

**Pathways to accessible, affordable and  
gender-responsive care services for  
older persons**

Peter Lloyd-Sherlock

2018

DEV Reports and Policy Papers

## **Pathways to accessible, affordable and gender-responsive care services for older persons**

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## 1. Introduction

This report consists of general analysis and two country case studies relating to long-term care (LTC) for older people. These form a background paper for UN Women, with particular reference to two forthcoming publications: Progress of the World's Women (on the theme of Families in a Changing World) and Gender Equality in the 2030 Agenda for Sustainable Development.

Key objectives of the report are, with a special focus on low and middle-income countries, to:

- Map the existing landscape of public support for LTC, their funding mechanisms and coverage.
- Provide evidence on how families deal with the care needs of older family members in the absence of comprehensive public support.
- Provide an overview of ongoing policy discussions and efforts to increase investments in supporting care for older persons.
- Assess the strengths and weaknesses of existing support for LTC services, placing special emphasis on quality, affordability, accessibility, equity, and gender responsiveness.
- Analyse the working conditions of the largely female workforce in this sector.
- Assess whether there are specific needs that older women may face that require special attention or interventions.
- Provide recommendations and pathways for building on or transforming the existing system of LTC support for older people in order to increase coverage, quality, affordability, equity and gender responsiveness.

The report begins with a brief discussion of key concepts and issues relating to LTC, for the non-expert reader. This is then followed by a more focussed review of LTC issues as they affect low and middle-income countries. Following on from this, there are detailed national case studies of LTC in South Africa and Argentina. The choice of national case studies was largely opportunistic, reflecting the availability of relevant material for what is largely a desk-study and the lead author's own familiarity with these settings. As such, they should not be taken as representative of a wider set of low or middle-income countries.

Nonetheless, they provide evidence of both similarities and differences in terms of the nature of LTC systems in diverse national settings. The final section of the report provides some comparative discussion of the two case studies and identifies key policy lessons.

## 2. Theory and concepts

LTC can be defined as:

*"...material, instrumental and emotional support provided formally or informally over an extended period to people in need, regardless of age" (United Nations, 2008: 166).<sup>1</sup>*

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<sup>1</sup> Despite this simple definition, LTC is a complex concept and relates in different ways to a range of policy fields, including chronic disease management, geriatric health, rehabilitation and social work.

A strict interpretation of this definition would include care for healthy young children. However, LTC usually refers to care for people with disabilities and for older people with limited functioning. Despite important parallels between care for children and care for older people, these issues are usually perceived as very different by policy-makers and society in general. For both forms of care, a key issue is the balance between family/state responsibility and informal support/institutionalised care. In terms of childcare, there is a strong international consensus that residential institutional care should be a last resort (Browne et al., 2006). By contrast, institutional care for older people has become increasingly common (Brodsky et al., 2003). Both forms of care require complex interactions between families and external agencies, such as social services, to ensure that appropriate forms of support are provided and that vulnerable individuals are not exposed to abuse. Managing these complex interactions, striking a balance between family and external roles, and respecting different cultural norms is a major challenge for policy-makers. In almost all societies, women provide the vast majority of care for children and older people, either as unpaid family carers or as salaried employees. For some women, this may lead to a double care role, with these two forms of care coinciding or following on from each other (Chisholm, 1999). However, since population ageing is almost always associated with fertility decline, increased LTC needs for older people may be off-set by decreased care needs of children.

In high income countries, increases in the number of older people with restricted functioning have led to a rapid expansion in residential LTC institutions, such as nursing homes and care homes.<sup>2</sup> In 2004 the United States contained over 18,000 LTC facilities with a population of 1.2 to 1.6 million people (Spillman and Black, 2015). As populations continue to age, there are growing concerns about the costs and long-run financial sustainability of residential LTC (Maarse and Jeurissen, 2016; OECD, 2005). There are also concerns that the quality of LTC institutions is uneven and that homes are often poorly regulated. More generally, it has been argued that institutionalisation can promote the social exclusion of older people and infringe their human rights (Clough, 1996). Numerous studies have found very high levels of abuse of older people in LTC homes by staff members (Goergen, 2001; Krug et al., 2002). There is also strong evidence that the great majority of older people prefer to remain in their own homes or live with relatives whenever possible (World Health Organization, 2015).

A combination of cost concerns and criticisms of care homes have prompted policies that seek to bridge the gap between independent living and permanent institutionalisation. These include state interventions that facilitate continued living at home and support informal carers. Table 2.1 presents the more common LTC approaches in high income countries as a continuum, ranging from intensive residential nursing to more limited interventions such as home help or support groups. There has been a pronounced shift away from more intensive approaches, so that home care accounts for nearly a third of state LTC spending in some countries (OECD, 2005). Given the reluctance of most governments to substantially increase spending in this area, it is likely that the majority of care will continue

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Sometimes the term LTC is used inter-changeably with other ones, such as “social care” (Ismail, Thorlby and Holder, 2014).

<sup>2</sup> Nursing homes usually provide some medical services on site, with trained staff. Care homes usually do not.

to be provided by family members, especially women, and that the quality of services will remain patchy. A more comprehensive response to LTC needs would require a significant reorientation in societal priorities, and this does not appear likely in the next few decades.

**Table 0-1 Long-term care option for older people**

Intensive institutional care	Long-term hospitalisation
	Nursing homes
Less intensive institutional care	Residential homes
	Short stay or respite care
	Sheltered housing
Community services	Day centres
	Nurse and professional carer visits
Family support	Home help
	Cash benefits for carers
	Support groups for carers

LTC is a labour-intensive process and meeting these demands represents a growing challenge for high income countries. It is estimated that around 1.4 million people were employed in LTC in the USA in 2005 (Browne and Braun, 2008). Of these, about 90 per cent were middle-aged and female, and 20 per cent were foreign-born (Montgomery et al., 2005). There is evidence that the proportion of foreign-born LTC workers in high income countries has increased sharply in recent years (Redfoort and Houser, 2005). The growing demand for LTC workers has contributed to wider trends in international labour migration, especially of women. Whether this represents an opportunity or exploitation for women workers is a matter for debate, since employment conditions for LTC workers are usually poor. In the USA average wages in 2005 were only 67 per cent those of the general workforce (Browne and Braun, 2008). Despite this, money sent home by relatives working abroad in the care industry is a substantial source of income for countries like the Philippines (de Parle, 2007).

Policy debates about LTC in high income countries mainly focus on the growing cost of LTC service provision and the need to minimise its fiscal impact (World Bank, 2010). Not denying the pertinence of this issue, a narrow, fiscal interpretation of “cost” obscures some important points. The first is that LTC always has a “cost”, be it in fiscal terms for states, out of pocket spending for individuals, time and opportunity costs for unpaid/ exploited carers or costs to the wellbeing of older people (if adequate care is not provided). As such, the critical issue is how these costs should be distributed: between public and private domains, between generations and between men and women. This requires an informed societal debate.

Secondly, cost concerns have reduced attention to the quality of LTC service provision. There is evidence that quality often leaves much to be desired, with harmful consequences for both dependent people and their carers. There is often a tension between aspirational principles and the “realpolitik” of LTC quality control. A key dilemma is the need to maintain both standards and profitability for service providers, at the same time as managing costs (Leone et al., 2014). A related issue is the challenge of developing effective institutional infrastructures to regulate and oversee LTC, including a general failure to

integrate LTC with mainstream health services for older people (World Health Organization, 2015).

High income countries are facing growing concerns about the future of LTC, both among policy-makers and the general public. There is an evident need to develop new policy models better-placed to manage trade-offs between cost and quality, and to permit a more equitable distribution of real costs. This requires an approach that is cognizant both of the rights of dependent older people and those of their carers, including potential conflicts between gender justice and generational justice.

## 2.1 Long term care trends and issues in low and middle-income countries

The populations of low and middle-income countries (LMICs) are ageing rapidly, with especially sharp increases in the number of people at very old ages (Table 3.1). Within older populations, there are strong associations between age, frailty and limited function (Fried et al., 2001; Harttgen et al., 2013). It is estimated that between 2015 and 2050 the number of people in LMICs with dementia will more than treble (ADI, 2015). To date, global policy has mainly focussed on the provision of pension benefits to people over the age of retirement (Bloom et al., 2015). There is an evident need for policies that take more direct account of the specific vulnerabilities faced by people at very old ages, including care dependency.

**Table 0-2 Population aged 75+(million) in less developed regions**

1990	54.0
2000	77.6
2010	115.7
2020	158.8
2030	250.6
2040	383.3

Source: United Nations Population Division (2015).

Table 3.2 presents old age dependency ratios for selected countries and regions. These ratios are a function of the total number of people aged 70 or more (assumed to be dependent) to the total number aged 20 to 69 (assumed to be supporting the dependent group). These assumptions are in themselves problematic, in the face of growing evidence that relationships between age and dependency are considerably more nuanced (Gietel-Basten et al., 2015). Setting this important reservation to one side, the dependency ratio data suggest a rapid increase in the “burden” of old age dependency in LMICs over the next 30 years. This is especially apparent for China, where the ratio of over 70s to adults aged 20 to 69 will quadruple.

There is, however, considerable variation in the relationship between chronological age and health and functional status. Table 3.3 compares the prevalence of functional limitations for older people in six LMICs. It shows that the proportion reporting no limitation varied from 20.3 per cent in Mexico to 1.9 per cent in the Russian Federation. The available research indicates considerable scope to improve the health and functional status of older people at a



given age (Feng et al., 2013; Ikeda et al., 2011). This can be achieved through specific interventions or through the promotion of a wider social and economic environment that is conducive to good health in later life (World Health Organization, 2015).

**Table 0-3 Old age dependency ratio (population aged 70+ as a percentage of population aged 20-69). Medium variant projection.**

	2015	2025	2035	2045
<b>China</b>	8.2	13.3	20.2	32.0
<b>Ghana</b>	4.0	3.9	4.5	5.6
<b>India</b>	5.8	7.3	9.5	12.1
<b>Mexico</b>	7.3	9.2	12.8	18.5
<b>More developed regions</b>	18.6	24.1	30.2	33.8
<b>Less developed regions</b>	6.6	8.7	11.7	15.3

Source: UN Population Division (2015).

**Table 0-4 Functional limitations for population aged 70 or over, 2007-10 (% of total population)**

	Any disability (%)	Difficulty moving around (%)	Difficulty with self-care (%)	Difficulty with cognition (%)
<b>China</b>	85.4	40.4	19.7	68.0
<b>Ghana</b>	88.1	63.4	35.8	74.3
<b>India</b>	97.3	72.5	36.3	80.7
<b>Mexico</b>	79.7	54.3	31.3	54.6
<b>Russia</b>	98.1	85.6	56.4	74.7
<b>South Africa</b>	86.0	51.7	24.8	67.6

Source: He et al (2012).

Given the elastic relationship between age and dependency, estimating care demand is not straightforward. Although survey data on care dependency in later life are increasingly available, they should be treated with caution. Care dependency is a complex, potentially subjective and often stigmatised label/concept. There is no specific or universally agreed definition of care dependency, nor are there agreed methods for assessing dependency in the field. Possibly as a result of varied definitions, understandings and methods, surveys of dependency can yield quite different results. Table 3.4 presents the findings of four separate recent studies for Mexico, which show considerable divergence. Moreover, the intensity (and hence cost) of care dependency can be highly variable, ranging from a need for occasional assistance with light housework to round the clock care for demanding conditions such as Alzheimer’s Disease. Within the gerontological literature care dependency is often related to older people’s capacity to do specific things for themselves. This includes a list of basic “activities of daily living” (eating, bathing, dressing, toileting, walking and continence) and “instrumental activities of daily living” which relate to more specific activities that enable older people to live independently (such as doing housework, preparing meals, taking medications as prescribed and managing money) (Katz, 1983). This

approach offers a more systematic approach for assessing some aspects of care dependency, and there is a need to apply it more consistently across LMICs.

**Table 0-5. Different estimates of care dependency among older people in Mexico, 2008-12**

	Source	Age range	Finding
2012	National Survey of Health and Nutrition	60+	27% report “some degree of dependency”
2008	10/66 Dementia Research Group	65+	Assessed “need for care” according to responses to open-ended questions. Care need reported for 8.2% in rural areas and 11.3% in urban ones.
2009	SAGE (World Health Organisation)	70+	31.3% report “some difficulty with self-care”
2011	<u>Encuesta de Opinión Pública</u>	60+	Younger adults asked about parents aged 60+. Do they “need help with basic activities such as dressing, eating and bathing?” 21 per cent report their mothers do; 15% their fathers

Sources: Pérez-Cuevas et al, 2015; Sousa et al (2010); He Muencrath and Kowal (2012); Centro de Estudios Sociales de Opinión Pública (2011);

The complexity of assessing functional status and care needs among older adults is reflected in comparisons between older men and women. It is generally acknowledged that in most LMICs women who survive to age 60 go on to have a longer life expectancy than is the case for men (Oksuzyan et al., 2009). However, women in both developed and developing countries often report higher rates of ill health and disability in later life than do men (Bora and Saikia, 2015; Oman et al., 1999). A simple explanation may be that the average age of older women is higher than that for older men. However, some studies have reported significant associations between female sex and disability even when controlling for age and lifetime medical history (Wood et al., 2005). The reasons for these disparities are not fully understood. Some studies suggest that older women are more likely to self-report as disabled than are their male counterparts (Merrill et al., 1997). However, most diagnostic studies based on objective criteria also find sex differentials (Hardy et al., 2008). One explanatory hypothesis is that older women have on average less muscle mass than older men, which reduces their resilience to functional decline (Wood et al., 2005). The combined effect of higher rates of age-specific disability among women and higher female life expectancy at older ages means that women account for a disproportionate share of long-term care demand, however this demand is assessed.

Assessing the extent to which the current care needs of older people are being met is even more challenging. This can be done in two ways. First, there are indirect indicators of the capacity and predisposition of different societies to provide care. These look at a range of trends including fertility rates, female participation in paid work, living arrangements and population mobility. There are reliable data on these trends for most LMICs, but we know

much less about their impact on the supply of care (Box 1). Available studies reveal that the effects of these wider social trends on care are nuanced, and vary across groups and contexts (Aboderin, 2004; Gomes da Conceição and Montes de Oca Zavala, 2004; Kreager and Schröder-Butterfill, 2015). This contradicts generalised claims that norms of family support for older people are stronger in LMICs and that residential care is more stigmatised (Brijnath, 2012). There is evidence that social attitudes towards family care-giving are changing, and that institutional care is becoming more acceptable (Jamuna, 2003; Sinunu et al., 2009). Some studies refer to increasing numbers of disagreements between family members about the provision of care for older members a rise in the number of associated legal disputes (Wong and Leung, 2012).

The second way to assess how far current LTC needs are being met is by directly mapping patterns of formal and informal care provision. Here, the evidence is very limited, especially for poorer countries. There are several reasons why information about formal care services is scarce. First, most LMIC governments have a minor role as direct formal LTC providers, with services provided mainly through NGOs, as well as private and religious organisations. Typically, governments run small numbers of residential care homes, often targeting indigent older people, but excluding those with challenging conditions such as dementia. The limited extent of government intervention in LTC provision can be seen in the Indian state of Uttar Pradesh, which contains more than 8 million people aged 60 or over (Lloyd-Sherlock, 2013). The government's Department of Social Welfare had established a LTC programme in 1971. In 2009 this programme consisted of two single-sex residential homes, with a combined capacity of no more than 100 people. In practice, the number of residents was considerably lower, in part because large sections of the original buildings were no longer deemed habitable. The main purpose of these homes was to provide shelter for "destitute" older people who had no other means of material support. Older people with chronic health conditions or functional limitations were not permitted admission.

## Box 1 Changing living arrangements and care for older people

A growing proportion of older people are living alone or without adult relatives (WHO, 2015). In China, for example, the proportion of older people living with children fell from 73 to 57 per cent between 1982 and 2005 (Herd et al., 2010). Living alone or without adult children is generally seen as detrimental to older peoples' wellbeing and their access to long term care. According to the United Nations: element of the flow of support between family members. This is particularly so with respect to informal support that depends on physical proximity such as assistance with activities of daily living" (United Nations Population Division, 2005: xvii) (United Nations Population Division, 2005: xvii).

In keeping with this, most studies show that older people living alone are more likely to suffer from loneliness and depression (United Nations Population Division, 2005). Since data on living arrangements are easier to collect and more generally available than more complex data on economic and social circumstances, they are sometimes used as an indirect "proxy" indicator of older people's wellbeing.

Although there is some truth in these general observations, they are based on a number of simplified assumptions about household care dynamics. The mere presence of an adult child in the same building as an older person is not a guarantee that this child will provide support when required. Simple assumptions about living arrangements are also challenged by research findings that wealthy older people are more likely to live alone (DaVanzo and Chan, 1994). Some older people express a strong preference for solitary living, which they associate with independence, privacy and personal autonomy. Conversely for the poor, co-residence may result from a lack of affordable housing options and entail overcrowding, especially in urban settings. This in turn may promote household tensions and generational conflict over control and ownership of the home (Sokolovsky, 2001).

In-depth interviews with older women in a socially excluded neighbourhood of Buenos Aires found almost all had large numbers of children, grandchildren and great-grandchildren living with them or in close proximity (Lloyd-Sherlock and Locke, 2008). However, many of these off-spring were facing economic, health and psychological difficulties. For example, one informant lived with a seriously disabled daughter and a violent, mentally unstable adult grandson. Another informant had been robbed by her drug-addicted daughter two days before the interview and was raising several of this daughter's children. More successful children often moved to wealthier neighbourhoods and did not maintain close contact. Rather than a potential source of care and support, co-resident offspring were more likely to be a source of vulnerability. Many LMICs are experiencing urbanisation, unemployment and high rates of crime, and so the experiences of these older women may not be exceptional.

By contrast, in most LMICs, there has been a rapid growth in private sector residential services as well as nursing agencies offering home-care. These new sectors are weakly regulated, if at all, raising concerns about the quality of care and the potential exposure of older people to abuse (Lloyd-Sherlock and Redondo, 2009; Sasat et al., 2013). Weak regulation reduces the quality and quantity of data about service providers.

Second, there is considerable institutional fragmentation of responsibility for managing and overseeing LTC, which acts as a barrier to data collection. This includes confusion between the roles of mainstream health-service providers (who are sometimes *de facto* formal LTC providers of last resort) and social service agencies. Most states administer and oversee LTC services at the local government level and there is evidence that provision varies markedly between local governments (Camarano, 2010; Wong and Leung, 2012). This makes it very difficult to provide a reliable national picture.

Obtaining credible evidence about the quality and quantity of informal LTC is equally challenging. Few household surveys in LMICs include items that refer to these forms of care-giving. Also, eliciting reliable information about family care-giving practices is highly problematic, since responses (especially to quantitative surveys) are strongly influenced by cultural norms of acceptable behaviour (Sinunu et al., 2009; Zhang and Jean Yeung, 2012). Respondents will not necessarily admit to themselves, let alone to an outsider, that the care they provide is inadequate. Likewise, dependent older people may find reporting poor family care is stigmatising or, if family members are present in the interview, unsafe. Without recognising and overcoming these challenges, it is likely that surveys will significantly understate the shortcomings of informal LTC.

Putting the limited and fragmentary evidence (including more anecdotal sources such as media reports) together, there are indications of a large and growing gap between need for LTC and the provision of adequate services. There are also indications of the harmful consequences of policy-makers failing to take action, including include a growing body of studies which identify high levels of stress experienced by mainly female family carers [Box 2]. By contrast, there have been almost no studies quantifying the effects of policy inaction on areas such as unnecessary hospitalisations.<sup>3</sup> Most notably, there is very little research on the consequences of policy inaction on dependent older people themselves, in terms of quality of life, exposure to abuse and preventable mortality.

Despite the rapid emergence of these issues in LMICs, LTC for older people is usually a very low policy priority (Lloyd-Sherlock, 2014). Policy-makers are not always aware of the speed at which population ageing is progressing and the multiple challenges this generates. Also, there is a pervasive view that in LMICs families are better placed to provide care than is the case in high income countries, and that there is therefore less need for policy interventions. In reality, the limited available evidence suggests that families struggle to cope, particularly without outside assistance.

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<sup>3</sup> One exception to this is a 2001-2007 survey of hospital inpatients aged 60 and over in Rio de Janeiro, which found that 2,260 had been in hospital for over a year. Of these, around a quarter were recorded as being in hospital due to a lack of family support (Romero et al., 2010).

## Box 2 The impact of paid and unpaid care-giving

Almost all family carers and the majority of paid carers are women, including older women caring for spouses. Most families contain several female members, so a key issue is which member takes on the main care role. Research from Mexico and Peru shows that in some cases day to day caring is imposed on less powerful family members, such as daughters-in-law and younger grandchildren. They do not always identify as the “main carer” in surveys and their contribution can go undetected (Lloyd-Sherlock et al, forthcoming). Usually, these family carers have no specific knowledge or training about meeting the care needs of older people.

There is considerable evidence that unpaid family carers can experience high levels of mental stress, reduced physical health status (due, for example, to lifting and carrying older people) and socio-economic stress (Choo et al., 2003)). This is particularly pronounced when the dependent person has complex care needs (Tamanini et al., 2011). Economic effects include the need for family carers to limit paid work outside the home (Prince et al., 2012), which can also generate labour market inefficiencies (Comunidad Mujer, 2010) (Comunidad Mujer, 2014). There are anecdotal indications that carers face particular forms of vulnerability after the person they care for dies, including grief, financial loss (due to losing the older person’s pension), family inheritance issues (many people in LMICs die intestate) and struggles to return to paid work and reinvent a new life role. This issue has not been studied and the assumption is that the carer “burden” disappears once their role ends. At the same time, it should not be neglected that carers may also experience more desirable effects in terms of self-esteem, affection from care-recipients and (in some cases) recognition of their role from wider family (Gray et al, 2016).

Paid carers, based in either domiciliary or institutional settings, can also experience high stress burdens, especially in the case of untrained immigrant workers (Gallart, Cruz and Zabalegui, 2013). Most are poorly paid, untrained, lack union representation and are exposed to exploitative practices (ILO, 2015).

### 3. Long-term care for older people in South Africa: the enduring legacies of apartheid and HIV/AIDS.<sup>4</sup>

#### 3.1 National context

For LMICs like South Africa long-term care for older people is primarily seen as a modern challenge. However, the specific nature of that challenge is strongly framed by historical effects. In the case of South Africa, the lasting impacts of Apartheid and the HIV/AIDS epidemic continue to exert powerful effects on most aspects of society and public policy. The Apartheid system was formally implemented in the late 1940s, with a raft of legislation discriminating against different racial groups. Among other things, this included forced geographical segregation, employment discrimination and different entitlements to services (Feinstein, 2005). Officially, Apartheid came to an end in 1994 with the election of the African National Congress government under the leadership of Nelson Mandela. However, such was the impact of Apartheid (as well as more general policies of racial discrimination which dated back to the 19<sup>th</sup> Century) that its effects continue to shape the country today. For example, per capita income of Africans (who account for around 80 per cent of the national population) is around an eighth of that for whites (who account for around 9 per cent) (Gradín, 2013).

Coinciding with this political transition, South Africa saw the arrival and rapid escalation of the HIV/AIDS epidemic (Sishana et al., 2012). Between 1990 and 1998 the proportion of antenatal clinic attendees who tested positive for HIV rose from less than one per cent to 22.8 per cent. Prevalence is currently estimated at around 20 per cent for the total population, with 280,000 deaths related to HIV/AIDS in 2010. Mortality has been concentrated among younger age groups, due to lower prevalence among people at older ages (around 4 per cent for both men and women aged 60 and over). This has had numerous effects on the age composition of the population and the composition of households, some of which have implications for long-term care. Since 2012 the rapid extension of anti-retroviral therapies (ART) has led to a fall in HIV/AIDS-related mortality, down to 180,000 a year in 2015. However, the social and demographic legacies of the epidemic are set to endure for several decades to come.

A more positive legacy of South Africa's past has been the emergence of a relatively embracing welfare system, including a non-contributory pension (known as the "Old Age Grant") which is paid to the large majority of older people, regardless of race. Before 1994,

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<sup>4</sup> This paper uses the artificial racial categories that have been officially applied in South Africa. These (as all racial categories) are essentially a social construction, but their importance in the country's development has been such that they are essential tools for analysis. The term "White" refers to people with European settler origins; "African" refers to indigenous, dark-skinned groups; "coloureds" refers to people of mixed race; "Asian" mainly refers to the descendants of indentured labourers brought from South and South East Asia. The term "black" has traditionally referred to non-whites in general, although the political interpretation altered somewhat with the inception of Black Economic Empowerment in the 1990s.

the value of benefits varied by racial groups, but they were subsequently harmonised, standing at approximately US\$110 dollars a month. It has been claimed that the social pension does not just benefit older people, but is pooled across entire households (Barrientos et al., 2004; Lloyd-Sherlock et al., 2012). Indeed, in settings of high unemployment, they may represent the only reliable source of household income and can lead to family members moving back to live with older people to share the pension income (Hamoudi and Thomas, 2014).

Taken together, pension pooling and care of AIDS orphans have generated a strong focus on the role of older Africans as carers of other family members.<sup>5</sup> This reflects both traditional roles for grandparents and public policy. (Sagner and Mtati, 1999) observe:

*By emphasising the poverty-alleviating function and the development oriented role of social assistance money in general and old-age pensions in particular ... the state also stresses the 'rightness' of pension sharing.... The state-supported ideology of the moral virtue of pension sharing and of the 'natural' selflessness of old-age pensioners dominates much of the public discourse on older people.*

The extent to which pension-sharing is always a consensual process is a moot point (Lloyd-Sherlock, 2016). More specifically, this focus on older Africans as carers has over-shadowed concerns about meeting the needs of those older people who are themselves care-dependent. This can be seen in the published literature which includes a substantial body of work on the former issue and almost nothing on the latter.

Inevitably, health policy has mainly focussed on HIV/AIDS, and associated issues such as TB and reproductive health. This focus is, however, growingly out of kilter with South Africa's main epidemiological challenges. Despite the scale of the HIV/AIDS epidemic, the leading causes of death and illness in South Africa are now non-communicable diseases, such as stroke, heart disease, cancer and diabetes (Mayosi et al., 2009). For example, South Africa has the highest reported prevalence of hypertension in the world (Lloyd-Sherlock et al., 2014). These conditions remain relatively neglected and this forms part of a wider neglect of health conditions of relevance to older people. For example, specialist gerontology training was recently removed by the South African Nursing Council from its required nursing qualifications. In 2010 South Africa only had eight registered geriatricians for a population of nearly four million people aged 60 or more. Where they exist, relevant health services are mainly concentrated in more prosperous urban areas, reflecting a geographical distribution of hospital infrastructure established under Apartheid (Mooney and McIntyre, 2008).

More specifically, there is very little research or policy focus on dementia in South Africa. For example, there are no reliable surveys of prevalence of the condition and awareness of the condition is extremely limited, even among health professionals (Jager et al., 2015). There is evidence of a link between HIV and dementia risk, including for populations receiving ART

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<sup>5</sup> There is less evidence for these effects among other racial groups, but they would appear to be less pronounced.



treatment. Consequently, the prevalence of dementia may be significantly higher than in countries less affected by HIV/AIDs.<sup>6</sup>

The lack of focus on non-communicable disease and geriatric health has several potential consequences for long-term care. First, they contribute to levels of care dependency in old age. For example, exposure to uncontrolled risk factors such as hypertension increases the incidence of conditions such as stroke, which are a major cause of disability in later life (Maredza et al., 2015). Second, the limited training of nurses in primary health centres represents a major barrier to the development of integrated health and social care systems for older people, especially in rural areas.

In sum, South Africa’s complex historical experience has given rise to a unique context and set of challenges for the provision of long-term care for older people. The following sections will demonstrate the extent to which current provision is profoundly shaped by these effects.

### 3.1.1 Demand for long-term care in South Africa

**Table 0-1 Population estimates and medium variant projections by sex (1000 people)**

	2015	2025	2040
<b>Males aged 70+</b>	574	613	1210
<b>Females aged 70+</b>	1,157	1546	2238
<b>Total aged 70+</b>	1,731	2,159	3,448
<b>Total 70+ (% of total population)</b>	3.2	3.7	4.3

Source: UN Population Division 2016.

Table 4.1 shows that the number of South Africans aged 70 and over will roughly double over the 25 years between 2015 and 2040, reaching 3.5 million people. It also shows that a disproportionate share of older people will be women. Rather than a single, national trend of demographic transition and population ageing, it is more useful to look at the experiences of racial categories separately. Even before the formalisation of the Apartheid system, the demographic profiles of these racial groups were very different. For example, between 1940 and 1950 the total fertility rate for white women was 3.5, compared to 6.5 for all other racial groups (Chimere-Dan, 1993). Africans have historically experienced much lower levels of life expectancy than other racial groups. In 1997 life expectancy at birth was 77 years for white women, compared to only 55 years for black women (Kinsella and Ferreira, 1997). These long-run demographic differences between racial groups continue to affect patterns of population ageing today. The HIV/AIDS epidemic has also had a major demographic impact, especially among Africans. In 2012, it was estimated that 15 per cent of Africans were HIV positive, compared to only 0.3 per cent of whites (Sishana et al., 2012). HIV/AIDS mortality has been concentrated among younger adults and children, which may have initially increased the percentage of Africans in older age groups.

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<sup>6</sup> It has been estimated that up to a quarter of adults aged 40 or over initiating anti-retroviral treatment for HIV have HIV-associated dementia (Robbins, et al, 2012). If this rate is representative of the total population with HIV, it would account for around a million people.

Table 4.2 compares levels of population ageing for the different racial groups in 2014 and shows that whites are disproportionately represented in the oldest age groups. This indicates that historical variations in fertility and life expectancy between racial groups more than counter-balanced racial variations in HIV/AIDS mortality. Nevertheless, Africans accounted for around two-thirds of the population aged 70 and over in 2014. Assuming that age-specific care-dependency rates do not vary by racial groups, this means that Africans also accounted for two-thirds of long-term care demand. The racial composition of South Africans aged between 50 and 69 indicates that whites will account for a shrinking proportion of the oldest old in future decades.

**Table 0-2 Sex and race composition of different age groups (per cent), 2014**

	All	50-59	60-69	70-79	80+
<b>Africans</b>	80.2	70.7	69.0	69.1	<b>63.9</b>
<b>Whites</b>	8.4	15.4	19.1	21.2	<b>27.2</b>
<b>Coloureds</b>	8.8	10.5	8.4	6.7	<b>5.7</b>
<b>Asians</b>	2.5	3.4	3.4	3.0	<b>2.7</b>
<b>Female</b>	<b>51.2</b>	<b>54.3</b>	<b>56.4</b>	<b>61.1</b>	<b>66.0</b>

Source: Statistics South Africa (2014).

Table 4.3 presents data on older people's living arrangements, by gender and race for 2001 and 2011. It shows significant differences in living arrangements for older people by racial category. Older Africans are much more likely to live in extended/complex households than are older whites, although the proportion has fallen somewhat since 2001. Despite this, it is noteworthy that 17.7 per cent of older African were living alone in 2011, with the proportion rising to over one in five older female Africans. This calls into question any generalised claim that almost all older Africans have direct access to family support.

**Table 0-3 Living arrangements of people aged 60 and over by sex and population group (%)**

Year	Type	Male	Female	African	White
<b>2001</b>	Single person	11.7	17.7	11.4	31.6
	Nuclear	40.0	10.3	16.1	54.0
	Extended/complex	48.4	72.0	72.5	14.4
<b>2011</b>	Single person	16.7	23.2	17.7	33.0
	Nuclear	39.5	13.2	17.4	52.6
	Extended/complex	34.8	63.6	64.8	14.5

Source: Statistics South Africa (2014).

Comparisons of living arrangements between older men and older women reveal a more complex pattern. Older men are more likely to live in nuclear households, mainly because they are less likely to experience widowhood than are older women. The proportion of older women living in extended/composite households is higher than for men, accounting for a particularly large share of African women. What this means for older men and women's potential access to care from family members is not easy to deduce. It is apparent that, in many cases, these extended households contain relatives who are more likely to be care-receivers than care providers. The category extended/complex households includes skip-generation households (in which grandparents live with a grandchild aged under 15, but no

adult children). It has been estimated that at least 15 per cent of Africans aged 60 and over were living in skip-generation households (Noumbissi and Zuberi, 2001).<sup>7</sup> As such, living with children and grandchildren may have at least as much to do with older people providing care as it does with their access to it.

As discussed in Section 3, relationships between chronological age and care dependency are variable and reliable estimates of care dependency rates are not easily obtained. Table 4.4 summarises available data from a nationally-representative survey of older people. It refers to different aspects of care dependency, with higher rates associated with rural location, older age and female sex. Since more women survive to older ages than men, female sex does not exert an independent effect. Table 4 shows that a quarter of South Africans aged 70 and over reported difficulty with self-care: this equates to 433,000 people in 2015.

Assuming that age-specific care-dependency rates do not vary by racial groups, older Africans would account for around two-thirds of long-term care demand. This assumption would, however, appear to be far from valid. Data from the 2011 National Census shows that the share of older Africans reporting difficulty with severe self-care was more than double that for whites, while they were four times more likely to report severe cognitive impairment (Jager et al., 2015; Statistics South Africa, 2015).<sup>8</sup> Despite this, the census shows that Africans were less likely to use assistive devices or medication to manage chronic conditions: for example, only 22 per cent used glasses, compared to 80 per cent of whites.

Despite the acknowledged link between HIV status and dementia risk, there is very little information on the prevalence of dementia in South Africa. There are no reliable data on prevalence for the country as a whole. A small survey of 200 Africans aged 60 and over in an urban setting found rates of around 6 per cent (Jager et al., 2015). Given the high rates of HIV prevalence among Africans, it is likely that this group will be disproportionately affected by dementia.

**Table 0-4 Indicators related to care dependency for people aged 50 and over**

	<b>Age 50-69</b>	<b>Age 70+</b>	<b>Women aged 50+</b>	<b>Men aged 50+</b>	<b>Urban 50+</b>	<b>Rural 50+</b>
<b>% reporting some difficulty moving around</b>	29.7	50.7	37.4	29.3	31.3	38.4
<b>% reporting some difficulty with self-care (ADLs)</b>	14.5	24.8	17.3	15.6	13.0	23.0
<b>% satisfied with ability to perform daily activities (IADLs)</b>	70.6	61.3	67.2	70.8	71.5	63.7

Source: calculated from (van Pletzen et al., 2014) He at al (2012).

<sup>7</sup> For Asians, whites and coloureds, lower rates of labour migration and AIDS mean that skip generation households are very uncommon, with nuclear households the norm.

<sup>8</sup> This is in keeping with studies in other countries show a strong link between early life disadvantage, related to race and the risk of care dependency in later life (Bowen, 2009).

### 3.1.2 Organised long-term care services in South Africa.

South Africa contains a large number of residential care homes for older people, including over 400 care homes which are on official registers. These homes are mainly run by NGOs or religious organisations, and only eight are run directly by local or national government agencies. The country has a well-established and diverse network of NGOs and other third sector organisations, which play substantial roles in many aspects of development, including the health sector (van Pletzen et al., 2014). Historically, charities and church organisations have been the main providers of care home services for the white population, albeit with considerable state funding. As demand has risen, many of these organisations have seen rapid expansion.<sup>9</sup>

Registered homes are entitled to apply for a state subsidy for individual residents, currently worth around £100 a month. The Department of Social Development screens applicants according to their level of frailty, family situation and economic status. In 2014 the total cost of this scheme was £50 million, indicating that around 42,000 care home residents were receiving subsidies (Government of South Africa, 2015).

There have been mounting concerns about the cost of these care home subsidies and efforts to rein them in (Department of Social Development, 2005). A government white paper published in 1997 stipulated that state subsidised residential care should only be made available for frail older people, but did not provide a definition of frailty. The monthly value of the subsidy has been reduced over time and now only represents a small part of the total cost of residential care. It has been observed that the reduction in the value of the subsidy has discouraged residential facilities from providing services to poor, frail older people (who are eligible for the subsidy) and focus provision on wealthier older people (who pay themselves) (Department of Social Development, 2005).

The use of residential care homes is heavily concentrated among white older people. In 1982 the percentage of White South Africans living in state-subsidised or private old age homes was the highest in the world, at 11 per cent of the population aged 65 and over (Seedat, 1984). By contrast, state and private provision for other racial groups was minimal. A survey of care homes conducted in 1998 found that 84 per cent of residents were white and added: *Welfare and church organisations, mainly from the white population groups, developed institutional care within their own cultural background to take care of their older people* (Perold and Muller, 2000).

This view was reflected in a comment from a prominent African politician, made in 2014: *Black and white are different in terms of their culture and traditions. While whites prefer to take their old to these homes for the aged, black people prefer to live with their children and grandchildren and be taken care of up until they die.* <http://www.news24.com/SouthAfrica/News/Old-age-homes-are-for-whites-Mabuza-20140413>

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<sup>9</sup> Rand Aid, established in 1903 and now providing care for 1,800 people, is a good example of such organisations (see <http://www.randaid.co.za>).

The validity for this polarised and culturally deterministic set of claims about race and elder care is open to question. According to an African voluntary worker, interviewed as part of a larger study:

*The government does not want this type of home for elderly people. It says that in our culture elderly people are the responsibility of the community. They must be left in their houses and relatives and friends must look after them....But when we leave them at night criminals come in and not only rob them but also beat them up, rape them and in some instances, kill them (Protasia and Torkington, 2000:143).*

There are indications that residential LTC is becoming increasingly acceptable among black South Africans and that the number of Africans in residential care has increased.<sup>10</sup> According to Chabeli (2003:143):

*..the black community is inclined to adopt the Western culture where children take their elderly people to the nursing homes to live there permanently. They are relieved when an institution takes over the responsibility of the family.*

There is evidence that the racial composition of old age homes has as much to do with discrimination as it does with cultural preferences. For example, a national survey conducted in 1998 found that less than half of care homes admitted people from all racial groups, and over 45 per cent only admitted whites (Perold and Muller, 2000). A government white paper published in 1997 stipulated that the race composition of care homes should broadly reflect that of the older population as a whole. However, there is little sign of progress. A survey of Western Cape conducted in 2010 found that only four per cent of care home residents were African (Department of Social Development, 2010). The national Department for Social Development observed:

*All the homes said that their admission criteria were based on non-discrimination... the practice of many homes was very different.... A few homes had residents of different race groups, [but] this was a very small minority... In at least 10 homes there was a physical separation between white and black residents and there was evidence to show that the residents were not receiving the same quality and standard of service... Some homes that had only white residents indicated that when black families brought their relatives to see the place they never returned their applications (Department of Social Development, 2010:40-41).*

By contrast, more than half of care home staff were black and it was noted that: Different home language orientation and cultural habits were often blamed for misunderstandings and cultural conflicts in old age homes (Perold and Muller, 2000: 91).

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<sup>10</sup> Robust data are unavailable since the South African national census does not include people living in communal establishments, such as care homes.

The limited available data point to a wider set of concerns about the quality of services provided by care homes and the treatment of residents. Whilst there are over 400 care homes that are registered with official agencies, it is thought that there are also growing numbers of informal, unregistered care homes. According to a representative of the South African Human Rights Commission:

*We don't know precisely how many (unregulated homes) there are out there, but we know that people have a tendency of opening their houses and converting them into residential homes for older persons... In Pretoria there are about six places operating within a very small radius from one another and they are functioning without control... We are saying that these places need to be registered so they comply with standards. <https://www.health-e.org.za/2015/06/05/unregulated-old-age-homes-may-be-on-the-rise/>*

Additionally, state oversight of registered homes would appear to be very limited. For example, in its 2012-2015 Strategic Plan, the Department of Social Development reported that only 13 of 412 registered homes had been assessed for compliance with norms and standards (Department of Social Development, 2012).

It is likely that these unregulated care homes cater particularly to poorer social groups, such as older Africans, by charging lower rates. Even for regulated care homes, information about service quality is limited and often points to serious shortcomings. In a qualitative study of one of the few official care homes catering for Africans, the testimonies of residents were suggestive of poor quality care and potential elder abuse:

*I cannot stand noise. I feel like being alone, but oh! Sister, I am scared here. People do whatever they like in this place. They bang doors and we cannot have a peaceful night. As it is, we sit on chairs, go for meals and come back to the chairs until we go to sleep. (Chabeli, 2003).*

Poor quality residential care does not just affect older Africans. The testimonies cited above resemble those collected from white residents in a separate study of a care home in Gauteng (Roos and Malan, 2012):

*It was at a grave like this where my loneliness and life alone started.  
Confidentiality is non-existing, it's non-existing, because before we know something, they know it. Time, there is too much time on your hands . . . you can't do anything . . . there is nothing to do . . .*

Similarly, a study of a mixed white and Indian care home in Durban found that only 17 per cent of residents reported that they trusted the nursing staff (Chipps and Jarvis, 2016).

A national survey of 405 regulated homes in 2010 found that only a quarter of staff knew about official norms and standards for LTC (Department of Social Development, 2010; Makgoba, 2017). Most homes reported that they did not feel suitably equipped for residents with complex care needs such as dementia. Over a fifth of care homes never had access to a trained nurse. There were indications of poor conditions for care home staff, including low

pay and a lack of managerial support (Department of Social Development, 2010). On the other hand, most care homes included in the survey appeared to comply with more formal regulatory requirements, including a limit of four people per room and the production of individual social and physical care plans for residents. Whether these plans were followed was less evident (Department of Social Development, 2010).

These accounts of poor care quality and resident abuse are echoed in numerous media reports. Despite these widely-acknowledged concerns, most regulated care homes were reported to have long waiting lists for admission (Department of Social Development, 2010).

Separately from nursing homes and residential facilities, since the 1980s South Africa has seen the private development of large numbers of housing projects specifically designed for the needs of older people. These are known locally as “retirement villages” and have mainly provided for the white population (Ferreira, no date). According to one study:

*At the height of these developments there were developers that exploited the situation causing several unknowing elderly to lose their money or make bad investment decisions as the elderly were easy targets. The elderly invested in retirement villages development schemes, and the developers took their money and vanished overnight (Burger and Vertongen, 2013: 116).*

### **Box 3 "No Guns: 94+ silent death and still coming"**

In February 2017 the Office of the Health Ombudsman published a report with the above title. It refers to a high profile political scandal relating to the transfer of 1,371 people with mental health problems from a reputable care home to a network of state-subsidised NGOs in Gauteng Province. It later came to light that conditions in the NGO homes were so poor that they had contributed to at least 94 deaths among the transferred population. The report concluded that the deaths had been unlawful and that the transfer of patients had been a “precipitate and disastrous” cost-cutting exercise, noting that: “Newly-established NGOs were mysteriously and poorly-selected, poorly prepared, ‘not ready’, their staff was not trained” (Makgoba, 2017:2). It highlights the case of a 61 year-old patient who died with: “a wound to the head, blisters around the ankles...”. His family were only allowed to visit him on the veranda of the care home and were told that he had died on unspecified natural causes”. The Ombudsman was able to systematically review 38 of the 94 deaths, of whom 15 were aged 60 or over and 15 were diagnosed with dementia.

Despite these concerns, a survey of residents in four villages found that residents strongly preferred living there to being in institutional care settings. Retirement villages offer some specialist services for dependent older people and are required by law to make provision for residents when they become frail. That said, there is evidence that some villages do not accept new residents who are care dependent and those residents who later become dependent are expected to move out (Burger and Vertongen, 2013).

There are indirect indications that many long term care needs, particularly of more affluent older people, are met by paid carers at home, rather than in an institutional setting. South Africa has strong traditions of paid domestic service, especially by Africans for whites (Fish, 2006). It has been estimated that there are nearly three million paid carer workers in South

Africa, almost all of whom are women. Reduced state support for residential care and population ageing may be leading to:

*Task-shifting upwards, doing more nursing-type care of elderly employees, though with no accreditation or extra reward (Lund and Budlender, 2009: 25).*

There is a considerable presence of private elder care agencies advertising on the internet, but there is no systematic data about the scale of this sector or the quality of care it provides.

In recognition of the costs of paid care at home, the Department of Social Development offers a “Grant-in-Aid” benefit to older people who “require regular care”. Eligibility requires a medical report or assessment report (less than three months old) that shows the applicant needs full-time care. In theory, medical eligibility for the grant should be reviewed every year. In 2012 68,000 benefits worth around £17 a month were being paid out, at a total cost of £14 million. In its Strategic Plan for 2012-15, the Department observed that there was a need to generate greater awareness of these grants (Department of Social Development, 2012). Progress seems to have been made: in 2016 the number of benefits being awarded had risen to 152,000. However, the geographical distribution of the benefits remains uneven. In 2015 18 per cent of South Africans aged 70 or over lived in the province of Kwazulu Natal, but the province accounted for 33 per cent of Grant-in-Aid benefits.

The prominent role of NGOs as residential care providers is also seen in community level provision. Many operate within a body called “Age in Action”, which claims to represent over 1,200 member organisations and has over 30 offices. Its members include care homes and community care providers. Age in Action has close links with the national Ministry of Social Development which provides a substantial part of its funding. Community level services include training for family carers and running day centres, and it is claimed that they reach around 150,000 older people. In rural areas this includes supporting a state-funded scheme of care support workers, who are paid around £150 a month to run outreach programmes for older people in their communities and refer vulnerable cases to government social workers. It would appear that this scheme is quite extensive, with several paid carers in each village, but little information is publicly available and there has been no independent evaluation.

### **3.1.3 Family care-giving for older people in South Africa.**

There is a large body of research and policy focus on the role of older people, particularly women, as carers for adult children who are ill with HIV/AIDS or their surviving grandchildren (Ardington et al., 2010; Kimuna and Makiwane, 2007). This is often framed in terms of a somewhat stylised narrative of heroic grandmother caring for vulnerable children within skip generation households (HelpAge International, 2005). It has been estimated that South Africa contained as many as 1.2 million AIDS orphans in 2005, and that up to 40 per cent of these children lived with their grandparents (HelpAge International, 2003; UNAIDS, 2006). This suggests that a very high proportion of older people, especially Africans who have been worst-hit by the epidemic, have been left with the sole responsibility for raising young children.



While there is some truth in this representation, it also needs some qualification. First, it should be noted that in many cases these grandmothers are aged in their 40s or 50s and are therefore better described as middle aged than in later life. Second, the prevalence of skip-generation households has increased with HIV/AIDS, but this was already a common household structure among rural Africans, as children migrating to cities would leave their children behind with grandparents (Merli and Palloni, 2006). This historically-established grand-parenting role is likely to continue in South Africa, despite reductions in AIDS-related mortality due to the roll out of ARV drug therapies. Third, some studies do not distinguish between the role of older men and older women, although there is evidence that men's care role is less substantial (Schatz and Seeley, 2015).

Some studies highlight the burden of care by grandmothers, in terms of physical and emotional health, as well as financially (Schatz, 2007; Schatz and Gilbert, 2014). However, there is a tendency to frame family relations in broadly altruistic terms which does not coincide with wider evidence of prevalent domestic violence. For example, it is widely observed that older people share pensions with household members and some commentators claim that this enhances the social status of the older person within the household, potentially increasing their authority to call on care from other household members (Barrientos and Lloyd-Sherlock, 2002). Yet there are growing indications that pension sharing is not always consensual and in some cases amounts to financial abuse (Bigala and Ayiga, 2014).

Some studies report that older women voice expectations that they will go on to receive care from children or grandchildren in return for the support they themselves provided (Schatz and Seeley, 2015). However, published research on family care for older people is extremely scarce in comparison to studies of older carers. One important exception is (Nyirenda et al., 2015) who conducted a survey of 422 people aged 50 and over in households in rural Kwazulu Natal where a member was either living with or had recently died of HIV/AIDS. Of these 104 respondents were aged 70 or more. Table 4.5 presents selected results from the study. These emphasise the high level of inter-dependency in households, with most respondents reporting that they both gave and received care from other family members. Predictably rates of care receipt increase with age. There is also a clear sex effect, with older women more likely to be care-givers. Given the specific nature of this sample and survey design, these findings may not be representative of all South African households containing older people. For example, it is conceivable that the care-giving role of older people will be less prominent in households unaffected by HIV/AIDS. They do, however, provide useful evidence of the complex and gendered nature of household care dynamics. The high proportion of people aged 70 or more who are care-givers may reflect the role of older women caring for spouses.

**Table 0-5 Proportion of older people giving and/or receiving care, households affected by HIV/AIDS, rural Kwazulu Natal**

		Neither (%)	Care-giver only (%)	Care-receiver only (%)	Both (%)
<b>Sex</b>	Male	13.2	2.8	44.3	39.6`
	Female	7.3	7.9	22.8	62.0
<b>Age</b>	50-59	11.7	11.7	22.3	54.3
	60-69	8.6	4.7	26.6	60.2
	70+	3.8	0	40.6	55.7

Source: Nyirenda et al (2015)

The old age grant is seen as a means to support LTC by increasing status of older people in households (and reduce financial burden of care). The value of the old age grant is marginally higher for people aged 70 and over (US\$112 instead of US\$110). Notionally, this small additional amount might be considered a contribution towards the care needs of people at very old ages. However, analysis of associations between receipt of the old age grant and enhanced family status of older people is inconclusive (Lloyd-Sherlock et al., 2012). At the same time, there is a growing body of evidence that older South Africans are exposed to high levels of violence and abuse in domestic settings, including financial exploitation by family members (Bigala and Ayiga, 2014; Burman, 1996; Lloyd-Sherlock et al., 2016). Chabeli (2003) observes that it is not uncommon for family members to lock older people in the home when they go to work.

### **3.2 Policy, legislation and debate in South Africa.**

There is evidence of a growing level of policy engagement and debate relating to long-term care, although this remains strongly focussed on care homes and formal services for richer sections of the older population. A number of legal frameworks for overseeing care quality have been enacted, the most recent and significant of which is the South African Older Persons Act, 2006 ([http://www.justice.gov.za/legislation/acts/2006-013\\_olderpersons.pdf](http://www.justice.gov.za/legislation/acts/2006-013_olderpersons.pdf)). This Act provides a regulatory framework for the care of older people One key objectives of the Act is to shift the emphasis from institutional care to community-based care, in order to ensure that an older people remains at home as long as possible. Another is to regulate the registration, establishment and management of residential facilities and other services for older persons.

However, several aspects of the Act have been criticised (Malherbe, 2007). First, the Act mainly focusses on residential services, which as seen above, are mainly provided to white South Africans. Family and community care account for less than three pages of the Act, residential care receive five pages. The Act states that the state should only be responsible for indigent, frail older people who lack relatives to care for them. The assumption would seem to be that almost all Africans do have family support. The Act stipulates that information, education and counselling should be provided to family carers, but does not set out specific responsibilities or delivery mechanisms.

Second, the Act does not include specific enforcement mechanisms to ensure the quality of residential and non-residential LTC. As part of this, some objectives appear to be unrealistic. For example, the Act stipulates that older residents be afforded privacy, but this contradicts the generally accepted practice that homes can contain up to four people in a dormitory. With reference to the racial discrimination in care homes admission discussed above, the Act stipulates that no person may unfairly discriminate against an older person applying for admission to a residential facility on the grounds referred to in Section 9 (3) of the Constitution.

In 2010 an influential report was published by the South African Human Rights Commission (South African Human Rights Commission (SAHRC), 2010). The report observed that residential care was under-funded, facilities were often in a poor condition and that few complied with official norms and standards. The state monthly subsidy of £100 per resident was viewed as woefully inadequate to cover care costs, leading to under-staffing, dangerous buildings and poor quality care provision. The report also observed that: Retirement villages are ripping off older persons and are a law unto themselves. (SAHRC, 2010: no page number).

The report provided a number of recommendations, including:

- The National Department of Social Development must ensure that all funded residential care facilities are registered by end of 2015 and the new ones are registered by the end of 2016.
- The Department of Health must within eight months from date of receipt of the report, consider a strategy for the supervision of care for frail older persons in communities.

No information is available about responses to the report from either the Department of Health or the Department of Social Development. The recent scandal of care home deaths in Gauteng Province has received a very high profile in the national and international media, and has led to a ministerial resignation. The Ombudsman report calls for more effective vetting and regulation of care providers, although reporting of the issue refers exclusively to people with mental illness and disability, and makes no direct reference to services for older people. The extent to which the current political storm leads to a substantial and sustained policy response remains to be seen, although it is likely that relationships between government agencies and subsidised NGO service providers will be reassessed.

### **3.3 Discussion**

In South Africa, long-term care competes against many other pressing policy priorities, which are often related to the lasting effects of Apartheid and the heavy impact of HIV/AIDS. While older people are well-provided for in terms of pensions, their wider needs, including both health and care, are largely neglected. There is a continued tendency for both researchers and policy-makers to view older people as agents of family welfare, rather than as people with their own vulnerabilities and care needs.

Some progress has been made in shifting the emphasis of state funding from supporting care homes (which mainly cater for richer whites) to community-based caring, such as the provision of carer benefits. At the same time, NGOs, most notably the Age in Action network, are playing a growing role in supporting poorer African family carers. It is, however, evident that the capacity of the state to regulate formal services and to support informal ones is extremely limited. It is likely that the private for-profit sector will become increasingly prominent in future decades, offering services of highly uneven quality.

Inequalities in the LTC system are best understood with reference to inter-sectionalities of race and gender. Despite the efforts of government, many aspects of the system continue to reflect principles of Apartheid, in terms of service segregation, discrimination against Africans and the privileging of older whites. Information about the paid LTC workforce is scarce, but it would appear to be overwhelmingly female and African. Strongly gendered norms of family obligation frame informal care-giving, whereby older women face a high burden of responsibility, a high level of care need and more limited access to family support. It is to be hoped that the racial legacies of Apartheid will diminish over time, as a result of focussed public policies, such as affirmative action. There is less evidence that gender disparities will be reduced: indeed, as demand for LTC rises, these are more likely to increase.

## **4. Long-term care in Argentina: a new challenge for the welfare state**

### **4.1 National context**

As in South Africa, Argentina's historical experience has had lasting legacies for the challenges of providing LTC to older people. In the first half of the 20<sup>th</sup> Century Argentina was by some distance the most prosperous country in Latin America. Since then, the country's economic performance has been less consistent, interspersed with frequent economic shocks.

One key legacy of the past economic boom was the large number of European immigrants who settled in Argentina, with people of European descent vastly out-numbering the indigenous population. Another legacy was that Argentina was able to establish a well-resourced set of welfare programmes. In 1904 Argentina became the first Latin American country to adopt a national social insurance programme, when a compulsory retirement fund was established for government workers (Lewis and Lloyd-Sherlock, 2009). Over the following decades separate schemes were set up for other influential occupations, including railwaymen and bank workers. By 1954 about two thirds of the economically active population were enrolled in pension schemes. Over the same time, Argentina achieved embracing primary and secondary education for both boys and girls, providing for an increasingly urban population.

The legacies of Argentina's indifferent economic performance since the 1950s have been more complex. First, the country struggled to sustain the generous welfare entitlements that had previously been established. Massive pension fund deficits contributed to periodic fiscal crises and little progress was made in extending coverage to rural workers or people in the informal sector of the labour force (IMF, 2004). Economic instability was often paralleled by political instability, both in terms of regimes and policy orientation. This led to concerns about the weakness of political and state institutions in Argentina, and growing awareness of problems of poor governance and corruption.

Argentina's historical experience has had lasting effects on gender relations and inequality. Referring to the typology established by Esping-Andersen, its welfare system has been characterised as conservative-informal (Barrientos et al., 2004; Esping-Andersen, 1990). Among other things, this viewed the family (essentially women) as the mainstay of welfare provision, with the state providing a subsidiary role (Faur and Jelin, n.d.). However, this model came under increasing strain, as larger numbers of women started to enter paid work, and family structures became increasingly complex (due to, among other things, a rapid increase in rates of divorce and separation (ECLAC, 2013)). Also, not all parts of Argentina or sections of Argentine society had shared in the benefits of the country's relative affluence. Populations in more peripheral parts of the country remained largely rural and impoverished. Nationally, a growing share of the labour force struggled to find secure employment in the formal sector and were consequently denied access to contributory pension schemes and health insurance.

During the past decade, Argentine governments have attempted to reorient social policies including, from 2005, establishing a de facto universal pension for all citizens aged 65 and over, as well as extending older people's entitlements to health insurance. This has led to mounting perceptions of inter-generational inequality. As in South Africa, secure livelihood opportunities for younger generations are increasingly scarce. By contrast, older people are seen as benefitting from both generous social policies today and better economic opportunities during their working years. These perceptions of inter-generational injustice can have important consequences for how society responds to the care needs of frail and vulnerable older people.

#### **4.1.1 Demand for LTC in Argentina.**

Prosperity in the early 20<sup>th</sup> Century led to falling fertility rates and increased life expectancy. As a result, Argentina experienced demographic transition considerably earlier than most other LMICs and has a high rate of population ageing. Table 5.1 shows that the proportion of population aged 70 or more in 2015 (7.4 per cent) was more than double South Africa's. Reflecting the country's historical development, there are large regional variations in Argentina's demographic profile. For example, the 2012 national census shows that 15.7 per cent of the population of Buenos Aires city were aged 65 or more, compared to just 6.9 per cent in the relatively poor northern province of Salta.

**Table 0-1 Population estimates and medium variant projections by sex (1000 people)**

	2015	2025	2040
<b>Males aged 70+</b>	1 217	1 573	2 237
<b>Females aged 70+</b>	2 104	2 509	3 355
<b>Total aged 70+</b>	3 231	4 082	5 592
<b>Total 70+ (% of total population)</b>	7.4	8.6	10.6

Source: UN Population Division 2016.

Table 5.2 presents different indicators of dependency and functional status for older Argentines. Gender differences stand out as particularly significant, with women aged 75 and over reporting around double the rate of dependency reported by men in the same age group. This may, in part, be an age effect, since women aged 75 and over live on average longer than men and therefore the median age for a woman in this age group will be higher than for a man. It is likely that gender still has an effect independently of age, a pattern that is seen in most other countries (Zimmer et al., 2003). Table 5.2 also shows a sharp age gradient in the prevalence of dependency, indicating that demand for care will rise in line with the growing proportion of Argentines at very old ages. Overall, over a fifth (20.7 per cent) of Argentines aged 75 or more had difficulty with ADLs, representing around 412,000 people in 2015. This group would require relatively intensive care support. A further fifth had difficulties with IADLs, requiring less intensive support.

**Table 0-2 Various indicators of dependency and functional status (per cent of age/sex group)**

	<b>Difficulty with activities of daily living (ADLs)*</b>	<b>Difficulty with instrumental activities of daily living (IADLs)**</b>	<b>Do not regularly get out of the house</b>
<b>Women 60-74</b>	6.0	16.1	6.2
<b>Women 75+</b>	25.2	48.8	19.2
<b>Men 60-74</b>	3.5	11.5	6.0
<b>Men 75+</b>	13.2	28.1	10.8

\* ADLs refer to basic self-care tasks, such as feeding, dressing and bathing. This broadly approximates the self-care indicator used for South Africa.

\*\* IADLs refer to a set of basic daily activities such as shopping, preparing food and housework.

Source: INDEC (2012).

Table 5.3 presents data on the composition of households containing older people. The proportion of older Argentines living alone or in single person households rises with age for both men and women. Section 1 discussed the dangers of presuming simple relationships between living arrangements and inter-generational support. Nonetheless, Table 3 suggests that people at older ages have less potential access to family support, despite their growing levels of dependency. The proportion of older women living alone is around double that of older men. This is largely due to the increased chance of being widowed for women, due to both their greater longevity and a tendency to marry men who are older than they are. Men aged 75 or more are roughly twice as likely to live in an older person household (in the vast

majority of cases as an older couple) than are women. In other words, older men are much more likely to be living with a spouse (and potential carer) than are older women. That said, around a fifth of men aged 75 or more live alone, partly as a result of a rising divorce rate.

**Table 0-3 Living arrangements (per cent of age/sex group)**

	<b>Alone</b>	<b>Older household</b>	<b>Multi-generation household</b>
<b>Women 60-74</b>	19.6	30.6	49.8
<b>Women 75+</b>	40.2	21.8	38.0
<b>Men 60-74</b>	11.2	33.0	55.7
<b>Men 75+</b>	20.3	41.9	37.8

Source: INDEC (2012).

**4.1.2 Organised long-term care services in Argentina.**

Until recently, LTC provision was almost entirely limited to a small number of publicly funded or charitable care homes for destitute older people (Redondo and Lloyd-Sherlock, 2010). Over the past decade, there has been a rapid extension and diversification of LTC services (Gascón and Redondo, 2015). These have included notable increases in the number of residential care facilities, mainly run on a private for-profit basis. For example, in 2010 Argentina’s Union of Gerontological Service Providers estimated that the country contained 6,000 residential care homes for older people.<sup>11</sup> The 2010 national census recorded 86,441 people living in residential care facilities for older people, of whom 70.3 per cent were women.

There has also been an extension of other kinds of LTC services. These include day care centres, again mostly on a private for-profit basis. Several programmes have been established to train geriatric nurses and professional home carers. These are run by a variety of state, charitable and private sector agencies, as part of a national programme which claims to have trained around 45,000 carers by 2015.<sup>12</sup> State agencies have rolled out new schemes of cash benefits for older people with care needs, as well as interventions to support family carers.

At the same time there has been a diversification in the range of actors and agencies involved in LTC services. These include national legislation and protocols, mainly set out by the Ministry of Health and the Ministry of Social Development. Beyond this, government engagement with LTC is largely decentralised and cuts across different agencies. The 2005 Federal “Geriatrico Law” stipulates that provincial governments should take lead responsibility for the regulation of LTC services, including the development of their own specific institutional arrangements and quality standards. Municipal and provincial health ministries provide “mainstream” geriatric health services. In some cases, these represent

<sup>11</sup> <http://www.taringa.net/posts/info/6916249/Cuatro-de-cada-diez-geriatricos-de-Buenos-Aires-son-truchos.html>  
<sup>12</sup> <http://www.desarrollosocial.gob.ar/noticias/los-adultos-mayores-bien-cuidados/>

default LTC provision, when older people are admitted to hospital and do not have suitable arrangements for discharge from hospital. Local health ministries also have an overall responsibility for regulating residential care providers. Separately from this, municipal and provincial social development ministries are also responsible for regulating LTC service quality and some run schemes for training paid home carers.

Social health insurance funds form a prominent part of the health sector in Argentina, with a large number of different funds for different occupation groups (Belló and Becerril-Montekio, 2011). Since 2012, social insurance coverage has become, at least in theory, universal for people aged 65 and over. These schemes were originally established as health funds and retain their focus on health services. However, they also finance a range of LTC services. The most important of these funds is PAMI (*el Plan de Asistencia Médica Integral*), which has specific responsibilities for health and social care services for Argentines aged 60 and over. This includes covering the cost of residential care in certified homes (of which there were 566 in 2015) and financial support for certified day care centres (including transport costs for older people with mobility problems). There are, however, long waiting lists for PAMI certified care homes and many on these lists die before admission.

PAMI and other health insurance funds also offer cash support to cover the cost of home care. In the case of PAMI these payments are widely available, but worth only £43 a month, representing only a small fraction of actual home care costs in most cases. PAMI also offers larger payments for older people with complex care needs, but the numbers they awarded are very limited. In 2010 a newspaper exposé revealed widespread corrupt contracting between a health insurance fund and private firms providing hospital at home services.<sup>13</sup> In May 2016, PAMI's new national director admitted that the organisation was highly corrupt, including making home care payments for hundreds of people who were no longer alive.<sup>14</sup> This is in keeping with PAMI's long history and reputation for poor governance (Lloyd-Sherlock, 2003).

Private, for-profit providers are highly diverse and play an increasingly prominent role, particularly in residential care. They range from informal, unregulated "boarding house" care homes with untrained staff, to luxury nursing homes which claim to have a full range of therapeutic services. In 2016 prices ranged from around £400 a month for the former to over £2,100 for the most expensive. Typically, this did not include the cost of items like incontinence pads or other medical supplies. Various private sector companies specialise in providing trained geriatric nurses and carers for home care and for running more intensive hospital at home services. Charitable, religious organisations have a small, but historically established role running residential facilities, usually co-funded by state agencies.

In 2015, the National Secretariat of Children, Adolescents and the Family of the Ministry of Social Development set out a minimum set of standards that should be reached by all residential LTC facilities. These include guiding principles, such as respect for residents'

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<sup>13</sup> [http://www.latecla.info/4/nota.php?nota\\_id=43320](http://www.latecla.info/4/nota.php?nota_id=43320) see also <http://www.lanacion.com.ar/1860028-denuncian-que-ioma-paga-por-unos-9000-servicios-fantasma>.

<sup>14</sup> <https://estodolocontrario.wordpress.com/2016/05/04/en-el-pami-revendian-medicamentos-y-se-encontraron-sillas-de-ruedas-nuevas-abandonadas/>.



dignity, privacy and (as far as possible independence). Similar principles have been set out in legislation enacted by most provinces. Data about the extent to which residential LTC facilities reach these standards are available from a national survey of 1,803 residential homes conducted by the national ministry of social development in 2013/4 (Roqué et al., 2015).

Table 5.4 presents selected findings from the national survey which show that significant numbers of care homes were falling well short of acceptable standards both in terms of facilities and treatment of residents. Few care homes contained individual rooms for residents: they accounted for less than 10 per cent of all rooms. The most common arrangement was double rooms, and rooms for three people or more were common than single ones. This calls into question the capacity of almost all homes to respect residents' privacy. Table 4 indicates that many homes took little account of residents' independence and dignity. In nearly half the homes surveyed, residents were not permitted to personalise their rooms. Residents' rights to go outside the care home were often curtailed and 13 per cent of homes permitted no variation in (and hence resident influence over) daily routines.

The proportion of care homes residents who were care dependent was surprisingly low. Paradoxically, a fifth of homes refused to admit older people with care needs and a third contained at least 40 per cent of residents with no care needs. This calls into question the main purpose of these care homes. Although the majority of residents were not significantly cognitively impaired, only 17 per cent of homes required their informal consent for admission. In 62 per cent of cases permission from a relative was sufficient. As discussed later in this section, these findings are not unrelated. Older people, especially widowed women, are often coercively admitted into care homes, regardless of their needs, by family members seeking to take control of their homes.

The national survey of care homes reveals a pattern of problems which in some cases goes beyond shortcomings of quality: there are grounds for concern that fundamental aspects of residents' human rights are being denied. The report's authors note that the findings are likely to have a positive bias, since the participation of care homes in the survey was entirely voluntary. This raises concerns about conditions in the homes that declined to participate. Additionally, the survey has a number of limitations. Data were mainly derived from pre-arranged visits and interviews with care home directors, rather than from unannounced visits and interviews with other staff, residents or residents' families. This may have added to the positive bias of its findings.

Table 0-4 Selected findings from national survey of residential LTC facilities (2013/14)

Item	Percent of care homes surveyed
<b>Building and facilities</b>	
Dirty appearance and unpleasant smelling	11
Some bedrooms lacking windows	17
No smoke detectors	45
Unsatisfactorily heated	24
Inadequate conditions of building	31
Problematic noise levels	61
No games available for residents	31
<b>Admission and treatment of residents</b>	
Only admit older people who are not care dependent	20
Require consent of older person for admission	17
Contain no residents with moderate/severe cognitive impairment	11
Fewer than 40% of residents with moderate/severe cognitive impairment	47
Fewer than 60% of residents with any level of care dependency	36
Residents not permitted to personalise bedrooms	43
Unsatisfactory appearance of residents (cleanliness, clothing, etc.).	16
No flexibility in daily routine (eating, bathing, bed)	13
Residents not permitted to go outside unattended	44
Residents not permitted to go outside	10

Source: Roqué et al (2016).

#### 4.1.3 Family long-term care in Argentina.

Tables 5.5 and 5.6 provide information about the main provider of care for older Argentines reporting difficulties with ADLs and IADLs. These data need to be interpreted with some caution. First, they are premised on an assumption that older people receive the care they need. As such they do not include a response category for older people who get care from nobody. Second, they do not indicate the amount or form of support that the “main carer” provides. While support needs for ADLs tends to be more demanding than support for IADLs, it should not be assumed that the response of carers is proportionate. Third, the data do not specify which relative provides the support, including whether or not they live with the older person. Fourth the data are taken from the national census which excludes people in residential care settings.

Despite these important limitations, some tentative observations can be made from the data in Tables 5.5 and 5.6. First, it can be seen that the vast majority of home carers for older people are either relatives or untrained paid carers. Overall, trained carers make up only 3.5 per cent of the main carers for people aged 60 or more with difficulty performing ADLs. Men aged 75 and over with ADL needs are more likely to be cared for by a relative (presumably a spouse) than is the case for women, who are more likely to be helped by an untrained paid carer. The survey does not include data on the sex of the carer, but there is evidence from other studies that the large majority are women. For example, an unsystematic survey of 200 family carers reported that only two were male (Arroyo Rueda, 2016).

**Table 0-5 Main provider of care for ADLs (per cent of age/sex group)**

	Relative	Friend/neighbour	Untrained paid carer	Trained paid carer	Other
<b>Women 60-74</b>	80.6	8.9	8.1	1.7	0.7
<b>Women 75+</b>	69.5	4.7	18.9	4.6	2.3
<b>Men 60-74</b>	95.8	3.1	0.8	0.3	0.0
<b>Men 75+</b>	83.0	4.0	6.5	5.1	1.5

Source: INDEC (2012).

**Table 0-6 Main provider of care for IADLs (per cent of age/sex group)**

	Relative	Friend/neighbour	Untrained paid carer	Trained paid carer	Other
<b>Women 60-74</b>	80.7	2.8	16.2	0.2	0.1
<b>Women 75+</b>	73.8	3.7	20.1	2.3	0.1
<b>Men 60-74</b>	86.5	4.2	8.0	0.7	0.6
<b>Men 75+</b>	77.9	3.8	15.6	2.6	0.1

Source: INDEC (2012).

Unlike South Africa, there is a growing body of academic research on dementia in Argentina, including a number of studies that focus on family care. Although there are not robust, nationally-representative data for the prevalence of dementia in Argentina, a number surveys estimate that cognitive impairment affects between 23 and 26 per cent of people age 60 or more (Arizaga et al., 2014; Bartoloni et al., 2014). Estimates of dementia itself range around 8 per cent of people 60 and over. If these findings are nationally representative, they are equivalent to around 530,000 million Argentines with dementia in 2015.

A survey of 100 older people with dementia in Buenos Aires found that over 40 per cent of primary care-givers who had previously been in paid work had either stopped or reduced this paid work (Allegrí et al., 2007). Over three-quarters of primary carers were female and the average amount of care they provided each week ranged from 24 hours for mild cases to 44 hours for more severe forms of dementia. Whilst severe cases were more likely to receive

support from a paid carer, in 60 per cent of these cases the main carer was still a family member. The same survey reported high levels of stress, ill health and depression among carers, particularly for more severe cases of dementia. It was estimated that the average annual direct cost for a family caring for an older person with dementia was US\$3,189, but this rose to US\$8,130 when the time provided by the primary carer was also considered. Costs were substantially higher for more severe cases. The findings of this study are broadly in keeping with a separate study of dementia care-givers in the city of Rosario, which reported that 74 per cent of primary carers were female, and that the average amount of care provided per week was 64 hours (Elnasseh et al., 2016). This second survey also reported that carers had on average been performing this role for around four years and that levels of care-giver stress were very high. A third study reports that care-giver stress and burden in cases of dementia were substantially higher than for caring for older people with conditions such as depression (Machnicki et al., 2009). Taken together, these studies demonstrate the rapidly growing impact of dementia care, particularly on women, in Argentina. It is likely that caring for older people with other complex needs (such as advanced Parkinson's Disease) has a similar effect. Given the evident stress experienced by family carers, it is likely that the quality of care received by highly dependent older people is not always satisfactory, but there are no data on this.

There is evidence that wider support for family dementia carers was limited. The national survey of care homes showed that only a small proportion of residents were cognitively impaired (Table 4). The Ministry of Health's mental health services (which traditionally treated people with dementia) have been pared down, as part of a wider policy of returning inpatients to the community. State-funded services for people with dementia mainly consist of falling number of non-specialist beds in general wards, with high rates of bed-blocking.

#### Box 4 The burden of dementia care

Mrs X is aged 54 and lives in Buenos Aires. Her mother has been suffering with Alzheimer's disease for the past 18 years. For the first five of those years, her mother was able to remain living in her own home, with daily support from Mrs X. She then spent three years living in Mrs X's own home: "It was very hard for us. My children were teenagers and still living with me, and it got to the point where even with medication we couldn't get her to sleep at night... I was hospitalised twice.... The doctors told me it was down to stress and the huge emotional burden I felt". Her mother was then admitted into a residential facility: "It was hard for me to accept, really hard. She would say to me: please take me home. I promise I'll behave well.... For the first three months, I kept on saying I would bring her back home, but everyone would say 'You'll go crazy. It'll kill you'....It's a psychological burden to see how she has deteriorated, and the things I see there –how the girls who work there abuse the residents, how the owner does it too, and it makes me feel guilty."

Mrs X currently pays £1,250 a month for the care home, of which £500 is covered by her mother's pension. They have insurance from PAMI, but this only covers the costs of incontinence pads and food supplements. Despite the high cost of the care home, Mrs X still provides much of the care herself. Her mother suffers from bedsores, which Mrs X and her sister treat for her, because the staff do not know how to. "I go there every morning... I give her breakfast and a glass of water. I stay for about three and a half hours. I pay someone else to do the same for her in the afternoons". She is despairing of the poor conditions in the care home, but feels there is nothing she can do to improve the situation. "The government doesn't regulate them... It's a joke. They know they will be getting inspected on the 12 of November at 9 in the morning and so the care home is suddenly clean, toilet paper in all the bathrooms. And when I try to make official complaints to the municipality, it's useless and I worry they'll take it out on my mother".

At first sight, Mrs X might be considered one of the "lucky few" who have been able to find a residential facility that is prepared to admit a person with dementia and who is able to afford their high prices. Despite that, it is evident that she faces a high burden of care and that her mother's situation is far from ideal.

#### 4.2 Regulation and the quality of LTC: a case study of La Plata city.

Given the complexity of Argentina's LTC system and the variation of practice across local governments, it is helpful to explore the experience of a single location in greater detail. La Plata is a medium-sized city of 650,000 people (70,000 aged 60 or more), 35 miles south of Buenos Aires. It is relatively prosperous by national standards and is the capital city of

Buenos Aires Province.<sup>15</sup> The case study is based on document review, interviews with local stakeholders and key informants, focus groups with pensioners' clubs and a "secret shopper" survey of care homes conducted by local older people.<sup>16</sup>

La Plata contains 63 residential care facilities, of which only two are directly run by state agencies, the remainder operating on a private for-profit basis. The case study findings confirm and add depth to the problems reported by the national survey. There were particular concerns about older peoples' consent for admission. Several key informants referred to cases in which younger relatives had coerced older people to go into residential care, both to reduce their own care responsibilities and to take control of the older person's home. According to one:

*We had the case of a woman who is diabetic and obese and was living in her own house with a carer quite happily, until her grandson got married. The girlfriend got pregnant and what did the family decide to do? Go and live at grandma's house... shove her into a care home and don't even go for her at the weekend... One day, the grandson came to me and said "I'm taking grandma away from this home. I'm taking her somewhere else, because this place is always bothering me". He was bothered that we phoned him now and again! [she was taken to another home]... "She cried every day because she just wanted to go to her old home, but he just took her to another care home. That was back in March. She died a few days ago, because she'd gone into a grim place, locked up. At least here [previous care home] the air was fresh, she had companions, she drank tea... In that other place, I can't imagine what conditions they kept her in....*

A number of contextual factors contribute to the coercive admission of older people into care homes. As in most of Latin America, Argentine inheritance law is based on the Napoleonic legal code, whereby the properties of the deceased are transferred directly to their children, not their surviving spouse. In a case where an elderly couple jointly own their home, the surviving partner only retains ownership of half. The surviving partner is not guaranteed continued usufruct of the property and, if the children insist, will be required to sell it. Additionally, once the older person is admitted to a care home, or if they are certified as legally incompetent, then the children obtain full control of the property. This legal system places surviving spouses, most of whom are female widows, in a highly vulnerable position. At the same time, more limited economic opportunities for younger generations in Argentina restrict their ability to obtain housing of their own, which may increase pressure to wrest control of accommodation from older relatives. As one key informant put it:

*These days, people don't even view this practice as abusive. The problem is that it is completely legal... The older person doesn't see it as an infringement of their rights. They just see it as a natural part of being old. The situation has come to be seen as normal. You get old, the children need a place of their own, so you just sell your house and go into a care home.*

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<sup>15</sup> According to the 2010 national census, 2.2 per cent of households in La Plata had unsatisfied basic needs, compared to 12 per cent in the country as a whole and 25 per cent in the poor northern province of Formosa.

<sup>16</sup> Full details of the study design and preliminary findings are available in Lloyd-Sherlock, et al (2017).

There was unanimity across all survey participants that the quality of many care homes in La Plata was very poor. Comments included:

*Most of these houses are very old and run down, miserable and dark. The people working there have no training and look after maybe 10 or 12 older people as best they can.*

*I've worked as a nurse in several care homes. The way they treat the residents is awful... They're always full, so at three in morning they start to get the residents up, take them to the toilet and bathe them.... I used to hear people say "I'll just give you a little pill so that you'll leave me in peace, OK? ... They used to know when relatives were due to visit... "We need to get grandma ready for when they get here", clean, tidy, in nice clothes, so the relative comes and hey presto happy grandma!*

*There isn't even any interaction [with residents]. Many times I've seen that in the process of transferring someone from a wheelchair to a bed the carer doesn't ask "Would you like to get up now?" "Would you like something to eat or drink"... Nothing..... When you go inside it's very [tails off]. It really upset me at first.*

The secret shopper survey included 30 of La Plata's care homes and in several cases provided clear indications of the inappropriate use of restraints and psychotropic medication to sedate residents.

One reason for the poor quality of care offered by many care homes in La Plata was limited regulation by state agencies. In theory, facilities should be subjected to periodic visits from local government multi-disciplinary teams of at least eight professionals, and they should comply with a long list of regulations and standards. The provincial and municipal ministries of health focussed almost exclusively focussed on physical aspects of care homes, such as fire exits and smoke alarms, but paid no attention to issues such as the number or type of staff, the use of restraints and sedative medication or the general conduct and respect of older people's rights. The respective ministries of social development were responsible for overseeing quality and responding to complaints. For both, resources were extremely limited and there were evident problems of governance. A change of provincial government in early 2016 had led to a virtual suspension of these services. To receive payments from health insurance funds such as PAMI, residential facilities had to be certified by them. In La Plata, several had obtained PAMI certification, but this did not include a requirement that any care-workers have specialist training. PAMI had the authority to temporarily suspend payments to care homes with serious and unresolved quality issues, but applied this sanction extremely sparingly.

There was evidence that the quality and regulation of other LTC services, such as paid home carers was also problematic. For example, home carers paid by PAMI were not required to submit proof of their qualifications or experience. Comments about paid home carers included:

*We've extended our training programme very quickly to meet the demand, so that we don't get to know the trainees as well as we used to. And we are now starting to get reports of theft... Our carers are stealing jewellery and other items.*

*Some people who go on those courses think they're going to be some kind of luxury nurse who will make house calls. Then they discover the great physical and psychological effort needed to clean an older person, toilet and wash them, and that it is an unpleasant job.*

*The first time they called me to their house, when I saw the old lady I nearly fainted. I was there to cut her hair, cut her finger and toenails... The old lady wouldn't let anyone touch her, not even the girl who was looking after her, who was meant to be a home care specialist... Oh, when I saw her feet I wanted to die! Between the toes which had not been cleaned properly for some time, there was a sort of brown shell. So with tweezers, cotton wool and cream I cleaned her feet. Then I called over to the carer and asked "Who's supposed to be bathing this lady"?*

The quality of LTC services in any setting is strongly affected by the extent to which these services are effectively integrated into more mainstream health provision for older people. Whilst the general health service infrastructure in La Plata was relatively well developed by Argentine standards, there were clear gaps in provision for older people. One key informant from a local hospital observed that health clinics almost entirely focussed on conditions such as mother and child health, and that nurses had little if any training in geriatric conditions. The main form of engagement with older people was through regular visits made by PAMI geriatric nurses to pensioner clubs. These provided a range of useful services, including checking blood pressure and offering health promotion advice. Whilst this represented a valuable service, PAMI itself estimated that only 17 per cent of its affiliates actively participated in these clubs. It is likely that rates of participation for older people with more limited mobility (and hence greater need of LTC) were considerably lower. Outside the pensioner clubs, access to health services covered by PAMI was limited and often required travel to central La Plata or Buenos Aires city.

### **4.3 Policy, legislation and debate in Argentina.**

As in most other LMICs, long-term care has been a low priority for policy-makers in Argentina, relative to other aspects of social policy. In part, this both explains and results from the decentralised structure of responsibility to local government agencies and parastatal health insurance funds. This policy neglect is mirrored in a limited public profile for the issue, with little media coverage or wider social or political debate. There are no significant civil society organisations equivalent to South Africa's Age in Action which have a specific interest in this issue. Older people's organisations primarily focus on pension entitlements and largely serve as patronage conduits for state agencies. Human rights organisations have not engaged with social care.



Despite this general neglect, there has been some recent progress in updating and strengthening legislation relating to old age homes. This legislation operates at the provincial level and each province has its own legal requirements. The more prosperous provinces, such as Buenos Aires city, have developed more ambitious laws and have more resources to enforce them.

In Buenos Aires city new legislation was enacted in 2016 with the support of all the main political parties. This legislation takes as its reference point the International Convention on the Rights of Older People of which Argentina is a signatory. The law has some positive elements, particularly its recognition that long-term care quality is related to human rights. Among numerous provisions are specific guidelines on use of restraints, including a requirement for judicial permission which must be renewed every seven days. The law requires routine inspections of all care homes and that older people can only be admitted for clear medical reasons, with the approval of a doctor and informed consent where possible. The extent to which these progressive measures will be implemented is open to doubt. According to one key informant:

*“The laws are fine, but the state can’t be everywhere. The systems of protection are fine, but they don’t work as they should in practice.”*

Whilst the law sets out more clearly which local agencies should have the lead responsibility to oversee care services, this has not been accompanied by a substantial increase in funding which would permit these agencies to effectively carry out this role. Key informants note that the system of medical certification for admissions is far from perfect: many care homes are owned by doctors, creating an obvious conflict of interest. The law does not permit the state authorities to close down care homes that do not meet minimum standards. There are also concerns that care homes will relocate to the outskirts of Buenos Aires which are part of a different province with looser legal controls. This reflects the wider reality of Argentina: large geographical disparities in legal provision, state capacity to enforce standards and varied social care infrastructure.

#### **4.4 Discussion**

Argentina’s long-run experiences of economic, social and political change frame many of the LTC challenges it currently faces, as well as its responses. The country has a highly aged population structure, with a large level of demand for LTC provision. Efforts to meet this new need have built on a state welfare system that has come under increasing pressure to continue support of established social guarantees. State institutions suffer high levels of fragmentation and, at times, problems of corruption and poor governance. In the absence of state intervention, a largely unregulated private sector has rapidly developed. Overall, the complexity of the LTC system in terms of different services, providers, funders and contracts appeared to create particular opportunities for institutional failure.

Despite what appears to be a wide array of services, it is evident that the large majority of care-giving is provided by family members and that these carers are disproportionately female. External support of family carers through cash benefits has expanded, but remains

very limited in relation to the actual direct and indirect costs of care-giving. As LTC has become increasingly privatised, it is likely that access to services will be particularly limited for poorer families. At the same time, many of the health and social care services offered by health insurance schemes such as PAMI require substantial co-payments and families often face substantial delays in receiving reimbursement.

The critical challenge for Argentina is to promote an informed national debate on LTC which is framed by concepts of gender justice and human rights. There is little evidence of this debate emerging. There is also a need to develop a more coordinated and effective state apparatus to regulate the quality of care provided by private agencies. The scale of this challenge may require a more fundamental overhaul of social policies in Argentina and a reformulation of an increasingly frayed social contract between the state and its citizenship.

## **5. Conclusions and policy recommendations**

The experiences of Argentina and South Africa fit into the general pattern of LTC in LMICs set out in Section 3 of this report. Both countries are seeing a rapid increase in demand for LTC services, limited state intervention, unregulated provision, heavy burdens of care on women and the widespread abuse of older people. At the same time, the LTC challenges facing each country have unique features, which are linked to longer-run development trajectories. In South Africa, the legacies of Apartheid continue to exert a very strong effect on the provision of and access to LTC services. In Argentina, there are also inequalities, but these mainly relate to socio-economic status and geographical location. In both countries, state organisations give a low priority to LTC, are highly fragmented and lack capacity to oversee services. There are also indications that state agencies are affected by problems of poor governance and corruption. On a more positive note, both countries have established programmes of financial support and training for family carers. These schemes remain limited both in terms of coverage and the value of payments, but they represent a potential platform on which more extensive interventions might be based.

The main response to unmet care needs has been a rapid emergence of the private sector, including a plethora of for-profit and, especially in South Africa, not-for-profit agencies. In both countries, although governments do acknowledge their overall responsibility for acceptable standards of care, they play very limited roles as direct service providers. This reflects both a desire to reduce the potential fiscal burden of LTC and the dominant paradigm of public service management which views sub-contacted provision as a panacea. In Argentina and South Africa the problems of this fragmented, decentralised approach are becoming increasingly apparent, but there appears to be little appetite for the state to play a more prominent role in the LTC sector. The growing presence of private providers represents a powerful interest group which is likely to resist more rigorous state intervention. As such, there are few indications that problems of substandard care, neglect and the abuse of many older people in care homes are likely to recede. Widespread human rights violations are facilitated by a convenient “conspiracy of silence”, whereby state agencies turn a blind eye to provider shortcomings and society continues to view LTC as a private matter rather than a public concern.

The current experience of LTC in countries like Argentina and South Africa has specific effects on women. First, women account for a disproportionate share of people who survive to very old ages and who are in need of care. Since women tend to outlive spouses, they are less likely to live with a potential family carer. Furthermore, gendered cultural norms of care-giving tend to restrict the role many men are prepared to play as family carers (World Health Organization, 2015). Additionally, gendered expectations mean that older women with care needs may still face demands to continue their support of other family members, both financially and in terms of domestic tasks. As seen in Argentina, older widows may be especially vulnerable to exploitation by relatives, including coercive admission into care homes.

At the same time, it is evident that women account for the large majority of the paid and unpaid care workforce. In the case of unpaid family carers, there is strong evidence that this role represents a substantial burden for many women, even when they undertake it willingly. This burden is qualitatively different to that exacted by more “traditional” forms of unpaid labour, such as childcare or housework, particularly when the older person has complex care needs. While there has been a growing number of initiatives to support and complement family caring in different ways, it is evident that the vast majority of family carers receive little, if any, external support. As such, the growing demand for LTC may mean that the window of opportunity for female empowerment that opened as a consequence of fertility decline is starting to close. At the same time, it is evident that more affluent women are able to purchase domestic care services from women in lower socio-economic strata. Consequently, the exploitative nature of family care is being felt most keenly by women who are already disadvantaged. The growth of paid care work may in some limited sense represent a new opportunity for women to participate in the salaried labour force. That said, it is evident that conditions and pay remain very poor and that paid caring remains a low status activity, with little training or professional accreditation.

One of the main challenges related to LTC is a need to reconcile the rights of both care-dependent older people and the rights of those people who provide the care. This links to wider issues around gender and inter-generational justice. There is an urgent need to develop ethical and socially acceptable policy frameworks that avoid framing LTC as an inevitable zero-sum trade-off between these two constituencies. This requires new contributions from feminist and moral philosophy, among other disciplines. A general insight emerging from the two country case studies is that informal and market mechanisms are not well-placed to reduce this trade-off. The capacity of states to operate as direct service providers is very limited. However, unless states play a significant role in regulating and managing LTC systems, trade-offs between carer-givers and dependent older adults are likely to be acute.

Linked to this moral dilemma is the fundamental question of who is paying the “real cost” of LTC: how are contributions or preventable suffering distributed across society? A key message is that LTC always has a cost for someone. Table 6.1 provides a simplified, highly stylised summary of how these costs are likely to be allocated according to different models of LTC provision. It demonstrates that the third combined model offers the most equitable

resolution. In the case of Argentina and South Africa, models one and two remain predominant.

The primary recommendation of this report is that across LMICs there is an urgent and evident need for informed public debate about how the dilemmas of LTC should best be tackled. Such debate is necessary to generate political constituency for more concerted state action and is also needed to guide the direction of state action. To date, LTC remains a highly neglected issue. Few influential state agencies or civil society organisations view LTC as a priority concern. Media portrayals of the issue are limited and often ill-informed and do not frame the issue in terms of human rights.

**Table 0-1 The distribution of the "real cost" of the LTC in three different provision models**

Model	Fiscal cost	Private cost	Cost for family care-givers	Cost for those in need of care
<b>i. Cheap, unregulated care homes</b>	<i>Limited direct cost:</i> subsidies for care home (although real cost will be higher due to unnecessary hospitalisations).	<i>Limited cost:</i> payment of care homes.	<i>Low cost:</i> as older people not cared for in community.	<i>Very high cost:</i> abuse, neglect, etc.
<b>ii. Family care without external support</b>	<i>Low cost:</i> although indirect costs of unnecessary hospitalisations of cared-for and of illness of carers.	<i>Potentially high costs:</i> such as paying for private domestic carers.	<i>Very high cost:</i> very large burden of care for family carers.	<i>Variable cost:</i> depending on quality of care received from family.
<b>iii. A combined model of provision with emphasis on external support for family carers</b>	<i>Moderate cost:</i> mainly providing support services and limited residential care for those in most need (eg severe dementia). Major savings in health spending and potentially fiscal boost from higher female productivity.	<i>Moderate cost:</i> contributing to cost of state provision.	<i>Moderate cost:</i> burden of care remains high, but mitigated by external support.	<i>Low to moderate cost:</i> depending on quality of care received from family and external providers. Quality is likely to be somewhat better when family carers are offered support.

More specific recommendations are that:

(i) LMICs should develop campaigns to increase awareness of quality and conditions in care facilities. This should be done to hold providers to account, raise standards and to empower service users. Most obviously, care homes should be subject to rigorous repeated inspections and the findings of these inspections should be made publicly available as far as is possible. The agencies responsible for inspections should themselves be accountable and independent.

(ii) National campaigns should be launched to raise public awareness of LTC issues. This could cover a range of issues ranging from understanding conditions such as dementia to recognising the rights of care-dependent older people and the contributions made by unpaid carers. As part of this, new

networks of civil society organisations, including human rights organisations, women's organisations and older people's organisations should develop strategic alliances to support these campaigns.

(iii) LTC service provision should be much more strongly focussed on supporting family carers, especially the carers of older people with challenging conditions like dementia. For too many families, care remains an "all or nothing" choice between unsupported home care or fully residential care. Currently, most interventions to support family carers are small-scale and receive limited resources. Such interventions should be rapidly-scaled-up, and viewed as a central plank of a reconfigured welfare system. Examples include: respite care, education and support groups for carers, payments for family carers and flexible employment contracts to allow workers to balance care and paid employment commitments.

(iv) LTC service provision should maximise integration with mainstream health care. Local primary health workers should play a pivotal role, linking between health services, social services and the families of dependent older people. Currently, primary health workers in most LMICs remain strongly focussed on other issues, such as mother and child health. There is an urgent need to modify their training and their function in line with the new reality of the communities they serve. This should include monitoring the health and wellbeing of both frail, dependent individuals and of those family members who care for them.

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