homes. Not everyone has a home and the homeless may receive some unpaid support on the street or in the shelters where they live. Not everyone in a health care facility receives the full range of support, creating the need within these facilities for various forms of unpaid health care.⁵⁰ Emotional and social support has long been expected from families and friends regardless of location, and this is especially the case for women.

However, increasingly paid workers in facilities are unable to carry out the full range of tasks required and must leave them to be done by unpaid providers or work unpaid overtime themselves in order to get the job done.⁵¹ Unpaid workers empty bedpans and feed patients, warm blankets and supervise exercises, to name only some of the tasks done by unpaid workers within care facilities. It is also important to note that, while it is possible to identify the needs for and aspects of unpaid health care work, there is no guarantee that such work is done or provided well and willingly.

Who Provides

Families, relatives, friends, neighbours, and volunteers individually or through organizations constitute the unpaid health care labour force. Who does what for how long each day and over time is difficult to determine, as Budlender's review of time-use surveys makes clear.⁵² Unpaid care is not included in Systems of National Accounts, although a number of countries have separate set of records on unpaid work that include housework, care of children, the disabled and the elderly as well as volunteer work. However, these often exclude factors such as travel that may be time-consuming aspects of health care work. Equally important, time may be underestimated or unrecorded when it is an extension of existing work, as in the case of women doing more cleaning or laundry when people are ill; or it may be overestimated if it is unusual, as might be the case when men take their mothers to the doctor or clean their toilet. Moreover, "unpaid care work is not identical to unpaid work since there are some types of activities that are not care work"⁵³ and care work encompasses work for children that would not usually be defined as health care. In short, unpaid health care work is difficult to count and often goes uncounted, especially for women.

Nevertheless, there are enough data to demonstrate that women do the bulk of unpaid health care work and that this is especially the case for Activities of Daily Living that are the most regular, time consuming and demanding. As Duxbury et al. put it, the "research is clear about the persistence of a gendered division of labour in the allocation of caregiving work, with women, regardless of employment status, income and family structure, being more likely than men to perform the more intensive personal and physical care tasks."⁵⁴ For example, a Mexican study found that "the time spent by women who perform each activity is noticeably longer than that spent by men for all activities except for care of ill people."⁵⁵ In Argentina, more than nine out of ten unpaid care workers are women and women account for more than four out of five

providing care in Chile, Cuba and Uruguay.⁵⁶ In Nicaragua, even though women's labour force participation rates are not very different from those of men, they are four times more likely than men to provide care for people and to spend significantly more time doing so.⁵⁷ In Canada in 2007, "nearly 40% of women caregivers and fewer than 20% of men caregivers provided personal care" for the elderly while women were twice as likely as men to perform regular tasks inside the house. Men did more work outside the house, work that was more flexible in terms of when and for how long it was done.⁵⁸ Women were much more likely than men to do high intensity unpaid health care work.⁵⁹

The male/female gap is especially wide when it comes to the care and supervision of disabled people, which is work that is likely to last for years and require support every day, even all day. Canadian research also indicates that women, unlike the men who were primary care providers, said there were no substitutes available to do the work when they took on the responsibility.⁶⁰ They have no alternatives. This lack of substitutes builds on and reinforces women's sense of responsibility for care at the same time as it reflects their limited economic and power resources as well as assumptions about women's work.⁶¹ It is women with the least education and the lowest incomes who have no alternatives to doing the unpaid health care work. It is the most vulnerable women who carry the heaviest loads, even though they do so with the fewest supports and the least visibility.

Most unpaid health care labour is provided to close family members, but unrelated others also participate in health care work. Canadian data on eldercare indicate that although half of the eldercare is provided to parents or in-laws, nearly 20 per cent is provided to a neighbor or friend.⁶² Women are more likely than men to receive care from a friend, a friend who is female.⁶³ As is the case with all data on unpaid care, however, the failure to recognize care as work must be taken into account. It is both the women who do the work and those who do the counting who fail in this way. That only 7 per cent of Canadian respondents report they care for a spouse may reflect women not considering the work they do for their partner as extra or even unpaid care work. It may also be a product of the way the questions are asked. Nevertheless, almost half of Canadian men report that their main provider is a spouse, while this is the case for only one in five women.⁶⁴

Care for younger people with disabilities is also disproportionately done by women and for partners or close relatives. Data from the United States indicate that women account for 72 per

cent of care providers for young children with disabilities and 59 per cent of those for young adults with disabilities.⁶⁵ Their numbers are growing, as is the time they spend daily and over the years in doing unpaid health care work. A quarter had been providing care for more than 10 years, with the average weekly hours ranging from 30 for children with disabilities to 20 for adults.⁶⁶ But here, too, others are often involved. In the case of people with multiple sclerosis, for example, one study in Belgium found that 20 per cent of unpaid health care was provided by those living outside the household.⁶⁷

Those living outside the household and family who provide care may be acting as individuals. But some at least are connected through community organizations.

Religious groups in particular are active in organizing volunteer help in various countries and in providing social support for caregivers. A range of other

community organizations are also involved, sometimes providing both paid and unpaid health care services. Many volunteers do unpaid care work within facilities. While similar numbers of women and men in North America are counted as volunteering, women do most of the volunteer direct health care work. Research in three Canadian hospitals indicated women made up between two-thirds and more than three-quarters of those providing volunteer care. When men were involved in direct care, they tended to seek work in the emergency department, although more volunteered for fund-raising work.⁶⁸ Not to be forgotten are those paid workers who put in unpaid time in order to make up for the care deficit.⁶⁹ Their work goes uncounted in all the data and it is women who do most of this form of labour both because they are the bulk of the paid health care labour force and because they are held responsible and feel responsible for the care deficit.

While adults provide most of the unpaid care, it is important to note the role children as young as five years old play. Data on children who do unpaid health care work may be even less reliable and more underestimated than those on adults because they rely mainly parents' reports. Parents who have drug or alcohol related illnesses or mental health ones in particular may not recognize their children's care work.⁷⁰ Nevertheless, there is enough information to suggest there are a significant number of children who do this work and the numbers may well

Base from the United States
hospitals that were accounted
for 72 per cent of care-
providers for young children
with disabilities and 59 per
cent of those for young men
and women with disabilities
in the emergency department,
although more volunteered
for fund-raising work

be growing, especially as HIV/Aids affects more mothers and fathers. US data indicate that 3 per cent of households with children include a child who does unpaid health care work.⁷¹ Over half of them say they help with ADLs and the overwhelming majority says they help with IADLs, although most have help doing this work.⁷² Most do the work for parents or grandparents, although some also help with siblings who have disabilities, and they are more likely to do this work in low income or lone-parent households. The patterns may well be different in low-income countries where children may do much more of the unpaid health care work when parents are absent as a result of war, HIV/AIDS or other infectious diseases, or when aspects of domestic work that are essential to care, such as carrying water, are assigned to girls.

In sum, the daily work of providing unpaid health care and especially the personal care is disproportionately done by women in every country for which we have data. Men are more likely to do the work that is most flexible in terms of when and where it can be done. Children, too, provide care and so do neighbours, volunteers and some workers otherwise paid to do the work. However, there is research to indicate that there are differences within these patterns depending on location, culture and economic status. For example, a Chilean case study found that women in higher income brackets were more likely to do nursing and management tasks compared to those with low incomes, although they were also more likely to have paid help in doing so.⁷³ But it is also the case that the overwhelming majority of health care work in the home is unpaid and that even when some paid care is provided, unpaid work is still required and is still done. In Canada for instance, close to 97% of all those receiving paid home care services have an unpaid care provider. Four in ten of these providers are distressed and more than a quarter say they cannot continue.⁷⁴

Consequences of Unpaid Health Care

Unpaid health care has consequences for both the individuals who need care and those who provide it. It has an impact on families and on the next generation as well as on social relationship between families and others. Governments too are affected, as are employers and the labour force. Unpaid health care has an impact on health and costs, on social solidarity and on equity. Given that women and girls bear the primary responsibility for the most intense and long-term unpaid health care, it is their health and future that is most at risk as the pressure to do the work and the work itself increases.

The **health** consequences of unpaid care work for individual providers are well documented. There are rewards to providing care, but these rewards may well be outweighed by burdens that can be especially heavy in the absence of economic and other supports. The health impact varies with the nature of the care demands. Research in Brazil, for example, found that those who dealt with incontinence were particularly burdened.⁷⁵ Paid work also influences the health of unpaid workers. “Employees who provide caregiving for elderly dependents who live with them experience the highest levels of financial strain, physical strain and emotional strain.”⁷⁶ Age, too, makes a difference, with older providers at greater risk of injury.⁷⁷ The impact varies as well with how much time is involved on a daily basis and over the lifespan. However, most unpaid providers experience physical changes when considerable time or particular illnesses are involved. More than a third of Canadians doing this work experienced moderate to high levels of physical strain.⁷⁸ Fatigue is especially common, and combined with difficulty sleeping. Headache, back pain, weight loss, colds and worsening of a health condition are also common.⁷⁹ Physical injury is frequent, especially if the person needing care is violent or particularly difficult to move. Mental health consequences may be even more likely and less varied in their impact. In Argentina, Chile and Uruguay, many suffer from depression and feel overwhelmed.⁸⁰ In Canada, “across caregiving types, ethnic groups and geographic location, many women reported that caregiving led to feelings of depression and helplessness”⁸¹ The more hours involved, the greater the stress. The more severe the health problems of those with care needs, the more severe the health consequences for those doing the unpaid care work.⁸²

In Argentina, Chile and Uruguay, many providing unpaid health care suffer from depression and feel overwhelmed.

Women’s health is more likely to suffer because they do most of the heavy, primary health care labour that is most commonly associated with negative health outcomes.⁸³ And women are more likely than men to be poor. “The strong association between increased financial and emotional caregiver strain and poorer physical and mental health does not, however, vary with caregiver group.”⁸⁴ Women in older age groups who cannot afford to either buy support or quit their paid jobs are most at physical risk while emotional strain is highest for women with little money who do unpaid care work for elderly dependents.⁸⁵ Lack of choice contributes to these feelings of depression and helplessness. While some care providers have chosen to do so, 40% of US caregivers for younger adults with disabilities did not feel they had a choice,⁸⁶ and this is

the case for the many who do unpaid work for the elderly as well. For Canadians, “three out of six factors that appear to be determinants of a woman’s decision to provide care represent external or structural constraints: the inadequacy of institutional and community resources, the imposition of the decision by the dependent person and woman’s economic dependency”.⁸⁷ Although Canada has, at least in theory, universal access to doctor and hospital care, other supports such as mental health services, residential care, respite care and home care are much more limited, more privatized and inaccessible, and so are income and employment supports. In other words, unpaid health care workers often have little choice and it is women who have the fewest choices and supports.

For Canadians, “three out of six factors that appear to be determinants of a woman’s decision to provide care represent external or structural constraints: the inadequacy of institutional and community resources, the imposition of the decision by the dependent person and woman’s economic dependency

According to Canadian and South American research, lack of financial resources exacerbates the health consequences and those providing care worry about money. Those particularly subject to physical strain were older women who lived with those for whom they provided care and who were unable to pay for support or quit their paid work. Emotional strain was highest for women with little money, without children, and providing care for elderly dependents. With the work characterized as high demand and low job control, it is not surprising that the health of these women suffers when they provide unpaid care.⁸⁸ Many are themselves frail or in ill-health and the extra work may not only exacerbate their conditions but also mean they are unable to provide adequate care. The lack of financial resources, combined with new managerial practices, put into public health services contributes to the growth of unpaid work in the formal sector as women employees in particular seek to make up for the care deficit by putting in uncompensated overtime. While it is difficult to determine with any precision how much this overload accounts for the high and growing rates of absences due to illness and injury in health services, it seems more than likely it is a factor.⁸⁹ For other women with paid work, there is added stress of doing unpaid care work for which they are not qualified.

The impact on the **next generation** may be most obvious for the children who themselves are directly involved in the work. On the one hand, children who provide care may develop skills and capacities that are useful to them as adults and their labour can also make it easier for employed adults to juggle demands.⁹⁰ On the other hand, children who provide considerable

care “can experience significant restrictions in their development, participation and opportunities, and educational attainment, even when there may be some ‘positives’ associated with caring—such as enhanced coping mechanisms, the development of life, social and other skills, maturity, as sense of purpose and closer attachments”.⁹¹ According to US research, children in minority households with low incomes are particularly vulnerable and boys have more difficulty than girls, perhaps because the work goes against cultural practices. At the same time, girls responsibility for unpaid health care work is reinforced. Less obvious are the ways the devotion of time and resources to health care for one or two family members may mean others have little support. The presence of people with heavy care needs can also result in social exclusion, both as a result of stigmatizing attitudes and because there is no time for developing or maintaining social networks.⁹²

Care provided in the **family and community** can bring people closer together as they share and learn from each other. However, the emotional stress that is a frequent consequence of unpaid health care may play out in family dynamics and in community relations.⁹³ Research of US families with children who have Autism Spectrum Disorder, for example, indicates that divorce rates are considerably higher among these families.⁹⁴ In the case of families of children with Down Syndrome, however, divorce rates were lower than in other families and when divorces did result, they were more likely in rural families and in families where the parents had low levels of formal education; in other words, in families that had lower incomes and fewer supports.⁹⁵ When many unpaid health care providers give up their leisure time to provide care, families have less time to have fun together.⁹⁶ Emotional strain in particular appears to have a negative impact on families.⁹⁷ According to the Anglican Consultative Council in the United States, “the family is being stretched ‘to the breaking point’ and ‘devastated’ by ever-growing burdens of care”.⁹⁸ Heavy unpaid care workloads also mean care providers have less time to be involved in building communities. It also means many women end up parenting alone.

Care may be unpaid but it is not without direct economic costs. Equipment, pharmaceuticals and supplies must be purchased. Renovation to housing is often required. Transportation to and from services adds to expenses, as does responding to special dietary needs. Often there are direct payments for health services involved. These costs, combined with restrictions on employment resulting from the workload, can move women especially into poverty.

Technologies have also served to increase some of the costs of care, both for the individual and for health systems. According to a British study, it costs three times as much to raise a child with

a major disability and more than half the families who provide such care live in poverty.⁹⁹ Canadian data indicate that the extra expenses are the most common problem for those providing unpaid care¹⁰⁰ and the problems increase if those doing unpaid care work live at a distance. “Even after other socioeconomic factors and the number of caregiving hours were taken into account, the odds of having extra expenses were three times higher for caregivers living more than half a day’s journey away than for those in the same neighbourhood” and this was especially the case for women.¹⁰¹

One clear impact on the **economy** is the reduction in labour force participation to those who take primary responsibility for the unpaid care work. While a survey of the literature shows that working age unpaid care providers are as likely as non-providers to take paid work, it also shows that they often reduce their hours when they take on unpaid health care work and that the heavy work of a primary caregiver frequently results in withdrawal from the labour force entirely.¹⁰² According to US research, “unpaid caregivers who assume primary responsibility for the personal care of frail older adults average 201 hours of help per month, more than the typical full-time job”,¹⁰³ making other work impossible. Given that women usually take on the heavy personal care loads that are difficult to combine with regular paid work and given that women on average earn less than men, it is mainly women who withdraw or reduce hours. It is mainly women who feel the emotional and physical consequences of the stress, stress that can also be felt in their families when women take the stress home. Unpaid healthcare work not only influences whether and how much women participate in the labour force, it also has an impact on the way they participate and on their future. Involvement in unpaid health care often restricts women’s employment options, encouraging them to take paid work close to home and with hours that can fit in with their unpaid work demands. It can make it too difficult to accept promotion or increased responsibility, to accept overtime or uneven work demands. It can also mean they become ineligible for pensions and new jobs after their unpaid care work is over, jeopardizing their future and

For women the total individual amount of lost wages due to leaving the labor force early and/or reduced hours of work because of caregiving responsibilities equals \$142,693. The estimated impact of caregiving on lost Social Security benefits is \$131,351. A very conservative estimated impact on pensions is approximately \$50,000. Thus, in total, the cost impact of caregiving on the individual female caregiver in terms of lost wages and Social Security benefits equals \$324,044.¹

reducing the flexibility of the labour force overall.¹⁰⁴ Those who reduce their hours have pensions based on lower earnings. Indeed, with many rights of citizenship and benefits linked to full-time employment, women with few options other than withdrawing from the labour force or reducing their time there in order to do their unpaid care work end up with fewer social rights and benefits now and in the future. At the same time, the double workload of women continues to be used as a justification for the segregation of women into the lowest paid jobs.¹⁰⁵

Employers feel the impact as heavy unpaid workloads are associated with high absenteeism and turnover.¹⁰⁶ Unpaid care work shows up in stress at work. Stressed workers are “more likely to be unhealthy, poorly motivated, less productive and less safe at work. And their organizations are less likely to succeed in a competitive market”.¹⁰⁷ In addition, those with heavy unpaid care work responsibilities may come in late or leave early, take calls from home while at work and lose their concentration. Indeed, one study found that this was the case for a majority of women and close to a majority of men who provide unpaid care, a not surprising gender difference given women’s greater responsibility for personal care.¹⁰⁸ Canadian research found that, among those providing four or more hours of care a week, approximately two-thirds of the women and nearly half of the men experienced significant job-related consequences.¹⁰⁹ In addition, conferences and training are less possible, making these workers and their organization less adaptable to change.

Government costs may be directly influenced by rising demands on those providing unpaid care. Some health care costs rise. Canadian research indicates that those unpaid care providers who are under financial strain visit emergency rooms more often than others and those experiencing physical or emotional strain see their family physician more.¹¹⁰ The risk of poverty increases with heavy unpaid workloads, as does withdrawal from the labour force, leading to increasing demands on governments for economic support in the future. Governments that fail to provide supports for those doing unpaid care work may find that those in need are abandoned entirely, leaving them to the formal system. Moreover, there is no clear evidence that post-acute care or home care for the severely disabled is cheaper at home even without factoring in the economic value of unpaid care¹¹¹. And there may be political consequences resulting from the failure to provide supports for those doing the unpaid work. For example, exposure of neglect for those needing care and of the health consequences for unpaid health care workers can contribute to election defeats.

The changing nature of unpaid health care work means that providers need more **skills**. New managerial skills are required to coordinate, record and arrange care, giving those with more formal education and language skills, as well as cultural ones, an advantage. Nursing work which in hospitals is only done by those with formal training is being transferred to the home, often without training provided as a Chilean case study demonstrates.¹¹² But it is not only nursing work that requires new skills. The work involved in providing ADL also requires training in lifting, for example. Even those aspects most closely associated with women's domestic tasks, such as laundry and cooking, require new skills when the person needing health care has an infectious disease such as HIV/AIDS or is old and especially vulnerable to infections. And the skills involved in providing social and emotional support cannot be considered natural or usual for women either. Alzheimer's provides just one example of cases that demand particular relational skills. At the same time, the transfer of so much work more often defined as skilled when done for pay can serve to denigrate the skills of both paid and unpaid providers. If it is assumed that anyone, and especially any woman, can take up the tasks or at least can be quickly taught them, then the skills of paid workers is undermined. Indeed, the result may be less paid care work. Given that women make up the overwhelming majority of those providing both the paid and unpaid care work, the impact is felt primarily by women

The undermining of skills and the transfer of care work to the household goes hand in hand with the increasing demand for **migrant female labour**. The lack of supports for care work sent home encourages the employment of the cheapest available labour; labour made cheap by the denigration of the skills required and by those government policies that simultaneously allow their employment and fail to protect them from poor conditions of work.¹¹³ It is made cheap as well by the assumption that any woman can do the work by virtue of being a woman. Discrimination against these migrant workers can serve to increase the risk to them while reinforcing the notion that any woman can do the work.

Linked to skills are the consequences for **those needing unpaid health care**. Unskilled assistance can put both the provider and patient at risk, resulting in poor quality care. Pressures on providers contribute to making direct abuse, or indirect abuse as a result of neglect, not uncommon. The person who needs care may have little choice about having the most intimate personal care provided by a daughter, even when they would prefer a professional provider and even when the work is done badly. They may also have little say about when and how care is provided if the daughter is employed in a job with fixed time

demands that also leave her with little energy. The dependency involved may create depression, especially if the person feels they are a burden, a risk to the care provider or that the nature of care puts them at risk. Given that women make up the majority of the elderly who need care, and are more likely to live in poverty in old age, women are particularly vulnerable to being financially dependent in ways that give them little choice about who provides what kinds of care.¹¹⁴

Unpaid health care work may be done willing and well. And it may be rewarding for both those who need the services and those who provide them. However, this is most likely to be the case when alternatives and supports are in place. Otherwise, the consequences are more likely to be negative. Given that women bear the primary responsibility for the most intense and long-term unpaid health care, it is women's health and future that is most at risk as the pressure to do the work and the work itself increases. In addition, the unpaid work limits women's labour force participation in ways that can make them more economically dependent on men, limiting their power in the household and beyond. It is not only the women doing the unpaid work who are at risk however. Males who take the primary responsibility for providing intensive care also experience negative consequences. Employers and governments can also face rising costs as a result, and so can the next generation. What suffers as well is equity, with women who are poor in particular losing out and differences among women increasing.

Strategies for Equity

Assessing the strategies for equity in unpaid health care work involves both an analytical framework and an ethical one, as well as an evaluation of impact on equity. A useful analysis of unpaid health care takes context into account, recognizing both overall patterns within and across countries as well as differences among them. It recognizes not only the developments but also the forces and power differentials at play, along with their consequences. In that play, the female unpaid care provider is often the least powerful and the most vulnerable and it is the poorest women, regardless of location or culture, who are most likely to provide the daily, heavy unpaid health care and who have the fewest options. While ideas about women play a role, they are far from the only factor contributing to the increase in the demand for unpaid health care work or to women's responsibility for that work. Thus strategies that focus primarily on values rather than on the structures and institutions that enforce women's work are bound to fail, as are strategies that focus on men doing more of the unpaid health care labour. In addition, it must be

recognized that not everyone has a place where health care can be provided and not everyone has someone who can provide any care at all.

Equity is central to the ethical framework. As the World Health Organization report on ethical choices in long-term care makes clear, “putting respect for human dignity at the centre of the social paradigm means accepting laws and social practices that protect the weak and vulnerable from domination, exploitation and neglect”.¹¹⁵ Both the unpaid health care provider and the person or persons for whom they provide care are weak and vulnerable in many cases. Most of them are women and girls. Their relationships, as well as their health, are too often at risk and inequities grow. Addressing these growing inequities means avoiding the assumption that unpaid health care is provided willingly and well by women; that health care choices are the same for all those who require care or that households have the time or membership to provide health care. The goal must be the right to care, which implies the right not to provide and not to rely on unpaid health care.¹¹⁶

Governments have a vital interest and the leading responsibility in ensuring people are treated equitably, and with dignity and respect.¹¹⁷ Essential to this goal is the right to health care. While the data are problematic and there is a great deal of diversity among and within regions, there are established patterns and enough evidence to use as the basis for strategies. One clear pattern is that regardless of context, the primary responsibility for the unpaid health care work is assigned to women. Another is that without appropriate supports or alternatives, the work may not be done, may be done badly or may result in more costs for the individual, the family, the government, employers and society as a whole. These consequences are often apparent immediately but many will not become obvious until later when they are more difficult to address. Meanwhile, inequities will increase among women as well as between women and men.

There is an array of tensions in policy options, tensions that are often the result of assumptions and values rather than of evidence. These tensions, which combine and balance in different ways in different places, need to be made explicit and taken into account in developing strategies for equity. One such tension is that between affection and obligation, or what has been characterized as a tension between caring about someone and the requirement to care for someone.¹¹⁸ Loving someone need not mean that you can, want to, or should provide their healthcare work, but women in particular feel pressure to express their love through care work,

pressure that comes from the absences of alternative resources as well as from their own values and those of others. A second, and equally critical tension is that between the rights of the person doing the unpaid care work and those of the person requiring the work. Assessments of needs and rights tend to focus on the person who requires the work while assessments of burden and cost tend to focus on the one doing the care work. Although their rights and needs may coincide, they frequently conflict and such conflict requires recognition rather than dismissal. Related to this second tension is a third around decision-making. Who decides what is done with and for whom for how long and in what way is acted out between the one providing care and the one needing care but the balance of power between them is shaped by forces outside their interaction, including health services, employers, and governments.

A fourth tension is about levels of responsibility. How responsibilities among governments at various levels, community and religious organizations, families, friends, households and the individual are allocated depends on power and values, with conflicts among them shaping unpaid health services. There are also tensions among the paid and unpaid health care providers. Although their interests often coincide, there can be conflicts over who does what when, who decides and who knows best. This tension may be exacerbated by the employment of migrant workers who usually have less power than other paid providers. A sixth tension is that between today and tomorrow, one that can take multiple forms. Generational tensions over who should provide what kinds of care are not uncommon; nor are those between devoting resources to paying for care today at the expense of debts tomorrow. These future debts may be individual, as in a woman leaving paid work in order to provide unpaid care, or collective, as in the family or the state going into debt to pay for services or failing to do so and as a result increasing the sickness load decades from now. And finally, there is tension between providing supports for unpaid health care work that makes the work itself an option and offering ones that reinforce women's responsibilities for unpaid care.

This list of tensions is not comprehensive and this paper is not intended to resolve them. Rather the purpose is to draw attention to the tensions that need to be recognized and balanced in developing country-specific strategies that promote equity and protect the most vulnerable.

The most fundamental support required for unpaid health care is **housing**. The housing must have a minimum of services, such as running water, heat and sanitation. Adequate housing not only reduces the risk of infection and injury for both the provider and the recipient of care. It also

reduces the time required. With unpaid care work comes more laundry, more demands on water and more demands on sanitation facilities. “Living in suitable housing and having appropriate equipment to assist with activities of daily living are also key factors promoting families' wellbeing” when unpaid care work is done for a child with disabilities.¹¹⁹ What may be termed supportive housing or assisted living and other forms of residential care are also an essential component in the right to care. Congregating people who need health care in either the same facility or in ones close to each other need not be oppressive or regimented. Such places can be more cost effective than providing individual services in a range of households because one paid person can look after several and there is no travel time. It can also be more effective because the paid health care provider can be fully trained for the job and focused on the work required. Family and friends can fill in the gaps with unpaid health care more easily under such circumstances. Both those who provide the unpaid health care work and those who need the care will have social contacts and will be less isolated. Canadian data indicate that “in 2007, more than one in five caregivers provided care to a senior living in a care facility such as supportive housing, a hospital or a nursing home.”¹²⁰

This residential care should be part of a continuum of **universal, public health services** that are essential to the right to care and the equity goal.¹²¹ In addition to residential care, these include at least primary care, mental health services, access to pharmaceuticals, therapies, home care and palliative care. Paid care workers in home or outside the home do not mean unpaid care is withdrawn. Rather, paid services can reduce the negative consequences of unpaid health care. Access to services outside the home such as therapies and counseling, can also help both providers and the people for whom they provide health care. Eligibility criteria can be developed to take the health of both the health care provider and the person who needs care into account. Moreover, those doing the work can be screened, educated and regulated to ensure that they have the skills required to provide the services and to connect with those doing the unpaid care work. Decent wages, hours and benefits would support recruitment of a qualified labour force. They would also mean the paid workers would be under less pressure to take on extra hours of unpaid care work and make the skills required more visible.

Respite services can provide care for a few hours while providers do tasks such as their essential shopping or allow some recuperative time for hours or weeks. The research on whether **respite services** save the government money by keeping people out of facilities or other, more expensive government programmes is ambiguous and limited. In part, the

consequences depend on the population served and the nature of the service. For example, “children with developmental disabilities are more vulnerable to mistreatment or placements out of the home without use of respite services.”¹²² While “there is evidence that respite services are most effective to caregivers when they are of high quality, used early in the caregiving life span and then regularly, frequently and in sufficient amounts”, there is also evidence that many do not use the services or use them for too short a time. How close the services are to where care is provided, costs involved, the quality of care and the information available can all have an impact on their effectiveness. Respite services may be beyond the means of those most in need and inaccessible to them because of factors such as lack of cultural sensitivity. As is the case with other supports, respite care may just allow the unpaid care workers to survive rather than flourish.

Adult day care is another support strategy. Most of these services are currently run during the weekday day, offering care Monday to Friday for nine hours a day. Such centres, like childcare ones, can make it possible for the person who does the unpaid health care work to take on paid employment and this person is most likely to be a woman. Like childcare centres though, these centres may not serve those who have irregular hours or who work at night. However, as with centres for children, it is possible to create alternatives that accommodate needs. A US programme, for example, focuses on those with Alzheimer’s, picking them up at 7 pm and returning them the next morning. Often sleepless, agitated and prone at night, these people are allowed and encouraged to be active all night. When they go home in the morning they are ready to sleep, giving a break to those responsible during the day.¹²³ Here, too, the impact may be that it is just possible for women to take on their double or even triple workload rather than increasing equity.

Canada's Compassionate Care Benefit' allows employees who are eligible for Employment Insurance Benefits to take up to eight weeks leave, paid at 55 per cent of their salary for six weeks up to a maximum amount to care for a gravely ill family member. Their job is protected during that time, the leave can be shared among family members and family is broadly defined. But to be eligible the employee must have accumulated 600 hours of work in the previous 52 weeks, leaving the many women with part-time or casual work ineligible and there is a two week waiting period before payments start. In addition, the application process is complex, and the financial support limited, preventing women who are sole supports to their families from taking it. The time allowed is quite short and is dependent on proof of grave illness. These leaves are primarily taken by women, reflecting both their lower pay and their greater responsibility for care work, and may serve to reinforce this responsibility.

Training is critical to care. A study of Chilean unpaid care providers found that most had no training for the care they provided. Yet many provided quite complicated care.¹²⁴

Research in other countries demonstrates that Chileans are not alone in this lack of training. The need for increasing skills with the increasing complex demands is clear and the introduction of training can not only improve care and reduce risk; it may also help make the skills involved more visible and valued. However, training courses for those who do the work without pay may serve to reinforce their responsibility for care and may even further denigrate the skills if the approach is to suggest the skills can be easily and quickly learned. Canadian homecare nurses report they are asked to train providers in minutes to do tasks they took months to learn and that there is little opportunity to teach about the risks involved. At the same time, training may suggest to care providers that they are not doing a good job and that the skills they have developed have little value. So caution is needed in offering training. There is no guarantee that those paid to provide care in the home have appropriate training either, given assumptions about this is work any woman can do. More attention needs to be paid to the regulation and training of those paid to provide care in the home, especially to the skills required to deal with chronic conditions.¹²⁵ And this training needs to address the relationship between unpaid and paid providers in ways that recognize the capacities of both.

Related to training is the issue of **information**. Those who provide care need easily accessible information in plain language. They need information on their rights and obligations, at their paid jobs and in the household. They need information on the services they can receive for themselves as well as for those in their care. They need information on where they can go for social and emotional support. A variety of organizations dedicated to providing such information are already in existence

in many countries, although large gaps remain. Many of the organizations also advocate on behalf of unpaid care providers. The charitable organization CarersUK, for example, says it helps get the best for the person they care for, make the most of their income, stay in paid work, keep healthy, get in touch with other carers for support, find a listening ear, and campaign for change.¹²⁶

Given that many of the women who provide unpaid health care need paid jobs in order to survive and that employers need their labour, **employment supports** are essential to maintain their participation and do so at an appropriate level. Employers benefit from a stable and reliable workforce; governments benefit from the ability of these workers to support themselves.

Universal standards such as minimum wages, guaranteed work hours, sick leave and paid vacation are particularly important for those who do unpaid health care work. Hours that are flexible for the employee and part-time employment that is both regular and comes with benefits can also allow unpaid care providers to balance their workloads. Compressed

workweeks for at least part of the year and working from home can help as well, although these may simply allow women especially to do double workloads. Temporary leave plans, such as Canada's Compassionate Care Benefit, can protect jobs and provide some financial support for short-term but intensive unpaid care work.¹²⁷ Unions can also be supportive to unpaid health care providers, providing some job protection and negotiating benefits such as family leaves to provide care. While employers as well as employees and those for whom they provide care can benefit from these strategies, as a study for the World Bank makes clear they have to be approached with caution. "Where women are the primary users of policies and particularly where the cost of such policies are paid for by employer mandate and linked to the level of female rather than total employment increased discrimination against women is virtually guaranteed"¹²⁸ Governments must set the employment standards, apply them to all enterprises and cover at least some of costs through taxation or social insurance, while ensuring the result is not to increase inequalities, and further disadvantage women or other unpaid health care workers.

Up until 1997, Australia provided a "Carer Pension" as an income and asset-tested income support payment (under the *Social Security Act 1991* to individuals who were unable to support themselves through paid employment due to substantial, full-time care responsibilities. As of July 1997, the Carer Pension was renamed the Carer Payment in an effort to recognize caregiving as work.¹

What Ungerson and Yeandle call **cash for care** is another strategy that has become increasingly popular.¹²⁹ The numerous plans in high-income countries vary in terms of who can be paid, who is eligible, how much is available, how the cash can be used, and the extent to which both those doing the work and those needing the work done are protected. In some schemes, governments pay money directly to those needing care. Some of these plans allow health care recipients to employ anyone, others prohibit payment to relatives while yet others promote family payment or hiring from an employment bank. Some schemes pay the care provider directly, and this person could be family, a friend or a stranger.

While payments paid directly to those who need care may empower them to hire who they want and allow them to direct the work, these programs raise critical question about the training, social rights and protection for the person providing care. Migrants may be particularly vulnerable to exploitation under schemes that do not regulate the hiring and ensure the rights of the care provider. Moreover, German research indicates that such payments can serve to reinforce women's responsibility for unpaid care work while reducing their options.¹³⁰ This can be the case whether the money is paid directly to the person providing care or to the person needing care. The authors warn there is "a potential downward spiral in which quality of care, the quality of care work, and the social rights of caregivers are all poor and deteriorating".¹³¹ Moreover, the low cash payments that are common can serve to reinforce the low value attached to such work while failing to provide adequate financial support.

Nevertheless, payments can help when there are no alternative available. In Canada, half of those doing high intensity unpaid care work said they wanted government financial support.¹³² Payments need to be high enough to dignify the work and the worker, and workers as well as those who require care need to be protected. Eligibility criteria need to be clear, simple and equitable. In addition, "financial compensation should not be offered in isolation, it should be provided in conjunction with home help services", along with other supports and training.¹³³

Tax benefits or credits offer another, more limited strategy. The United States, for example, offers a small tax credit for those who provide at least half of dependent support and a number of states allow minimum deductions from income, while others such as Arizona permit tax deductions for those paying at least a quarter of home support costs. In Sweden, the formal care allowance is exempt from taxes.¹³⁴ Tax credits can be either refundable, as in sending

money back, or non-refundable, as in only allowing for tax reduction. Tax deductions lower the income on which taxes are paid while exemptions mean no tax is paid on the amount. Tax benefits, credits and exemptions are useful only to those who have taxable income and disproportionately benefit those in the highest tax brackets. Eligibility requirements further restrict access. Moreover, these tax approaches do little to help those who are currently in financial need because they delay rewards.

Who pays for the additional services and support is of course an issue. **Insurance plans** for long-term care introduced now would not help those currently providing unpaid health care, although they could make it possible to incur debts based on future funding and would help the next generation when they are in need of care. Insurance schemes would have to be made compulsory, however, given that only a small minority buy the insurance plans now available. Insurance schemes would also have to take into account those who cannot afford to pay for insurance and develop methods to ensure they are included. After concluding that “voluntarism does not work in providing for people’s needs in retirement”, the Joseph Rowntree Foundation in the United Kingdom has proposed a “care levy” which would vary by age. Older people would pay an asset levy, based on a percentage tax on all inheritances. Younger people would pay through an employment levy. Governments would also contribute financially from general tax revenues, which perhaps could address how to include those employed in the informal economy. The point is not to endorse this particular scheme but rather to indicate that there are ways to increase the funding available to support the work of care without unfairly burdening one or another generation.¹³⁵

What would be more equitable and easier to implement than an insurance plan would be a **guaranteed annual income** for everyone combined with a minimum of universally accessible health care services, funded through progressive taxation. With such a guarantee, there would be both more choice and more security in providing unpaid care and there would be fewer negative consequences for doing so. There could also be more choice for those requiring care. Moreover, a guaranteed annual income would promote health among younger people and thus help reduce the demand for health services in old age. At a minimum, **universal pensions** would free unpaid care providers from the prospect poverty in old age.

To adopt any of these strategies, or others, requires the **measurement and valuing of unpaid work**.¹³⁶ Without an accurate accounting of who does what for whom for how long, it is difficult

to either appreciate the work involved or to develop means to support the work and those who need care, let alone promote equity. In many countries that are members of PAHO, the extent and nature of the work is difficult to determine. As a result, additional research intended to provide a basis for evidence-informed policy development is difficult to conduct. Without such measures, it is hard to see the “real wealth of the nation” or to address inequities.

Listed here are only some of the most common strategies. They are described individually but they are not intended to be read as alternatives to each other. Rather, they suggest multiple means of addressing the inequities that should be considered together and in the context of other social and economic programs. To be effective, they need to be offered in a culturally sensitive and accessible manner that takes various social locations into account. To achieve the goals of equity and the right to care, they need to be assessed in terms of both the short and long-term consequences for women and girls in particular.

Conclusions

Unquestionably the demands for unpaid health care are increasing, and the work itself is becoming more demanding. Unpaid care cannot continue to increase without profound negative consequences for individuals, families, communities, employers and governments. Indeed, the demand needs to shrink and governments have a responsibility to develop strategies to ensure this is the case. Without such strategies, inequalities will increase not only between women and men but also among women and among men. It will also increase among countries, which is one reason why unpaid health care work provides an indicator of equity.

The research is clear that unpaid health care is primarily women’s work, even though many undertake this work unwillingly and without training or other supports. In any case, a labour of love is still labour. Too often the consequences for women are deteriorating health, uneven labour force participation and a compromised future, even when women gain some benefits from the relationship. The consequences are also felt by those who need health care, although the extent to which they have a say in what services they receive, by whom, when and how varies enormously. Balancing the needs and rights of those with care needs with those who do the unpaid care work is no easy task. However, any approach must recognize that unpaid care workers are often disadvantaged to start with and the intensification of unpaid work too often leads to further disadvantage for them as well as for those for whom they do the care work.

The complexity of unpaid health care, combined with the significant variation in demands and supports, mean other patterns are less clear and vary more by location. This unpaid care work may be provided in homes, on the street or in facilities of multiple kinds, and it may be provided by relatives, friends or volunteers who are strangers. Different conditions exist in urban and rural areas, for those with families and those without. Governments shape what unpaid care is required, how it is provided, by whom, for how long and in what ways. For-profit and not-for-profit service organizations also play a role, as do people paid to offer care. Employers, governments, families and communities all feel the consequences of the growth and change in unpaid care work demands, and the consequences are often negative.

There are no simple answers to the question of how to support unpaid health care work and how to reduce the load. There are multiple tensions that shape alternatives in every country and for every group. There are, however, many strategies currently in place that can be evaluated in terms of their efficacy in any specific place and in terms of their consequences for equity. It is clear that, regardless of location, the right to care for both providers and recipients requires structural supports especially from governments but also from employers and communities. The right to care also requires real alternatives to unpaid health care work for those who now provide or are pushed to provide the labour and for those who need the care. And these alternatives must take culture, location, age and resources into account. Without them, inequalities will increase not only between women and men but also among women and men.

¹ Statistics Canada (2011) *2006 Census of Canada. Topic-based Calculations Unpaid Work.*
<http://www12.statcan.gc.ca/census-recensement/2006/dp-pd/tbt/Rp-eng.cfm?LANG=E&APATH=3&DETAIL=0&DIM=0&FL=A&FREE=0&GC=0&GID=0&GK=0&GRP=1&PID=92100&PRID=0&PTYPE=88971,97154&S=0&SHOWALL=0&SUB=0&Temporal=2006&THEME=74&VID=0&VNAMEE=&VNAMEF=>

² Organization for Economic Cooperation and Development (2011) *Help Wanted? Providing and Paying for Long-Term Care Geneva: OECD* www.oecd.org/.../0,3746,en_2649_37407_47659479_1_1_1_37407..

³ Statistics Canada (2011) *2006 Census of Canada. Topic-based Calculations Unpaid Work.*
<http://www12.statcan.gc.ca/census-recensement/2006/dp-pd/tbt/Rp-eng.cfm?LANG=E&APATH=3&DETAIL=0&DIM=0&FL=A&FREE=0&GC=0&GID=0&GK=0&GRP=1&PID=92100&PRID=0&PTYPE=88971,97154&S=0&SHOWALL=0&SUB=0&Temporal=2006&THEME=74&VID=0&VNAMEE=&VNAMEF=>

⁴ United Nations Development Programme (2010) *Human Development Report 2010 20th Anniversary Edition The Real Wealth of Nations: Pathways to Human Development* New York: PalgraveMacmillan, p.iv.

-
- ⁵ DESA Department of Economic and Social Affairs. World population to exceed 10 billion <http://www.un.org/en/development/desa/news/population/population-exceed-10-billion.html> May 5, 2011
- ⁶ United Nations Development Programme (2010) *Human Development Report 2010 20th Anniversary Edition The Real Wealth of Nations: Pathways to Human Development* New York: PalgraveMacmillan, Table 2.1.
- ⁷ Pan American Health Organization (2011) *Health Situation in the Americas 2011*. Demographic Indicators. http://ais.paho.org/chi/brochures/2011/BI_2011_ENG.pdf
- ⁸ SABE/PAHO (2000) *Health of Older Adults* www.paho.org/english/dd/ikm/rc/Pelaez-Health-Older-Adults.ppt
- ⁹ SABE/PAHO (2000) *Health of Older Adults* www.paho.org/english/dd/ikm/rc/Pelaez-Health-Older-Adults.ppt
- ¹⁰ Pan American Health Organization (2011) *Health Situation in the Americas 2011*. Demographic Indicators. http://ais.paho.org/chi/brochures/2011/BI_2011_ENG.pdf
- ¹¹ DESA Department of Economic and Social Affairs. World population to exceed 10 billion <http://www.un.org/en/development/desa/news/population/population-exceed-10-billion.html> May 5, 2011
- ¹² Pan American Health Organization (2011) *Health Situation in the Americas 2011*. Demographic Indicators. http://ais.paho.org/chi/brochures/2011/BI_2011_ENG.pdf
- ¹³ Harbison, Sarah F. and Warren C. Robinson (2003) Globalization, Family Structure, and Declining Fertility in the Developing World *Review of Radical Political Economics* 35(1):44-55
- ¹⁴ Wallace, Steven et al. (2011) *The Health of Aging Lesbian, Gay and Bisexual Adults in California*. Health Research Policy Brief. UCLA Center for Health Policy Research <http://www.healthpolicy.ucla.edu/pubs/files/aginglgbpb.pdf>
- ¹⁵ Steck, Philippe (2009) Addressing Changes in Family Structures. Adapting Family Policies to Global Changes in Family Life *Technical Seminar on Family Policies*, Piriápolis, Uruguay, 19-20 March. International Social Security Association. <http://www.issa.int/Resources>.
- ¹⁶ Statistics Canada (2007) *Family Portrait: Continuity and Change in Canadian Families and Households in 2006*. 2006 Census. (Cat. No. 97-553-XWE2006001). Ottawa: Statistics Canada
- ¹⁷ Statistics Canada (2004) *2003 General Social Survey on Social Engagement, cycle 17: an overview of findings* <http://www.statscan.gc.ca/pub/89-598x2003001-eng.pdf>
- ¹⁸ World Bank (2010) Labor force participation rate, female (% of populations ages 15+) <http://data.worldbank.org/indicator/SL.TLF.CACT.FE.ZS>
- ¹⁹ Armstrong, Pat and Hugh Armstrong *The Double Ghetto: Canadian Women and Their Segregated Work* Wynford Project Edition, with new Preface. Toronto: Oxford University Press
- ²⁰ French-Davis, Ricardo (2011) *Macroeconomy for Decent Work in Latin America and the Caribbean* Geneva: ILO., p. 5. http://www.ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_156121.pdf
- ²¹ OECD (2011) *Divided We Stand. Why Inequality Keeps Rising*. <http://www.oecd.org/dataoecd/40/12/49170449.pdf>
- ²² Antonopoulos, Rania (2007) *The Unpaid Care Work-Paid Work Connection*. Hudson, New York: The Levy Economic Institute, Working Paper #541, p.23. http://www.levyinstitute.org/pubs/wp_541.pdf
- ²³ Jacobs, Jerry A. and Kathleen Gerson (2004) *The Time Divide. Work, Family and Gender Inequality*. Boston: Harvard University Press. Vosko, Leah, ed. (2006) *Precarious Employment. Understanding Labour Market Insecurity in Canada* Montreal: McGill-Queen's University Press.
- ²⁴ Armstrong, Pat and Hugh Armstrong (2010) *Wasting Away: The Undermining of Canadian Health Care* Wynford Project Edition. Toronto: Oxford University Press; Vosko, Leah ed. (2006) *Precarious Employment Understanding Labour Market Insecurity in Canada* Montreal: McGill-Queen's University Press.
- ²⁵ Pan American Health Organization (2011) *Health Situation in the Americas 2011*. Demographic Indicators. http://ais.paho.org/chi/brochures/2011/BI_2011_ENG.pdf
- ²⁶ Budlender, Debbie (2007) *A Critical Review of Selected Time Use Surveys* Gender and Development Programme Paper Number 2, June. Geneva: United Nations Research Institute for Social Development, p.2.
- ²⁷ Bedford, Kate (2010) *Harmonizing Global Care Policy? Care and the Commission on the Status of Women*. Gender and Development Programme paper number 7, February. Geneva: United Nations Research Institute for Social Development, p.9.
- ²⁸ Pan American Health Organization (2011) *Health Situation in the Americas 2011*. Demographic Indicators. http://ais.paho.org/chi/brochures/2011/BI_2011_ENG.pdf
- ²⁹ Canadian Institute for Health Information (2011). *Health Care in Canada, 2011: A Focus on Seniors and Aging*. Summary. http://www.cihi.ca/CIHI-ext-portal/internet/en/document/health+system+performance/quality+of+care+and+outcomes/release_01dec11?WT.ac=home_banner_20111201_e (English)
- ³⁰ Groce, Nora Ellen (1999) *An Overview of Young People Living with Disabilities*:

Their Needs and their Rights. Inter-Divisional Working Group on Young People
Programme Division, New York: United Nations Children's Fund Programme Publications

³¹ World Bank (2004) 'Fact Sheet on Disability in Latin America and the Caribbean'

<http://siteresources.worldbank.org/DISABILITY/Resources/Regions/LAC/LACfactsheetEng.pdf>

³² Mont, Daniel (2007) *Measuring Disability Prevalence* World Bank.

<http://siteresources.worldbank.org/SOCIALPROTECTION/Resources/SP-Discussion-papers/Disability-DP/0706.pdf>, Chart 7.

³³ Convention on the Rights of Persons with Disabilities. 2006 *Some Facts about Persons with Disabilities*.

<http://www.un.org/disabilities/convention/facts.shtml>

³⁴ World Health Organization (2002) *Ethical Choices in Long-Term Care: What Does Justice Require?* Geneva: World Health Organization, Chapter 2, p.8.

³⁵ United Nations Joint Programme on HIV/AIDS (UNAIDS) and the United Nations Development Fund for Women (INIFEM) (2008) *Caregiving in the Context of HIV/AIDS*. Paper prepared for the CSW Expert group Meeting, United Nations Economic Commission for Europe. Geneva, 6-9 October, P.9.

³⁶ Ilcan, Suzan and Tanya Basok (2004) Community Government: Voluntary Agencies, Social Justice, and the Responsibilization of Citizens *Citizenship Studies* 8(2):129-144.

³⁷ United Nations Expert Group Meeting on Health, Mortality and Development

New York, 10-12 November 2009 Report of the Meeting, p.14.

http://www.un.org/esa/population/meetings/EGM_HealthMortDev/EGMHealthMortalityDev.pdf

³⁸ Rose, H. (1996) Governing "Advance" Liberal Democracies, p. 37-64 in A. Barry, T. Osborne and N. Rose eds. *Foucault and Political Reason: Liberalism, Neoliberalism and Rationalities of Government* Chicago: University of Chicago Press.

³⁹ Land, H. and H. Rose (1985) Compulsory Altruism for Some or an Altruistic Society for All? Pp. 74-96 in P. Bean, J. Ferris and D. Whynes eds. *In Defense of Welfare* London: Tavistock.

⁴⁰ National Forum on Health (1997) *Value Working Group Synthesis report in Canada Health Action: Building on the Legacy. Synthesis Report and Issues Papers*. Ottawa: Public Works and Government Services.

⁴¹ Guberman et al. (2006) Families' Values and Attitudes Regarding Responsibility for Frail Elderly: Implications for Aging Policy *Journal of Aging and Social Policy* 18(3/4):59-78, p. 74.

⁴² Chubachi, N. (1999) *Geographies of Nisei Japanese Canadians and Their Attitudes Towards Elderly Long-Term Care*. M.A. Dissertation, Queen's University, Kingston Ontario; Dorozio-Migliore, M. (1999) *Eldercare in Context: Narrative, Gender and Ethnicity*. PhD Dissertation, University of British Columbia; Guberman, N. (2004) Designing Home and Community Care for the Future: Who Needs to Care? Pp. 75-90 in Karen R. Grant et al. eds. *Caring For/Caring About. Women and Unpaid Caregiving*. Aurora: Garamond Press.

⁴³ Espinosa González, Isolda (2007) The Case of Nicaragua, pp. 219-250 Debbie Budlender *A Critical Review of Selected Time Use Surveys* Gender and Development Programme Paper Number 2, June. Geneva: United Nations Research Institute for Social Development, p.239.

⁴⁴ Arango-Lasprilla et al. (2010) Needs and Psychological Outcomes of Caregivers of Individuals with Multiple Sclerosis in Guadalajara, Mexico. *International Journal of MS Care* 12:71-82 http://www.ms-care.org/cmssc/images/journal/pdf/ijms_summer_10_4.pdf

⁴⁵ Braun, Anette et al. (2009) *Special Issue on Healthcare. Healthy Aging and the Future of Public Healthcare Systems* Luxembourg: European Commission, p.13.

⁴⁶ Becker, Saul (2007) Global Perspectives on Children's Unpaid Caregiving in the Family *Global Social Policy* 7(1):23-50.

⁴⁷ Armstrong, Pat and Olga Kits (2004) One Hundred Years of Caregiving. Pp. 45-74 in Karen R. Grant et al. eds. *Caring For/Caring About. Women, Home Care and Unpaid Caregiving*. Aurora:Garamond Press.

⁴⁸ Mellow, Muriel (2011) Voluntary Caregiving? Constraints and Opportunities for Hospital Volunteers pp.215-235 in Cecilia Benoit and Helga Hallgrimsdóttir eds. *Valuing Care Work: Comparative Perspectives* Toronto: University of Toronto Press.

⁴⁹ Home, Alice (2002) Challenging Hidden Oppression: Mothers Caring for Children with Disabilities *Critical Social Work* 3(1):1-6. <http://www.uwindsor.ca/criticalsocial/work/>

⁵⁰ Mellow, Muriel (2011) Voluntary Caregiving? Constraints and Opportunities for Hospital Volunteers pp.215-235 in Cecilia Benoit and Helga Hallgrimsdóttir eds. *Valuing Care Work: Comparative Perspectives* Toronto: University of Toronto Press.

-
- ⁵¹ Armstrong, Pat and Tamara Daly (2004) *'There are Not Enough Hands': Conditions in Ontario's Long-Term Care Facilities*. Report prepared for the Canadian Union of Public Employees. Toronto. Armstrong, Pat et al. (2009) *They Deserve Better: The long-term care experience in Canada and Scandinavia* Ottawa: Canadian Centre for Policy Alternatives.
- ⁵² Budlender, Debbie (2007) *A Critical Review of Selected Time Use Surveys* Gender and Development Programme Paper Number 2, June. Geneva:United Nations Research Institute for Social Development
- ⁵³ Budlender, Debbie (2007) *A Critical Review of Selected Time Use Surveys* Gender and Development Programme Paper Number 2, June. Geneva:United Nations Research Institute for Social Development, p.3.
- ⁵⁴ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada
- ⁵⁵ Budlender, Debbie (2007) *A Critical Review of Selected Time Use Surveys* Gender and Development Programme Paper Number 2, June. Geneva:United Nations Research Institute for Social Development, p.19.
- ⁵⁶ Pelaez, Martha (2008) *Family Caregiving in Latin America: an overview of issues*www.aarpinternational.org/.../PELÁEZ-UN_family_caregiving_2008
- ⁵⁷ Espinosa González, Isolda (2007) The Case of Nicaragua, pp. 219-250 Debbie Budlender *A Critical Review of Selected Time Use Surveys* Gender and Development Programme Paper Number 2, June. Geneva:United Nations Research Institute for Social Development, p.230.
- ⁵⁸ Cranswick, Kelly and Donna Dosman (2007) Eldercare:What We Know Today *Canadian Social Trends* 86:47-56, p.50
- ⁵⁹ Pyper, W (2006) Balancing Career and Care *Perspectives on Labour and Income* Winter 18(4): <http://www.statcan.gc.ca/pub/75-001-x/11106/9520-eng.pdf>
- ⁶⁰ Lilly, M. B., Laporte, A., & Coyte, P. C. (2010). Do They Care Too Much to Work? The Influence of Caregiving Intensity on the Labour Force Participation of Unpaid Caregivers. *Canadian Journal of Health Economics*, 29(6), 895-903.
- ⁶¹ Aronson, J. (1992). Women's Sense of Responsibility for the Care of Old People. "But Who Else is Going to do it?" *Gender and Society*, 6(1), 8-22.
- ⁶² Cranswick, Kelly and Donna Dosman (2007) Eldercare:What We Know Today *Canadian Social Trends* 86:47-56, Chart 1.
- ⁶³ Cranswick, Kelly and Donna Dosman (2007) Eldercare:What We Know Today *Canadian Social Trends* 86:47-56, p.54
- ⁶⁴ Statistics Canada (2007) Women and men aged 65 years and over who received assistance because of a chronic health problem, by relationship to main caregiver, Canada, 2007 Table 13. <http://www.statcan.gc.ca/pub/89-503-x/2010001/article/11441/tbl/tbl013-eng.htm>
- ⁶⁵ National Alliance for Caregiving in collaboration with AARP (2009). *Caregivers of Younger Adults. A Focused Look at Those Caring for Younger Adults Aged 18-49. P.2* http://www.caregiving.org/data/Report_Caregivers_of_Younger_Adults_11-12-09.pdf
- ⁶⁶ National Alliance for Caregiving in collaboration with AARP (2009). *Caregivers of Younger Adults. A Focused Look at Those Caring for Younger Adults Aged 18-49. P.3.* http://www.caregiving.org/data/Report_Caregivers_of_Younger_Adults_11-12-09.pdf
- ⁶⁷ Carton, H. et al. (2000) A Quantitative Study of Unpaid Caregiving in Multiple Sclerosis *Multiple Sclerosis Journal* 6(4):274-279.
- ⁶⁸ Mellow, Muriel (2011) Voluntary Caregiving? Constraints and Opportunities for Hospital Volunteers pp.215-235 in Cecilia Benoit and Helga Hallgrimsdóttir eds. *Valuing Care Work: Comparative Perspectives* Toronto: University of Toronto Press, p.221-222.
- ⁶⁹ Baines, Donna (2004) Caring for Nothing: Work Organization and Unwaged Labour in Social Services. *Work, Employment and Society* 18(1):29-49.
- ⁷⁰ Becker, Saul (2007) Global Perspectives on Children's Unpaid Caregiving in the Family *Global Social Policy* 7(1):23-50, p.27.
- ⁷¹ National Alliance for Caregiving in collaboration with United Hospital Fund (2005) *Young Caregivers in The U.S.* <http://www.aacy2.org/publications/youngcaregivers.pdf>, p.5
- ⁷² National Alliance for Caregiving in collaboration with United Hospital Fund (2005) *Young Caregivers in The U.S.* <http://www.aacy2.org/publications/youngcaregivers.pdf>, p.5

-
- ⁷³ Reça, Inés, Madelin Alvarez and M. Emilia Tijoux (2010) The Invisible Costs of Caring for Patients in the Household: A Chilean case Study. Pp. 167-180 in PAHO (2010) *The Invisible Economy and Gender Inequalities: The Importance of Measuring and Valuing Unpaid Work*.
- ⁷⁴ Canadian Institute for Health Information (2011) NCRS QuickStats Table 9. Informal Care of Assessed Home care Clients 2010-2011. http://www.cihi.ca/CIHI-ext-portal/xls/internet/HCRS_Quickstats_2010-2011_en
- ⁷⁵ Tadeu Nunes Tamanini, José (2011) Association between Urinary Incontinence in Elderly Patients and Caregiver Burden in the City of Sao Paulo/Brazil: Health, Wellbeing, and Ageing Study *Neurology and Urodynamics* 30(7):1281-1285, September
- ⁷⁶ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada p.63.
- ⁷⁷ Jull, Janet (2010) *Seniors Caring for Seniors* Ottawa: Canadian Association of Occupational Therapists.p.8.; National Alliance for Caregiving, p.1.
- ⁷⁸ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada p. 60.
- ⁷⁹ Jull, Janet (2010) *Seniors Caring for Seniors* Ottawa: Canadian Association of Occupational Therapists.p.8.; National Alliance for Caregiving and AARP, *Caregiving in the U.S.*, Bethesda, MD: National Alliance for Caregiving, and Washington, DC: AARP, 2009.
- ⁸⁰ Pelaez, Martha (2008) Family Caregiving in Latin America: an overview of issues www.aarpinternational.org/.../PELAEZ-UN_family_caregiving_2008
- ⁸¹ Brannen, C. (2006). Women's Unpaid Caregiving and Stress. *Centres of Excellence for Women's Health Research Bulletin*, 5(1), 12-13. Retrieved November 28, 2010, from <http://www.cewh-cesf.ca/PDF/RB/bulletin-vol5no1EN.pdf>
- ⁸² Canadian Institute for Health Information (2010) *Supporting Informal Caregivers-the Heart of Home Care* Ottawa: CIHI. http://www.cihi.ca/cihi-ext-portal/internet/en/document/types+of+care/hospital+care/continuing+care/release_cont_26aug10
- ⁸³ Lee, Christina (1999) Health, Stress and Coping among Women Caregivers: A Review *Journal of Health Psychology* (January), 4 (1), pg. 27-40
- ⁸⁴ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada, p.74.
- ⁸⁵ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada, p.79-80.
- ⁸⁶ National Alliance for Caregiving in collaboration with AARP (2009). *Caregivers of Younger Adults. A Focused Look at Those Caring for Younger Adults Aged 18-49. P.3.* http://www.caregiving.org/data/Report_Caregivers_of_Younger_Adults_11-12-09.pdf
- ⁸⁷ Guberman, Nancy (2004) Designing Home and Community Care for the Future: Who Needs to Care? Pp. 75-90 in Karen R. Grant et al. eds. *Caring For/Caring About. Women and Unpaid Caregiving*. Aurora: Garamond Press, p.81.
- ⁸⁸ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada
- ⁸⁹ Armstrong, Pat, Hugh Armstrong and Krista Scott-Dixon (2008) *Critical to Care The Invisible Women in Health Services* Toronto: University of Toronto Press
- ⁹⁰ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada, p.64.
- ⁹¹ Becker, Saul (2007) Global Perspectives on Children's Unpaid Caregiving in the Family Global Social Policy 7(1):23-50, p.25.
- ⁹² Home, Alice (2002) Challenging Hidden Oppression: Mothers caring for Children with Disabilities *Critical Social Work* 3(1):1-6. <http://www.uwindsor.ca/criticalsocial> work/

-
- ⁹³ Olicker, Stacey (2000) "Examining Care at Welfare's End" pp 167-185 in Madonna Harrington Meyer ed. *Care Work: Gender, Labour and the Welfare State* London: Routledge.
- ⁹⁴ Hartley, Sigan L. et al. (2010) The Relative Risk and Timing of Divorce in Families of Children with Autism Spectrum Disorder *Journal of Family Psychology* 24(4):449-457.
- ⁹⁵ Urbano, Richard C. and Robert M. Hodapp (2007) Divorce in Families of Children with Down Syndrome: A Population-based Study *American Journal on Mental Retardation* 112(4):261-274, July. <http://www.dsagsl.org/storage/forms-for-news-posts/DivorceDownSyndrome.pdf>
- ⁹⁶ Cranswick Kelly. 2003. *General Social Survey, Cycle 16: Caring for an aging society*. 89-582-XIE. Ottawa, Ontario: Statistics Canada, Housing, Family and Social Statistics Division
- ⁹⁷ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada, p. 71.
- ⁹⁸ Bedford, Kate (2010) *Harmonizing Global Care Policy? Care and the Commission on the Status of Women* Gender and Development Programmes paper Number 7, Geneva: United Nations Research Institute for Social Development.
- ⁹⁹ Sloper, Tricia (2006) Families with Disabled Children Social and Economic Needs are High but Remain Largely Unmet *British Medical Journal* November 4; 333(7575): 928-929, p. 298.
- ¹⁰⁰ Keefe, Janice (2011) *Supporting Caregivers and Caregiving in an Aging Canada* Montreal: Institute for Research on Public Policy, Figure 2.
- ¹⁰¹ Statistics Canada (2010) Study: Consequences of Long Distance Caregiving *The Daily*, January 6, <http://www.statcan.gc.ca/daily-quotidien/100126/dq100126a-eng.htm>
- ¹⁰² Lilly, M.B. A. Laporte and P. Coyte (2007) Review of Labor Force Participation Rates, Predictors of Labor Market Withdrawal, and Hours of Work *The Milbank Quarterly* 85(4):641-690.
- ¹⁰³ Johnson, Richard and Joshua M. Weiner (2006) *A Profile of Frail Older Americans and Their Caregivers* New York: Urban Institute, p. vii.
- ¹⁰⁴ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada.
- ¹⁰⁵ Armstrong, Pat (2011) "Pay Equity: Yesterday's Issue?" (2011) Pp. 211-214 in Lorne Tepperman and Angela Kalyta, eds., *Reading Sociology: Canadian Perspectives, Second Edition*. Oxford: Oxford University Press, 2011
- ¹⁰⁶ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada, p. 68.
- ¹⁰⁷ Partk, J. (2007) Work Stress and Job Performance *Perspectives on Labour and Income* December 8(12):5-17, p.5. <http://www.statcan.gc.ca/pub/75-001-x/2007112/article/10466-eng.htm>
- ¹⁰⁸ Keating, N. & Fast, J. (2000) Time and Consequences of Informal Care to Frail Seniors. *Journal of the Society of Obstetricians and Gynecologists of Canada*, 22(2), 939-943.
- ¹⁰⁹ Pyper, W (2006) Balancing Career and Care *Perspectives on Labour and Income* Winter 18(4): <http://www.statcan.gc.ca/pub/75-001-x/11106/9520-eng.pdf>
- ¹¹⁰ Duxbury, Linda, Christopher Higgins and Bonnie Shroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* Ottawa: Human Resources and Skills Development Canada, pp. 71-71.
- ¹¹¹ Keefe, Janice, Jaques Légaré and Yves Carrière (2007) Developing New Strategies to Support Future Caregivers of Older Canadians with Disabilities: Projections of Need and Their Policy Implications *Canadian Public Policy* xxxiii, Supplement:S65-S80,p.S66.
- ¹¹² Reça, Inés, Madelin Alvarez and M. Emilia Tijoux (2010) The Invisible Costs of Caring for Patients in the Household: A Chilean case Study. Pp. 167-180 in PAHO (2010) *The Invisible Economy and Gender Inequalities: The Importance of Measuring and Valuing Unpaid Work*, p. 167.
- ¹¹³ Spencer, Sarah et al (2010) *The Role of Migrant Care Workers in Aging Societies: Report on Research Findings in the United Kingdom, Ireland, Canada and the United States* Geneva: International Organization for Migration
- ¹¹⁴ Canadian Institute for Health Information (2011). Health Care in Canada, 2011: A Focus on Seniors and Aging Ottawa:CIHI, Ch. 4.

-
- ¹¹⁵ World Health Organization (2002) *Ethical Choices in Long-Term Care: What Does Justice Require?* Geneva: WHO, p.vii.
- ¹¹⁶ Armstrong, Pat et al. (2012) The Charlottetown Declaration on the Right to Care . Appendix in *Thinking Women and Health Care Reform* Toronto: Women's Press
- ¹¹⁷ Bedford, Kate (2010) *Harmonizing Global Care Policy? Care and the Commission on the Status of Women*. Gender and Development Programme paper number 7, February. Geneva: United Nations Research Institute for Social Development.
- ¹¹⁸¹¹⁸ Noddings, N. (1984) *Caring: A Feminine Approach to Ethics and Morality* Education Berkeley: University of California Press
- ¹¹⁹ Sloper, Tricia (2006) Families with Disabled Children Social and Economic Needs are High but Remain Largely Unmet *British Medical Journal* November 4; 333(7575): 928–929, p. 298.
- ¹²⁰ Statistics Canada (2008) *The Daily*, October 21 <http://www.statcan.gc.ca/daily-quotidien/081021/dq081021a-eng.htm>
- ¹²¹ Maritime Data Centre for Aging Research and Policy Analysis et al. (2005) *Supporting Caregivers of Dependent Adults in the 21st Century* Halifax: Healthy Balance Research Program
- ¹²² Keefe, Janice M. and Marlie Manning (2005) *The Cost Effectiveness of Respite: A Literature Review*. Ottawa: Health Canada. http://hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2005-keefe/2005-keefe-eng.pdf
- ¹²³ The New York Times (2012) *A Nighttime Program for Alzheimer's Care* January 29. <http://newoldage.blogs.nytimes.com/2009/06/12/a-nighttime-program-for-patients-with-alzheimers/>
- ¹²⁴ Reca, Inés, Madelin Alvarez and M. Emilia Tijoux (2010) The Invisible Costs of Caring for Patients in the Household: A Chilean case Study. Pp. 167-180 in PAHO (2010) *The Invisible Economy and Gender Inequalities: The Importance of Measuring and Valuing Unpaid Work*, p. 167. http://new.paho.org/hq/dmdocuments/2010/unpaid_work.pdf
- ¹²⁵ World Health Organization (2005) *Preparing a Healthcare Workforce for the 21st Century*. Geneva: WHO
- ¹²⁶ CarersUK. <http://www.carersuk.org/about-us>
- ¹²⁷ Williams, Allison et al. (2010) *Evaluating Canada's Compassionate Care Benefit from the Perspective of Family Caregivers*. <http://www.coag.uvic.ca/eolcare/documents/CCB%20evaluation%20final%20report%20-%20English.pdf>
- ¹²⁸ Gornick, Janet and Araine Hegewisch (2010) *The Impact of "Family Friendly Policies" on Women's Employment and on the Costs and Benefits of Doing Business*. A Report Commissioned for the World Bank. <http://www.hsph.harvard.edu/centers-institutes/population-development/files/gornick-hegewisch-wb-prepubversion-2011.pdf>
- ¹²⁹ Ungerson, Clare and Sue Yeandle, eds (2007) *Cash for Care in Developed Welfare States* London: Palgrave
- ¹³⁰ Schneider, Ulrike and Carlos Reyes (2007) Mixed Blessings: Long-term Care Benefits in Germany, pp. 137-165 in Ungerson, Clare and Sue Yeandle, eds *Cash for Care in Developed Welfare States* London: Palgrave
- ¹³¹ Ungerson, Clare and Sue Yeandle, eds (2007) *Cash for Care in Developed Welfare States* London: Palgrave, p.10
- ¹³² Pyper, W (2006) Balancing Career and Care *Perspectives on Labour and Income* Winter 18(4): <http://www.statcan.gc.ca/pub/75-001-x/11106/9520-eng.pdf>
- ¹³³ Keefe, Janice and Pamela Fancey (1997) Financial Compensation or Home Help Services; examining Differences among Program Recipients *Canadian Journal on Aging* 16(2): 254-278, p.274
- ¹³⁴ Keefe, Janice and Pamela Fancey (1999) Compensating Family Caregivers: An Analysis of Tax Incentives and Pension Schemes *Health Law Journal* 7:193-204, p.195
- ¹³⁵ Hirsch, Donald (2010) *Funding Care: How Can Each Generation Pay Its Fair Share?* York: Joseph Rowntree Foundation
- ¹³⁶ PAHO (2010) *The Invisible Economy and Gender Inequalities: The Importance of Measuring and Valuing Unpaid Work* http://new.paho.org/hq/dmdocuments/2010/unpaid_work.pdf

