

Impact case study (REF3)

Institution: University of East Anglia		
Unit of Assessment: 22 – Anthropology and Development Studies		
Title of case study: Putting long-term care in low and middle income countries on the global policy agenda		
Period when the underpinning research was undertaken: 2001 – December 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Peter Lloyd-Sherlock	Professor	1999 - to present
Period when the claimed impact occurred: August 2013 to December 2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>UEA research was the first to demonstrate that long-term care (LTC) for older people is no longer just a priority for rich countries. UEA research has led to the identification of LTC as a new global development issue by the World Health Organisation and other influential agencies post 2014.</p> <p>As well as catalysing this new policy agenda, UEA research substantively shaped it, both globally and nationally, and has generated specific downstream impacts. For example, UEA's finding that LTC is emerging as a leading driver of gender injustice has influenced agencies such as UN Women to address the issue for the first time. The same insights informed interventions in Brazil to support female care-givers, and these have been positively evaluated and extended.</p> <p>Similarly, pioneering UEA research insights about the rapid expansion of weakly regulated care homes in low and middle-income countries (LMICs) and widespread abuses of residents' human rights has promoted a rights-based approach by global agencies and prompted new civil society interventions in Argentina. These have improved care home accountability and reduced residents' potential exposure to abuse. They have enabled new strategies in Mexico and other countries to limit care homes' vulnerability to the COVID-19 pandemic.</p>		
2. Underpinning research		
<p>Long-term care (LTC) refers to support needed by older persons with limited ability to care for themselves due to chronic physical or mental health conditions. It can be provided by families, but also includes interventions by state, private sector and not-for-profit organisations. In 2015, 61% of people aged 70+ (238 million people) lived in low and middle-income countries (LMICs): this population experiences a high prevalence of disability and care dependency.</p> <p>UEA research led by Prof Peter Lloyd-Sherlock has led the way in identifying the scale and rapid emergence of this new policy challenge. It included, in 2001, the first academic publication on LTC in LMICs [R1]. As part of a comparative analysis of social policy in Argentina, Thailand and South Africa, it found LTC to be a fast-growing issue. Most older people were cared for at home and overwhelmingly by female workforces of unpaid carers. However, non-family provision was expanding quickly. For example, in 2010 Argentina's Union of Gerontological Service Providers claimed the country contained 6,000 care homes.</p> <p>Building on this finding, UEA research showed these 3 case studies reflected the experiences of other LMICs and revealed specific areas of concern [R2]. Lloyd-Sherlock found substantive differences between LTC policies in most high-income countries (HICs) and those in most LMICs. HIC governments usually offer a broad range of services with a focus on supporting care in family and community settings. By contrast, LMIC government intervention is almost entirely restricted to funding small numbers of care homes, reflecting an assumption that family care-giving requires no external support [R2]. This had led to growing numbers of unregulated, informal care homes and a lack of support for growing numbers of unpaid female family carers. As a result, LTC</p>		

systems in most LMICs essentially offer an “all or nothing” choice between unsupported family care and unregulated private provision.

Problems of care home regulation and their effects on the quality of care.

UEA research demonstrated the limited capacity of state agencies in different LMICs to regulate care homes [R5, R6]. Regulatory responsibility is split between different government agencies (typically health and social welfare), operating locally and without coordination. Care standards are based on HIC best practice, which are unrealistic in resource-constrained settings and hardly, if ever, enforced. For example, care homes usually have multiple room occupancy (typically more than 5 people) which contravenes official requirements. Government agencies have minimal engagement with providers, many of which are unregistered and effectively invisible to the authorities. UEA research found this reduced accountability between providers and service users, enabling elder abuse and infractions of residents’ human rights [R5, R6]. Lloyd-Sherlock applied a range of innovative methodologies, including ethical, covert research by local older women, in Argentina to reveal care home practices in more depth. This confirmed the abuse of residents’ human rights, including coercive admission, deprivation of liberty and over-crowding [R5, Grant D].

These findings indicated the potential vulnerability of care homes in LMICs to crises such as COVID-19 and the need for specific strategies. COVID-19 policies applied in HICs require adaptation for settings where regulation is absent, resources are limited and multiple room occupancy the norm. Based on these findings and with rapid stakeholder collaboration, UEA led the development of an original emergency strategy: the Coordinate, Identify, Assess and Target (CIAT) Framework. This guides priorities, including closer coordination between agencies, strategies to locate and engage with unregulated care homes, and targeted interventions based on assessed needs. This activity has been supported by an ongoing GCRF/Newton Agile COVID-19 Fund award (Grant A).

Unsupported and unpaid family carers.

In collaboration with researchers in Mexico, Peru, China and Nigeria, as well as King’s College London, UEA research examined family caring for highly-dependent older people. This linked quantitative epidemiological analysis to nested in-depth qualitative case studies [Grant C]. The project found a lack of external support for family carers and that caring was associated with opportunity costs, such as foregone paid employment and education. Processes of family negotiation over care roles were found to be complex and strongly framed by gender norms, and by power dynamics; both between men and women, but also between different women. The role of “primary carer” was often appropriated by more powerful family members who would delegate daily care work to less powerful ones [R3]. Carers had little knowledge about the specific demands of elder care and received no support from local health or social welfare agencies. This increased their vulnerability, as well as that of the cared-for older people.

Informed by these insights, UEA research explored interventions to address the vulnerabilities of family carers and older people. This included an MRC-funded study of a novel intervention based on UEA research in Brazil [R4, Grant B]. This trains and pays a basic wage to women from poor neighbourhoods to support family carers and liaise with local health agencies. The intervention was found to reduce carer stress, enhance quality of life for older people and reduce the unnecessary use of health services. It was demonstrated to be a feasible intervention of high potential value to other cities across Brazil.

3. References to the research

- [R1] Formal social protection and older people in developing countries: three different approaches
P. Lloyd-Sherlock
Journal of Social Policy, **2002**, 31 (4), pp.695-713. DOI: 10.1017/S0047279402006803
- [R2] Living longer. Ageing, development and social protection: Older people and the care economy
P. Lloyd-Sherlock. *Zed Books*, **2004**. ISBN: 1842773577, 9781842773574

- [R3] Allocating family responsibilities for dependent older people in Mexico and Peru
P. Lloyd-Sherlock, R. Mayston, A. Acosta, S. Gallardo, M. Guerra, A. Sosa, V. Montes de Oca and M. Prince. *Journal of Development Studies*, **2017**, 54(4): 682-701.
 DOI: 10.1080/00220388.2017.1308489
- [R4] Belo Horizonte's pioneering community care programme for older people
P. Lloyd-Sherlock, K. Giacomini. Corona Older Global Platform, **2020**,
corona-older.com/2020/11/24/belo-horizontes-pioneering-community-care-programme-for-older-people/
- [R5] Evaluating the quality of long-term care services in the city of La Plata, Argentina
P. Lloyd-Sherlock, **B. Penhale** and N. Redondo. *Ageing and Society*, **2019**, 1-23.
 DOI:10.1017/S0144686X1900103X
- [R6] An emergency strategy for managing COVID-19 in long-term care facilities in low and middle-income countries: the CIAT Framework (Version 2*)
P. Lloyd-Sherlock, K. Gaicomini, M. Duarte, M. Frank, N. Redondo, **L. Sempe**, L. Geffen, G. Kelly, V. Montes de Oca, M. Vivaldo, A. Ocejro Rojo, S. Sasat. Corona Older Global Platform, **2020**, corona-older.com/2020/11/24/an-emergency-strategy-for-managing-covid-19-in-long-term-care-facilities-in-low-and-middle-income-countries-the-ciat-framework-version-2/

Grants and other funding sources:

- A. **Project: Emergency strategies for mitigating the effects of Covid-19 in care homes in low and middle-income countries.** P. Lloyd-Sherlock.
 Funder: EPSRC, GCRF/Newton Agile COVID-19 Fund.
 Amount: GBP250,961.79. Dates: 2020-2022
- B. **Project: Improving the effectiveness and efficiency of Health and social care services for vulnerable Older Brazilians.** P. Lloyd-Sherlock.
 Funder: Medical Research Council.
 Amount: GBP197,436. Dates: 2018-21
- C. **Project: The economic and social effects of care dependence in later life.** (PIs) P. Lloyd-Sherlock (UEA) M. Prince (King's College London)
 Funder: ESRC.
 Amount: GBP407,334 (UEA GBP24,059.73). Dates: 2011-14
- D. **Project: Evaluating and replicating local accountability platforms for residential care homes and social care services.** P. Lloyd-Sherlock.
 Funder: UKRI.
 Amount: GBP47,221. Dates: 2020-21

4. Details of the impact

Prompting WHO and other UN agencies to engage with LTC as a priority issue.

UEA research was instrumental in WHO's pioneering prioritisation of Long-Term Care (LTC) as a global development issue. It also influenced other agencies to engage with LTC for the first time. In 2020, it had specific impact on global agencies' responses to COVID-19.

According to the former Director of the WHO Department of Ageing and Life Course (2010-2018): "Peter's [Lloyd-Sherlock] research demonstrated to me that these were no longer just issues of importance to relatively affluent countries, but had become a global concern and that WHO should play a leading role in shaping this new agenda" [S1]. This led WHO to devote a substantial chapter on LTC in its flagship 2015 World Report on Ageing and Health for which Lloyd-Sherlock was the core author [S2]. This was the first report by any global agency to present LTC as a global challenge and states: "In the 21st century, no country can afford not to have a comprehensive system of long-term care... In low- and middle-income countries, the challenge may be to build a system where one does not already exist." [S2]. The report emphasises (i) a rapid increase in LTC demand in LMICs [R1, R2], (ii) important implications for gender justice [R3], and (iii) an urgent need for policies to support unpaid family carers and to strengthen regulation of private services [R2, R3, R5, S2].

The 2015 Report shaped subsequent WHO activities relating to older people. According to the former Director of the WHO Department of Ageing and Life Course:

“The World Report on Ageing and Health has been highly influential and has stimulated government action globally and has gone on to shape WHO’s ongoing activities in this area, including our Global Strategy and Action Plan on Ageing and Health” [S1].

One of the 5 Strategic Objectives for WHO’s Global Strategy for Older People is: *“Developing sustainable and equitable systems for providing long-term care”* (including home, communities and institutions), and including *“freeing women to pursue what they value”* [R3; S3]. This was followed by the recognition of LTC as a global priority for the WHO’s Decade of Action on Healthy Ageing (DAHA), ratified by the World Health Assembly in 2020. The 2020 Launch Document reiterates every country should have a LTC system, adding: *“Current approaches to providing LTC rely heavily on informal care –predominantly families and notably women, who may not have the necessary training or support...”* [R1, R2, R3; S4]. The DAHA was ratified by the United Nations General Assembly in 2020, which commits all UN agencies to support global LTC policies under WHO leadership.

UEA research on LTC has influenced other UN agencies. For example, it led to UN Women highlighting the global importance of LTC for the first time in its flagship report, *“Progress of the world’s women 2019–2020: Families in a changing world”* [S5a]. According to Chief of Research and Data at UN Women (2013-2020):

“Peter’s work brought to my attention for the first time the wide range of social development challenges being posed by population ageing in low and middle-income countries (LMICs)... [and] enabled UN Women to develop a more nuanced appreciation about gender justice and care... the need to avoid an all or nothing choice between unsupported family care and poor quality nursing homes through the development of new interventions to support unpaid carers... All of these issues featured prominently in UN Women’s 2019 flagship report and have continued to influence the organisation’s own thinking... I believe this has prompted an overdue process of reframing global policy discourse about these issues.” [S5b]

In the context of the COVID-19 pandemic, UEA research influenced WHO’s Technical Guidance for Managing COVID-19 in care homes which is expected to be followed by all UN member states [S6]. Lloyd-Sherlock was on the scientific expert committee for the first version of the Guidance published in March 2020. The Guidance drew on UEA research to consider specific LMIC issues, such as a lack of space for case isolation and a need for enhanced regulatory coordination. Lloyd-Sherlock was an external peer reviewer for the revised Technical Guidance which was launched in January 2021. This draws on UEA research, referring to a need for *“a mechanism to support unregulated providers”* and to other elements of the CIAT Framework.

Influencing and supporting care home regulation by government and civil society.

Specific local and national impacts have been achieved in Argentina, drawing on UEA’s in-depth research in that country. These impacts have started to inform actions in other countries, including Mexico [S8], a process accelerated by the COVID-19 pandemic.

UEA research led to the inclusion of several novel elements in a revised Argentina Ministry of Health regulatory protocol. For example, it is the first such protocol in any LMIC to address coercive care home admission as a potential deprivation of liberty [S10a]

UEA insights about the limited capacity of governments to regulate care homes prompted the development of a pioneering new civil society intervention. A public meeting disseminating UEA research in the city of La Plata led to the establishment of a coalition of government agencies, NGOs, academics and care home operators. This coalition developed an interactive online platform providing information and feedback about the city’s regulated and unregulated care homes (Red Mayor La Plata). This site, the first of its kind in an LMIC, was receiving over 12,000 hits and over 50 messages each month by the end of its first year of operation. Messages include examples of abuse (to quote directly from one message): *“I found my mother lying naked on the floor, with nobody trying to help her.... They over-medicate the residents”* [S7]. These were followed up and led to official investigation of the providers in question [S10a]. In 2020, this

intervention won a UKRI Healthy Longevity Global Grand Challenge Award, which is providing funds and expert support to extend and scale up the intervention in other cities [Grant D].

Since the COVID-19 pandemic, policy-makers in LMICs have looked to improve regulation and engagement with care homes. A core element of the CIAT Framework [R6] is rapid mapping of all care homes (including previously unregistered ones) and realistic forms of engagement. This contributed to a decision by Buenos Aires Province to offer an informal amnesty to care homes not complying with less essential pre-COVID-19 standards in exchange for their cooperation during the pandemic [S10b].

The ongoing development of the CIAT Framework is both drawing on and feeding back into the practice of government agencies beyond Argentina. For example, the Director of Mexico City government's lead agency for care homes stated:

"...we consider the CIAT Framework... highly relevant to the challenging context of Mexico City... Many long-term care facilities are not registered with official agencies and so we took specific measures to update our registers and to include new service providers. This has enhanced our capacity to engage with different care homes, including those which operate more informally and which may be more vulnerable to the pandemic. The CIAT framework has also informed our strategy of monitoring the situation in these facilities, developing a more robust information base and in identifying different types of targeted interventions [such as more intensive surveillance and additional access to testing] based on the experiences of other cities in developing countries." [S8]

Influencing government policy and interventions to support family carers.

UEA research on family caring and gendered aspects of LTC has directly influenced government policy at the national and local levels. For example, since 2014 over 3,000 families in poor neighbourhoods of Belo Horizonte, Brazil have benefitted from an innovative care-support intervention, Programa Maior Cuidado (PMC – Older Person's Care Programme). PMC was established in 2011, in response to Brazil's first national report on LTC. This report, published by the leading federal government policy think-tank (IPEA) in 2010, extensively cites UEA research [R2] highlighting the gendered impacts of caring for older people and the need to support family care.

PMC families receive support from PMC trained carers (mainly women recruited from similar communities and paid a basic wage). These carers offer families respite from daily caring and help to develop their competencies in caring. UEA researchers conducted impact and process assessments of PMC, the publication of which was delayed by the COVID-19 pandemic. Preliminary results shared with government stakeholders influenced a decision in 2019 to convert this temporary project into a permanent one and to extend it across the city [S9]. Based on the UEA research, other local governments, including the cities of Fortaleza and Contagem, have been persuaded to initiate similar interventions, and the Federal Ministry of Health presents it as a model of good practice in national policy forums [S9].

5. Sources to corroborate the impact

[S1] Testimonial from Director of Department of Ageing and Life Course, WHO, 25.06.2019

[S2] WHO 2015 Report on Ageing and Health, p.127 – 147, accessed on 07.02.2021

[S3] WHO 2017 Global Strategy and Action Plan Ageing and Health, p.17, accessed on 07.02.2021.

[S4] WHO Decade of Healthy Ageing, p.14, accessed 07.02.2021

[S5] a. UN Women, Progress of the world's women 2019–2020

b. Testimonial from Chief of Research and Data, UN Women, 01.09.2020.

[S6] WHO COVID-19 Infection Prevention Guidance for Long-Term Care Facilities, 21.03.20

[S7] Confidential email from a visitor to the Red Mayor site, 04.09.2019

[S8] Testimonial from Director of Ministry of Social Inclusion, Mexico City, 07.12.2020

[S9] Testimonial from Brazil Federal Ministry of Health, 09.02.2020

[S10] a. Testimonial from President of Camara de Hogares, Argentina, 03.03.21

b. Argentina's Amnesty document, 21.05.20