POLICY BRIEF NO. 9

LONG-TERM CARE FOR OLDER PEOPLE

A NEW GLOBAL GENDER PRIORITY

SUMMARY

Population ageing is a global reality. So is the fact that, as people age, they tend to require greater care and assistance in activities related to daily living. Nevertheless, current debates about long-term care for older persons are remarkably narrow. First, long-term care is yet to be recognized as a burning policy issue in low- and middle-income countries, which is where the majority of older persons live. Second, even in developed countries where long-term care has been on the public agenda for some time, it is rarely discussed in gendered terms. Instead, debates are dominated by concerns over its fiscal implications. As this brief shows, however, long-term care always has costs, even if it is provided by family members on an unpaid basis. Currently, the societal costs of policy inaction in both developed and developing countries are borne disproportionately by women: the elderly women who do not receive the care that they deserve, and the women of all ages who are overrepresented among those who provide care under inadequate and exploitative conditions. Finding ways to share these costs more equitably across society is paramount. This brief underlines the need to build long-term care systems that are financially and socially sustainable and discusses a set of measures that can be taken to improve the situation of care-dependent older persons as well as their caregivers.

Why should we care about long-term care?

Long-term care (LTC) refers to caregiving for older people over a protracted period of time. This may include material assistance, help with daily activities and emotional support. Evidence shows that the likelihood of requiring care increases beyond the age of 70. In 2015, 57 per cent of the world's population aged 75 and above—more than 138 million people—lived in developing regions (see Figure 1), and this is expected to rise.[1] Thus, the need for LTC is growing in countries where crucial preconditions for care and healthy ageing—such as universal access to water, sanitation and electricity as well as robust primary health-care systems—are often lacking.

In an increasingly unequal world, access to and provision of LTC also reflects inequalities of many kinds. While more affluent countries are recruiting LTC workers from overseas,[2] poor countries in Africa and Asia lack the millions of staff to run their health-care systems.[3] Within developing countries, such as China or Peru, higher-income households in urban areas often rely on insufficiently trained and poorly paid domestic workers to cover their LTC needs,[4] while older persons and their unpaid family caregivers in low-income households lack even the most basic forms of support.

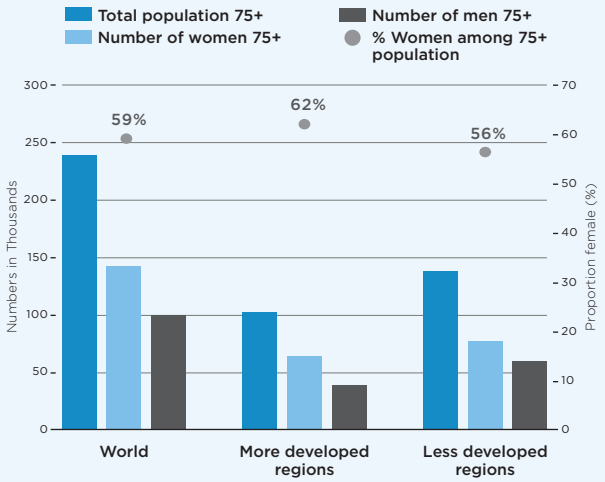
Older women are particularly affected

Women are overrepresented among the elderly population, in both developed and developing regions (see Figure 1), and are also critical providers of unpaid care—for ageing spouses and partners, friends or grandchildren. They are also more likely to report disabilities and difficulties with self-care than older men, partly due to their greater longevity.[5] In Russian Federation, for example, 31 per cent of women aged 50 and over reported difficulty with self-care compared to 21 per cent of men.[6]

FIGURE 1

Population aged 75+ by region and sex

Total numbers (thousands) and proportion of women (%), 2015



Source: UN DESA, Population Division 2017.

The discrepancy between older women and men's needs for LTC and the capacity of families to meet them is growing.[7] Changing household structures are part of this story as are broader economic shifts. Domestic and transnational migration mean generations are more likely to be separated from each other; adult children may not be able to care for their elderly parents even if they want to. At the same time, women's increasing labour-force participation makes it difficult for them to provide full-time care for ageing spouses or parents while also holding on to their jobs.

Meanwhile, alternatives to family care for older people remain scarce, unaffordable and often of sub-standard quality, compromising their quality of life and, in some cases, constituting an outright violation of their rights.[8] In 2017, for example, South Africa's Health Ombudsman published a report referring to the transfer of 1,371 people with LTC needs from a government-run care home to a network of state-subsidized non-governmental organizations (NGOs). The report found that conditions in the NGO-run homes were so poor that they had contributed to at least 94 deaths among the transferred population.[9]

These issues can be particularly pressing for women. Older women are much more likely to live alone than older men—globally, 16 per cent of women over 60 live on their own compared to 9 per cent of men[10]—and thus less likely to be cared for by a co-resident family member when they get frail. This, alongside their greater longevity, explains why women often make up the majority of care home residents. They are hence particularly vulnerable to low quality standards and potential maltreatment. In Argentina and the United States, older women make up over two thirds of the nursing home population.[11] In most countries, however, data on residential care for older persons—as well as the gendered dimensions of elder abuse in these settings—are largely lacking.[12]

Women do more unpaid care for older persons

Across the world, the bulk of care for older people is carried out by family members on an unpaid basis. The majority of these carers are women: spouses, daughters or daughters-in-law who form the invisible backbone of all LTC systems. While data on the value of this work are not readily available for most countries, calculations for the United Kingdom show that if the time that unpaid family carers spend on adult care was valued at basic market rates, it would have amounted to over US$70 billion in 2014.[13]

Studies have shown that unpaid family carers can experience reductions in their mental and physical health, particularly when the dependent person has complex care needs, such as advanced Parkinson's or Alzheimer's disease.[14] Research from Mexico and Peru also shows that the day-to-day caring responsibilities may be imposed on younger, less powerful family members, such as daughters-in-law and grandchildren.[15] Often, these family carers have no specific knowledge about or training on the care needs of older people, and their responsibility for this work can disrupt their access to education and paid work.

Unpaid carers also often experience greater socio-economic stress. A recent survey of LTC arrangements in China, Mexico, Nigeria and Peru found that the principal caregivers of care-dependent older people with dementia were mostly women and that many of them had cut back on paid work to look after family members.[16] In addition to losing a family member when this person dies, family carers may also lose the little access they had to income or assets. Despite having cared for them, they may not be able to lay claim to the older person's pension or to survivor benefits; may face family inheritance issues, particularly in lower- and middle-income countries, where many people die intestate; and may struggle to re-enter the labour market.[17]

The specific cost to female carers could be somewhat reduced by the more equitable division of responsibility between the sexes. However, cultural norms limiting men's involvement in caring remain entrenched in most countries and resistant to change.[18]

More women do paid long-term care work

The paid workforce[19] providing LTC in both home and institutional settings is highly diverse, ranging from domestic workers with little formal education working in private homes to highly trained geriatric care professionals in hospitals and nursing homes. Between these two extremes there is a wide variety of LTC-related occupations with different levels of skill, status and remuneration.

Women account for the majority of the paid care workforce. While reliable data for low- and middle-income countries are lacking, it is estimated that around 1.5 million people were employed in LTC in the United States in 2014; of these, about 90 per cent were middle-aged and female and 20 per cent were foreign-born.[20] The proportion of foreign-born LTC workers has increased sharply in recent years. The growing demand for LTC workers has spurred international labour migration, especially of women. In 2017, for example, Taiwan Province of China contained around 240,000 officially registered migrant home-based elder carers, mainly recruited from Indonesia and the Philippines.[21] In many countries, care workers face low pay and difficult conditions, with immigrant workers especially vulnerable to exploitation.[22]

The way forward: Policy options

Despite arguments about the cost of long-term care solutions to the state, in fact the costs are borne by families who are left to make their own arrangements, often under severe constraints and with dire consequences for women across generations. No country can afford not to invest in long-term care.[23] While there is no single pathway to better LTC systems, all strategies should be aimed at protecting the rights of care-dependent older persons and caregivers alike. Doing so is sometimes portrayed as a trade-off, but the opposite is true: improving the conditions under which caregivers—both paid and

unpaid—carry out their work is likely to increase their capacity and motivation to give older people the support they need.

The functional capacities of care-dependent older persons are neither uniform nor static, but on a continuum.[24] Not all frail elderly persons need intensive institutional care. Various policy options exist (see Table 1), but they are often implemented in a fragmented and disjointed manner, focusing on one end of the continuum or the other.[25]

Working towards integrated and gender-responsive long-term care systems

LTC systems should pursue a number of key objectives, including promoting the well-being, dignity and rights of care-dependent older people; reducing and redistributing the heavy responsibilities placed on unpaid family carers; improving the accessibility, affordability and quality of LTC services (whether public, private for-profit or not-for-profit); and respecting the rights of paid LTC workers. There is scope in all countries to better integrate health and social care for older people at the community level.

Providing support to family caregivers

In most countries, interventions to support family caregivers are small scale and receive limited resources. Such interventions can take a variety of forms and should be rapidly scaled-up. Some governments in developed countries, for example, have offered payments to previously unpaid caregivers to support and compensate them, at least partially, for potential lost earnings.[26] Respite care is another, more hands-on form of support that allows unpaid caregivers to take a break from their tasks while someone else provides care to the person for whom they are responsible (see Box 1).

Not all approaches will suit all countries. For example, Finland's respite care model may not be readily transferred to low-income settings where residential service infrastructure is usually limited. As an alternative, some respite care can be brought to people's homes. In the Brazilian city of Belo Horizonte, for example, the local health district established a pilot programme in which trained health and social care professionals spend a week working with the families of dependent older people, offering them respite as well as some training and support.[27] Studies have shown that simply providing family carers with information about conditions such as dementia and strengthening their relationships with local health workers significantly reduces stress and may increase the quality of care older people receive.[28]

Investing in the paid care workforce

Although some paid care workers are highly qualified and well paid, the vast majority are not. Paid home carers are a case in point. The fact that these workers have little workplace contact with peers both reduces their status as paid workers and limits their capacity to organize for better working conditions. They require access to training and accreditation, as well as initiatives to raise collective awareness and support organized activism. There are some useful precedents from high-income countries. In the US state of California, for example, a labour union that had traditionally represented black and Latino health workers saw paid LTC carers as a natural extension of their activities. The union drew attention to exploitative aspects of these

TABLE 1

The continuum of long-term care for older people

Intensive institutional care

- Long-term hospitalization
- Nursing homes

Less intensive institutional care

- Residential homes
- Short stay or respite care
- Sheltered housing

Community services

- Day centres
- Nurse and professional carer visits

Home-based services

- Home help
- Cash benefits for carers
- Support groups for carers

BOX 1

Finland: Providing respite for family caregivers[30]

Finnish LTC policy places significant emphasis on respite services for people who care for older relatives. This forms part of a wider policy goal to ensure that at least 90 per cent of people aged 75 or more can remain living at home. Few family carers receive cash benefits from the state or home-based support. However, the 2006 Act on Family Caregiving grants long-term family carers three days of respite care each month. This takes the form of dependent relatives being temporarily admitted into a local nursing home. There is evidence that these short respite periods often reduce carer stress. However, there is also evidence that these short-term placements can be problematic for frail older people, especially those with conditions such as dementia. An evaluation suggested that closer liaison between family carers and staff in the respite centres could help overcome these limitations.

workers' contracts, which led to some increases in pay and improved working conditions.[29]

Strengthening women's participation in long-term care debates

Women's rights organizations and gender equality advocates can and should play a leading role in framing LTC agendas in gender-responsive ways. They can challenge narrow views of long-term care as a predominantly fiscal issue and raise awareness about the hidden costs of policy inaction to women across generations. Where governments are unwilling or unable to regulate the quality of available long-term care, women's rights organizations have taken matters into their own hands by making information about service quality more widely available (see Box 2). There are opportunities for strategic alliances with groups that have related interests, such as disability rights organizations. Equally, there is a need for engagement with health policy and related organizations to go beyond obviously gendered issues, such as reproductive and maternal health. A key focus should be the need for health professionals at the community level to provide support for family carers and dependent older people.

BOX 2

Argentina: Women taking action to improve local long-term care services

In the city of La Plata, Argentina, a network of older women activists participated in a survey of local LTC service quality. They found that local residents lacked information about services and that standards were often very poor. Local government capacity to resolve these problems was limited and so the network took direct action itself. In partnership with a local ombudsperson, academic experts and certified service providers, they created a website providing information about local services. Providers listed on the site are required to maintain a set of agreed quality standards and are removed if they do not do so. A process of monitoring compliance is currently being set up and will be overseen by a committee consisting of members of older people's organizations and the local ombudsperson.[31]

RECOMMENDATIONS

- **Develop focused public communication campaigns highlighting the need for societal engagement with long-term care as a human rights and gender equality priority**
- **Generate and publicize data and knowledge about the effects of LTC on women and address key evidence gaps, including the working conditions and well-being of paid and unpaid carers as well as the vulnerability of frail older women to abuse and neglect**
- **Support and promote efforts by paid and unpaid carers, as well as those who rely on their care, to organize and form political alliances to reduce their marginalization from policymaking and emphasize their key stakeholder status**
- **Ensure that activities aimed at enhancing the status and reducing the exploitation of domestic workers reflect their growing involvement in elder care**
- **Grow organizational expertise about gender and LTC by facilitating and supporting strategic alliances between women's rights**