



Towards a Long-Term Care System in Chile

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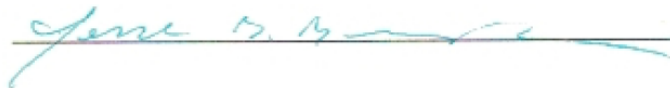
This DELTA Doctoral Project, TOWARDS A LONG-TERM CARE SYSTEM IN CHILE, presented by PABLO ANDRÉS VILLALOBOS DINTRANS, and Submitted to the Faculty of The Harvard T.H. Chan School of Public Health in Partial Fulfillment of the Requirements for the Degree of Doctor of Public Health, has been read and approved by:

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Jesse B. Bump

April 3, 2018

TOWARDS A LONG-TERM CARE SYSTEM IN CHILE

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A DELTA Doctoral Thesis Submitted to the Faculty of

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in Partial Fulfillment of the Requirements

for the Degree of *Doctor of Public Health*

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A mis padres y mi hija, Eloisa.

Que vivamos nuestras vidas felices y en plenitud.

Towards a Long-Term Care System in Chile

ABSTRACT

Chile is experiencing an unprecedented demographic change, which is reshaping the country and imposing tremendous challenges to its social security system. One of these challenges is related to the increase in long-term care (LTC) needs in the country, i.e. the rise in demand for services for people that require care and help to carry out every day activities, for an extended period of time. Considering this context, this DELTA project was developed in order to answer the question: how to implement a LTC system in the country?

The DELTA project was developed during July 2017 and February 2018 jointly with the Chilean Ministry of Health, and was focused on presenting the state of the art regarding LTC in the country and its future impact, discuss alternatives for designing LTC system in Chile, and advocating for a public policy response to the several challenges faced today and in the coming years. The activities included meetings and interviews with key stakeholders, literature review and analysis of international experiences on long-term care systems, and analysis of several data sources. The project involved professionals and authorities at the Chilean Ministry of Health and other public institutions, experts from international organizations, and politicians.

The study showed the existence of an increasing interest in the topic, but a poor level of information and consensus to push for bigger changes. Even though people acknowledge the importance of LTC and the increase in dependency prevalence in the country, initiatives remain small and isolated. The project contributed to starting the design of a LTC system in the country

by creating consensus within the Ministry of Health, as a required first step into planning a coordinated effort to deal with the issue. It also generated awareness of the importance of LTC and the need of a LTC system in the future, by synthesizing information on the topic and advocating among current and future government authorities.

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List of abbreviations and acronyms

AADL: Advanced Activities of Daily Living

ACA: Affordable Care Act, United States

ADL: Activities of Daily Living

APS: Primary Care, MINSAL (*Atención Primaria en Salud*)

AUGE/ GES: Explicit Guarantees in Health (*Plan de Acceso Universal a Garantías Explícitas en Salud / Régimen General de Garantías Explícitas en Salud*)

AWBZ: Exceptional Medical Expenses Act, Netherlands (*Algemene Wet Bijzondere Ziektekosten*)

BIPS: Integrated Registry of Social Programs, MIDESO (*Banco Integrado de Programas Sociales*)

CASEN: Socioeconomic Characterization Survey, MIDESO (*Encuesta de Caracterización Socioeconómica*)

CLASS: Community Living Assistance Services and Supports Act, United States

CLP\$: Chilean pesos

COMPIN: Preventive Medicine and Disability Committee (*Comisión de Medicina Preventiva e Invalidez*)

DEIS: Department of Statistics and Information in Health, MINSAL (*Departamento de Estadísticas e Información en Salud*)

DELTA: Doctoral Engagement in Leadership and Translation for Action

DIPLAS: Division of Health Planning, MINSAL (*División de Planificación Sanitaria*)

DRG: Diagnosis-Related Group

DrPH: Doctor of Public Health

DSC: Sociocultural Office of the Presidency, Chile (*Dirección Sociocultural de la Presidencia*)

ENCAVI: National Quality of Life Survey, MINSAL (*Encuesta Nacional de Calidad de Vida*)

ENS: National Health Survey, MINSAL (*Encuesta Nacional de Salud*)

EFAM: Elderly Functionality Exam, MINSAL (*Examen de Funcionalidad del Adulto Mayor*)

EMPAM: Preventive Exam for Elderly, MINSAL (*Examen de Medicina Preventiva en el Adulto Mayor*)

EPS: Social Protection Survey, SPS (*Encuesta de Protección Social*)

FONASA: National Health Fund, MINSAL (*Fondo Nacional de Salud*)

FONADIS: National Disability Fund, MIDESO (*Fondo Nacional de la Discapacidad*). See
SENADIS

GDP: Gross Domestic Product

IADB: Inter-American Development Bank

IADL: Instrumental Activities of Daily Living

ICD: International Classification of Diseases

ICF: International Classification of Functioning, Disability and Health

INE: National Institute of Statistics, Chile (*Instituto Nacional de Estadísticas*)

LTC: Long-Term Care

MIDESO: Ministry of Social Development, Chile (*Ministerio de Desarrollo Social*)

MINSAL: Ministry of Health, Chile (*Ministerio de Salud*)

MINTRAB: Ministry of Labor, Chile (*Ministerio del Trabajo y Previsión Social*)

MMSE: Mini-Mental State Examination

OCAI: Office for International Cooperation, MINSAL (*Oficina de Cooperación y Asuntos Internacionales*)

OECD: Organisation for Economic Co-operation and Development

OPS: See PAHO

PAHO: Pan American Health Organization

PFAQ: Pfeffer Functional Activities Questionnaire

PRAIS: Comprehensive Reparation and Healthcare Program (*Programa de Reparación y Atención Integral en Salud*)

REM: Monthly Statistical Summary, MINSAL (*Resúmenes Estadísticos Mensuales*.)

RSH: Social Registry of Households, MIDESO (*Registro Social de Hogares*)

SENADIS: National Disability Office, MIDESO (*Servicio Nacional de la Discapacidad*)

SENAMA: National Elderly Office, MIDESO (*Servicio Nacional del Adulto Mayor*)

SES: Socioeconomic Status

SNAC: National System for Care, MIDESO (*Sistema Nacional de Cuidados*)

SPS: Undersecretary of Social Welfare, MINTRAB (*Subsecretaría de Previsión Social*)

US\$: United States dollars

WHO: World Health Organization

WLZ: Long-term care insurance, Netherlands (*Wet Langdurige Zorg*)

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* People, sorry for the avoidable use of the proverbial “us”.

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You must write a thesis that you are able to write.

Umberto Eco

I. INTRODUCTION

Chile has been experiencing an important demographic transformation during the past decades, with population aging due to increases in the elderly and a decrease in young population (Lee 2003; 2011; Bongaarts 2009). As shown in Figure 1, the share of the population over 65 years will grow 4% per year during the next six years (2017-2023), with the share of people over 65 years going from 11% of the population to 20% in 20 years (by 2038). Additionally, population over 80 years will grow even faster (4.5% average for the next 20 years), comprising 5% of the total population in 2035. Estimates show that by 2100, 30% of the population will be over 65 years, and half of them will be older than 80 years old (CEPAL 2017).

These changes impose several challenges to the country, particularly to its social security system. Demographic transition requires thinking about how to fund people's pensions when they are living longer, adapting the health system to deal with a different burden of disease, and design new social policies for a different kind of society.

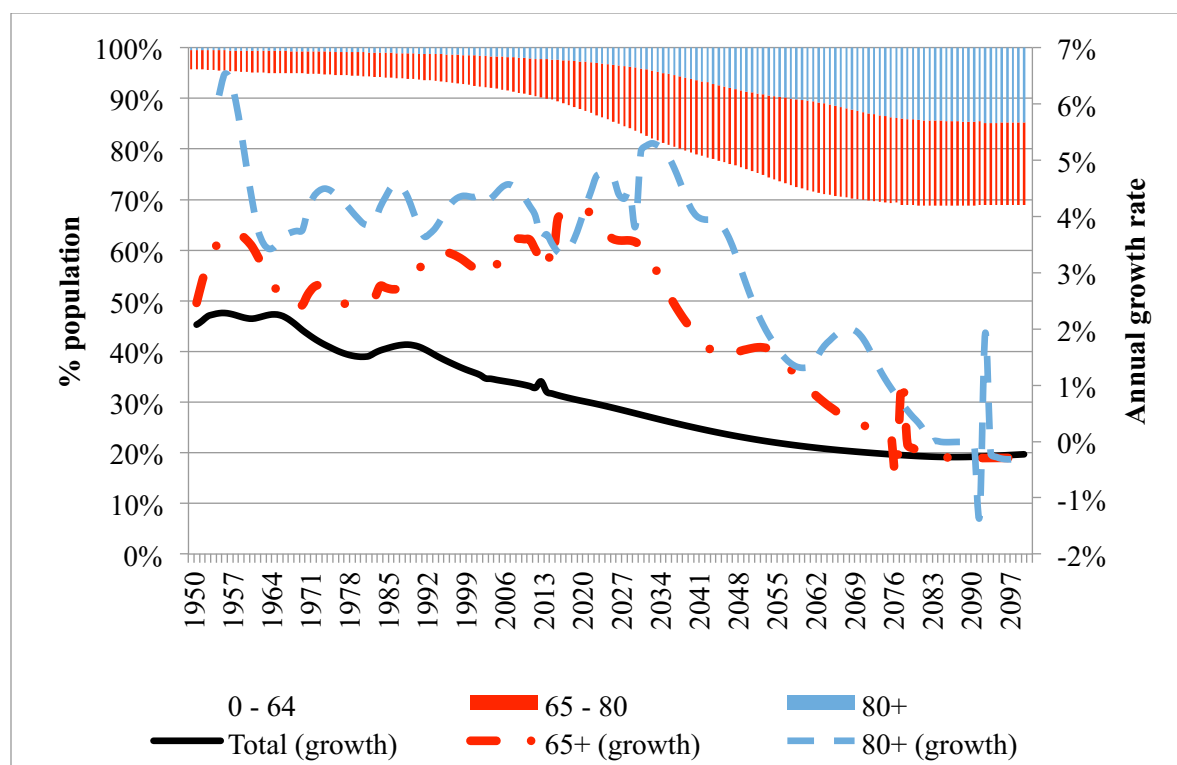


Figure 1. Population distribution and growth rate by age range, Chile (1950-2100)

Source: Author's elaboration based on CEPAL (2017).

One of the main issues experienced by countries in an advanced stage of the demographic transition is the emergence of long-term care (LTC) needs. According to the definition of the OECD and the European Commission (OECD/European Commission 2013), LTC is “a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL).” Similarly, the World Health Organization's Report on Aging and Health (WHO 2015) defines LTC as "activities undertaken by others to ensure that people with a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity." Even though LTC is not

constrained exclusively to the elderly population, it is closely related to aging (Manton and Stallard 1994; Freedman et al 2008; Carrera et al 2013); demographic change is expected to be the main factor driving change in LTC needs.

This is also true for Chile. Data shows that dependency –the concept usually used to measure long-term care needs– increases with age, becoming particularly important for people over 85 years (Figure 2). The figure also shows the relevance of taking into account mental health issues, because it impacts dependency directly, its burden of disease has been historically underestimated (Vigo et al 2016), and it is expected to triple in the next 35 years in the country (Gajardo and Monsalves 2013).

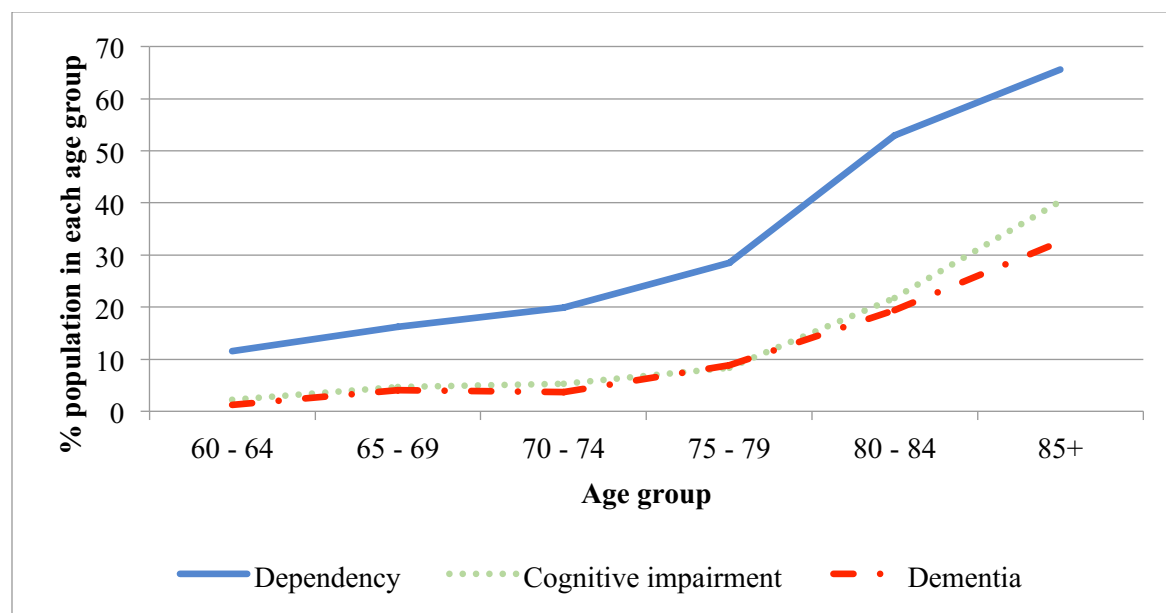


Figure 2. Age, mental health, and dependency, Chile (2009)

Source: Author's elaboration based on SENAMA (2010) and MINSAL (2015).

The issue of aging and long-term care is present in many countries around the world, and the way to tackle these many challenges is an ongoing debate (Swartz 2013; Norton 2016).

Countries have dealt with the challenges of aging in different ways; many countries have implemented LTC systems as a response to these demands.

As shown in Figure 3, Chile is still a relatively young country compared to other OECD countries, but it is aging very fast: in less than 15 years, the elderly population will represent almost 20% of the total population, similar to the figures exhibited by the Netherlands today.

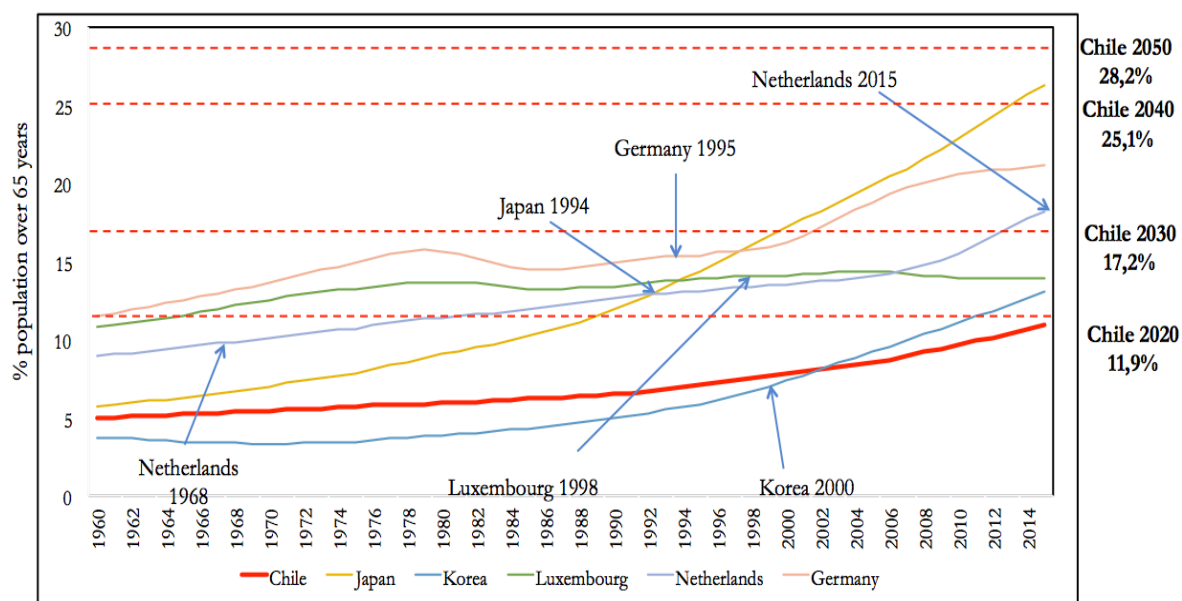


Figure 3. Population over 65 years (1960-2015) and implementation year of LTC systems in selected countries

Source: Author's elaboration based on OECD (2016) and CEPAL (2017).

This means that Chile will be facing soon similar issues to those lived by countries that started their demographic transitions some decades ago. The figure also exhibits that many countries put in place their LTC systems when the issue of aging and the problems derived from the increase in LTC needs was urgent; considering that designing and implementing these kinds of reforms takes time, Chile is facing this urgency today. The country needs to face this reality and start thinking about the challenges of aging and the provision of LTC services before it is too late.

This is the context in which this DELTA project was designed and developed. Several studies have pointed out the fact that the country is aging quickly and it is not prepared to deal with the challenges posed by this new stage (Thumala et al 2017; Villalobos 2017). The aim of the project is to build the pillars for the future design and implementation of a long-term care system in Chile. The primary research question is how to develop a strategy to adopt and then implement a long-term care system in the country. The project intends to generate consensus on basic definitions as well as increase awareness about the importance of LTC, in order to install it as the main axis for implementing health and social policies in the elderly and disabled population. Additionally, it will provide strategies to deal with the challenges of LTC in the country. The project was designed according to the Harvard DrPH guidelines for the DELTA Doctoral Project, intended to be an opportunity to practice and develop leadership skills while engaging in a project that contributes substantially to public health results (Harvard DrPH Program 2017), in an effort developed jointly with a host institution for an eight-month field-based experience.

The document describes the project, including its design, implementation, results and conclusions. After the Introduction, Chapter III (Analytical Platform) presents the problem and the strategy to address it. It includes the description of the problem, the project's goals and a theoretical framework underlying the whole project; it also presents the description of the

DELTA project, including activities, expected results, and timeline. Chapter IV (Results Statement) describe the implementation of the project, its findings and main results. It presents the main results coming from the project, including information collected about long-term care in Chile, proposals for the future, and changes generated within the Ministry of Health and other institutions. Finally, Chapter V (Conclusion) summarize the key learnings and discusses the project's implications.

II. ANALYTICAL PLATFORM

This chapter presents the context in which the DELTA project was designed and developed, putting emphasis in the problems identified and the main motivation behind trying to establish the fundamentals for a LTC system in Chile. It also explains the analytical framework in which the project was based and how it relates to the DELTA's goals, activities and expected results.

1. The overarching problem: Consequences of growing LTC needs

Demographic transition and aging are increasing long-term care (LTC) needs in a number of countries, including Chile. LTC has been highlighted as a crucial issue not only because of its effects on the elders' health but also because of its effects on the rest of society. The study of LTC has several characteristics that make it particularly interesting and different from traditional health care (Norton 2000; Brodsky and Clarfield 2008): first, LTC is related to chronic disease or disability care rather than acute disease treatment: its objective is not to cure, but to enable individuals to achieve and maintain the highest possible level of functionality; second, the market for nursing homes and care institutions is dominated by for-profit facilities that sometimes face an excess of demand while the hospital industry is dominated by non-profit facilities with oversupply of beds; third, LTC is often provided by unpaid caregivers, rather than professionals (paid caregivers); fourth, LTC private insurance is scarce, and public insurance is usually linked to income-related eligibility criteria and have large copayments; finally, the issue is important from a gender perspective since in most countries –including Chile– the burden of care is assumed by women, generating an inequity that reinforces gender roles already present in the society (Vaquiroy and Stiepovich 2010; Arriagada 2011; Colombo et al 2011; Hardy 2017).

LTC needs can be met through a formal care system or through informal care. Traditionally, formal care has been provided in nursing homes, whereas recently many countries have experimented with new ways of providing care, such as cash benefit delivery and counseling, and home care strategies (Colombo et al 2011; Swartz 2013; Norton 2016). On the other hand, informal care is often an unpaid activity, frequently provided by family members (Knapp and Somani 2008; Norton 2016).

In Chile, as in many other countries, LTC services have been traditionally provided by informal caregivers. This informal environment generates several problems. First, because care occurs within the home, it often remains invisible to the rest of society, including policymakers; since the issue is considered a private problem, information is not generated, which makes the designing of public policies to address it more difficult (Scheil-Adlung 2015). Second, although informal caregiving is an unpaid occupation, it generates economic impacts. Informal caregiving affects labor market decisions, which implies implicit transfers of resources: people who engage in this activity exhibit higher unemployment rates, work fewer hours in the formal labor market, and face a higher risk of poverty (Chang and White-Means 1995; Arno et al 1999; Knapp and Somani 2008; Colombo et al 2011; Norton 2000; 2016; WHO 2017a). Third, informal care is time-intensive: it requires a considerable time investment that not only prevents active participation in the labor market but also limits the time that caregivers devote to themselves and their social relationships. This fact, together with the physical and emotional burden of the care activities, has important health effects (Schultz and Martire 2004; Wolff and Kasper 2006; Murphy et al 2007; Colombo et al 2011), even increasing mortality (Schultz and Beach 1999). Fourth, informal care also affects the formal care market, as it can act as its substitute and complement (van Houtven and Norton 2004; Coe et al 2015; Norton 2016; EU 2016). Finally, in

this context of informality, the demographic transition increases demand and reduces the supply of LTC services, threatening their sustainability (WHO 2015; Norton 2016).

On the other hand, formal care also needs to be designed in order to provide a response to the LTC needs. In Chile, nursing homes have been the main way of providing formal long-term care. In this case, also several issues have to be considered. First, formal LTC coverage is scarce and the actual supply of nursing homes does not meet LTC needs across the country. Data from the National Elderly Office (SENAMA)* shows that currently, 19,608 people live in nursing homes, about 0.1% of the population over 65 in the country, and less than 5% of elders with some level of dependency. Second, there is a financial cost associated with the provision of these services in a formal context. Today there are two types of facilities in the country: for-profit and non-profit. More than 65% of nursing homes in the country are for profit, mostly concentrated in the Metropolitan Region, and almost 40% have a co-payment of more than CLP\$ 350,000 (roughly US\$ 650) per month, higher than the median income of workers employed in 2015 –CLP\$ 340.000– according to INE (2016). Some non-profit facilities also have copayments, which raises questions about how to design a LTC system that can not only provide care services but also provide financial protection to its beneficiaries (Spillman and Lubitz 2000; Brown and Finkelstein 2008; Brown et al 2012; Favreault et al 2015). The mix of for-profit and non-profit institutions is important, as the literature has found important effects –for example in terms of quality, utilization, and costs– of the role of management and ownership styles in the results of LTC systems (Carcagno and Kemper 1988; Norton 2000; Grabowski 2001; Chou 2002; Grabowski et al 2008). Third, a factor that must be considered regardless the type of institution (whether or not for profit) is quality. Measuring and implementing quality in LTC services

* <http://catastroeleam.senama.cl>

remains a challenge in many countries, even though it is one of the most important dimensions of the system (Castle and Ferguson 2010; Frijters et al 2013; OECD/European Commission 2013; Gascón and Redondo 2014; Donnelly and MacEntee 2016; WHO 2017a). Finally, there is also an emotional component attached to formal care, especially when the only option offered by the system is the institutionalization of the family members in a nursing home or a hospital. The decision to provide informal care is not merely based on economic factors, but also on individual and social preferences (Brodsky and Clarfield 2008; Colombo et al 2011; Rhee et al 2015; Gentili et al 2017). This decision requires taking into account the experiences of caregivers, according to the idea of social suffering as a relevant component of LTC, a perspective not only usually ignored but also insufficiently understood (Graubard 1996; Kleinman et al 1997; WHO 2002).

2. The inaction problem: Ignoring an urgent issue

The analysis starts from the fact that people in country are getting older and aging increases long-term care needs in the country; these challenges have been widely recognized and highlighted in recent years (Matus-López and Cid 2014; Dirección Sociocultural de la Presidencia de la República de Chile 2017; Thumala et al 2017; Villalobos 2017). Despite this aparent consensus, the topic has not been prioritized and there are not coordinated policies to address it in place.

In order to explain this apparent paradox, the DELTA project relies on Kingdon's agenda-setting framework (Kingdon 1995). The model has been widely used to understand the way in which topics enter (or not) in the agenda of policymakers, based on the alignment of three different

streams: problems, policy, and politics. According to Kingdon, when these three elements come together, a “policy window” opens, putting topic on the agenda and enabling change. The DELTA project uses this model both to explain the inactivity regarding long-term care policies in the country and to design a strategy for generating concrete changes. Figure 4 presents the framework for analyzing the problem. As stated before, it includes Kingdon’s three streams but explicitly addresses the fact that LTC is a multidimensional topic that requires multisectoral responses. This adds an extra challenge to the picture, since now not only problems (conditions), solutions (responses) and politics need to be aligned (black arrow and red bracket), but also problems and responses require internal consensus between the health and non-health sector (green arrows), as proposed by Frenk (1993).

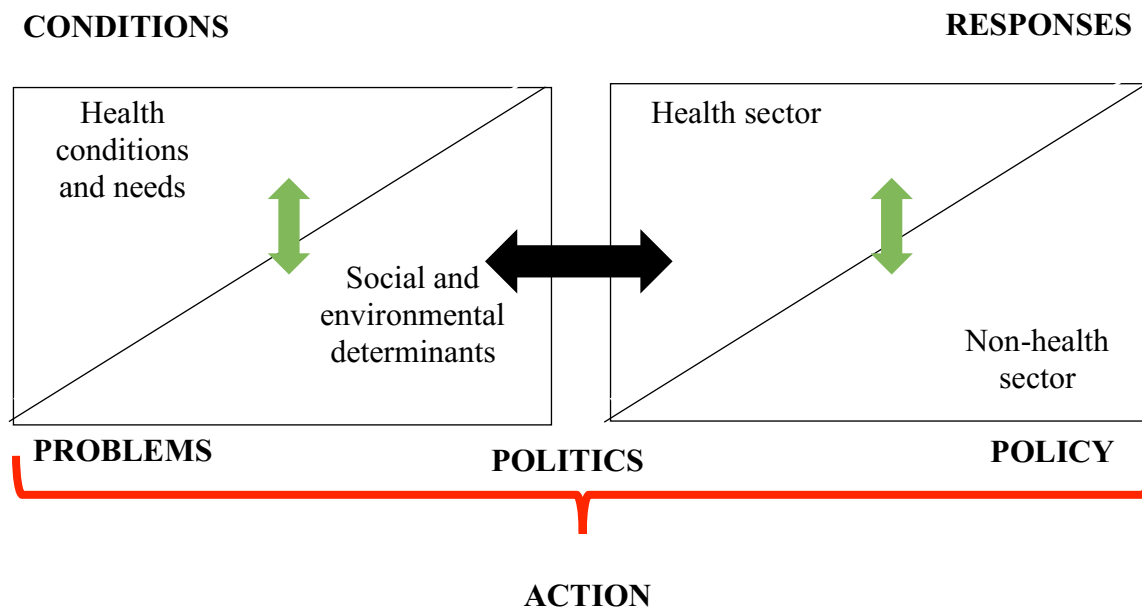


Figure 4. Framework for analyzing the problem

Source: Author’s elaboration based on Frenk (1993) and Kingdon (1995).

The project was designed based on a setting of lack of consensus about the problem or its magnitude among different stakeholders, absence of agreement that had hindered the search for solutions (WHO 2017a). In this scenario, the topic has not been addressed by politicians and policymakers and, consequently, the discussion on long-term care has been absent from the public agenda.

The problem –the increase in long-term care needs in the country– had been incorrectly identified, and decomposed into several related issues (aging, disability, vulnerability, epidemiologic transition) each of which has been addressed independently, ignoring a holistic approach and preventing the design of a comprehensive and coordinated solution (Figure 5).

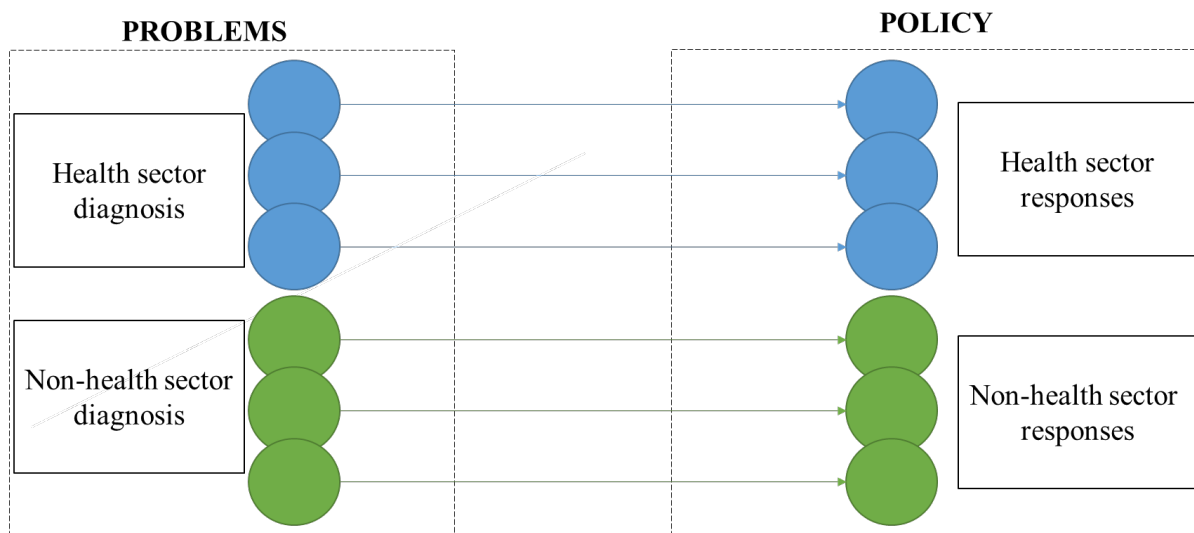


Figure 5. Independent diagnoses and uncoordinated response

Source: Author’s elaboration based on Frenk (1993) and Kingdon (1995).

This atomization of problems and solutions could be justified as a short-term response to seemingly unrelated problems, but it is inefficient and unsustainable in an environment in which elderly population and long-term care needs are the norm, not the exception. As shown in Figure 5, with several independent problems, synergies are lost and the underlying problem (big dashed box) simply disappears, which make impossible to advocate and look for solutions.

In summary, the DELTA project advocates for facing the demographic change and its challenges from a holistic perspective, looking for comprehensive solutions to a multidimensional problem. A narrow definition of the problem (aging, vulnerability) presents a narrow set of solutions and hides the big problem, slowing the creation of new alternatives to address it (Brodsky and Clarfield 2008).

3. Designing a project for enabling change: Theories of change

As previously described, the goal of the DELTA project is to establish the foundations for the design and implementation of a long-term care system in Chile, and the primary research question is how to implement it in the country. Following Kingdon's framework, the project needed to address the following questions:

- Why is a LTC system required in Chile?
- What are the alternatives (system design) and how do they fit into the Chilean context?
- How to move from ideas to policy?

As in Kingdon's model, these elements as well as different participants interact and, are simultaneously determined. The preceding section described the diagnosis over which the project

was designed (DELTA proposal): lack of information and consensus make the problem invisible and the solution hard to design and implement.

The project's theory of change describes how the project intends to achieve its expected results, describing the causal logic (results chain) of how and why the project's elements will produce the desired effects, establishing the channels from inputs to results. This is a key element in impact evaluation and a useful tool to design and evaluate interventions (WHO 2010a; Gertler et al 2011). In the case of this project, the theory of change in Figure 6.

Figure 6 presents theories of change in two level, recognizing this DELTA project as a piece of a larger project, i.e. the establishment of a long-term care system in Chile. The goal of the DELTA project is to generate the conditions to start a well-informed discussion on LTC in the country, in order to design and implement the system in the medium term. Consequently, the design and implementation of the LTC system are defined as the impact of the project, i.e. a goal to which the DELTA project will contribute but that can be influenced by multiple factors. This incremental strategy –build consensus to move forward– is aligned with Kingdon's framework and the DELTA project's goal.

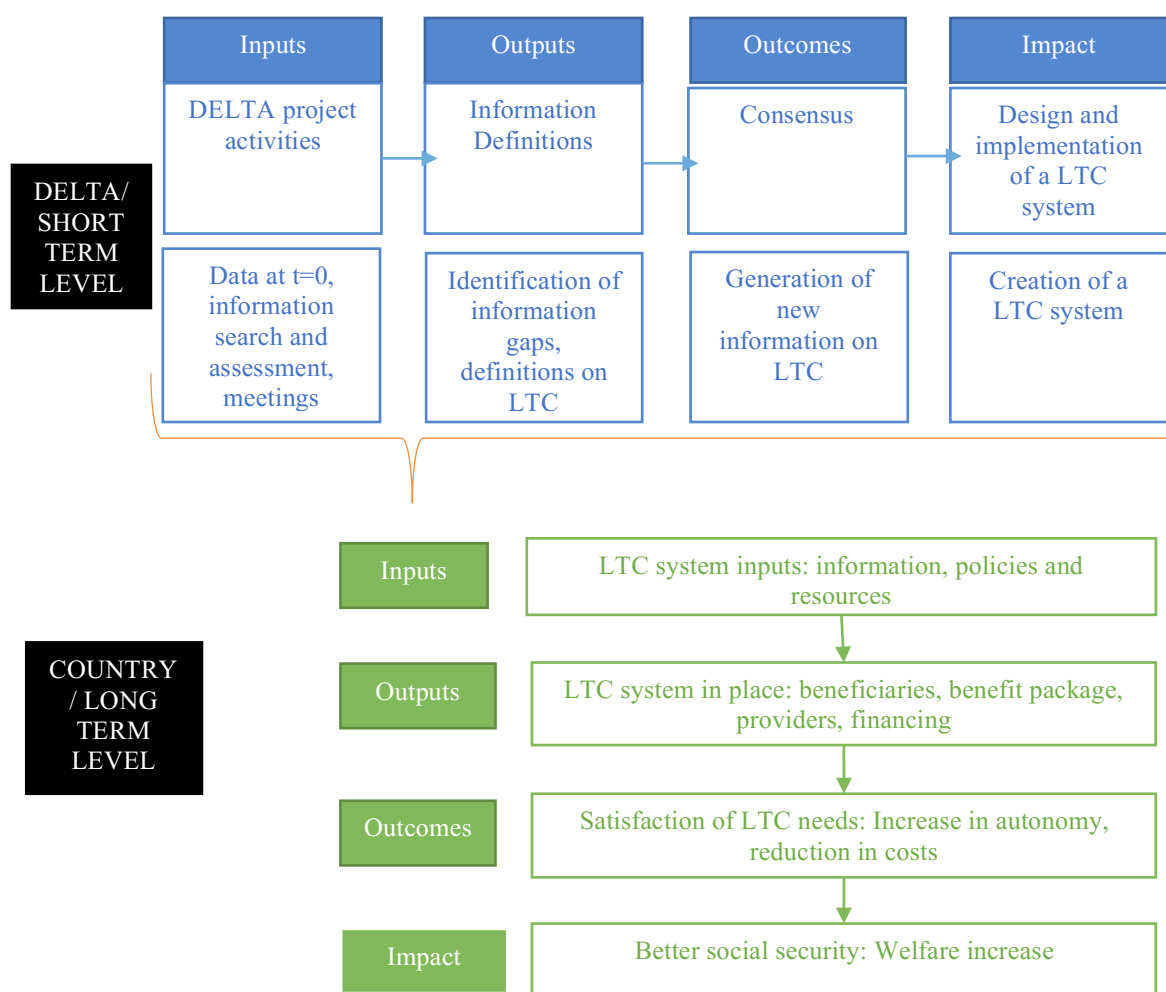


Figure 6. Theories of change: DELTA project and LTC system

Source: Author's elaboration.

The outcomes –results derived from the use of the outputs– of the project are related to change in behavior of its beneficiaries; in this case, the main outcome is the change in attitudes towards LTC needs (problem definition) and the recognition of the need of a LTC system (policy alternatives). In concrete, it is expected that, as result of the project, the host organization will introduce changes related to LTC in order to better respond to the challenges posed by aging and the increase in dependency. Some potential results expected from the implementation of the

project are the redesign of information systems in order to produce statistics on LTC (not available today), new eligibility criteria –criteria aligned with the information and definitions produced by the project– for current programs, and the design and implementation of new LTC-related initiatives.

Finally, the activities of the DELTA project, described in the next section, are expected to generate direct results (outputs); the outputs of the project are related to the identification of information gaps, as well as the generation of institutional definitions on the topic of LTC. The expected results at this level are the agreement on a single definition and instrument to measure dependency in the country, as well as the identification of information gaps regarding LTC needs (number of people requiring LTC services, type of need, socioeconomic variables) and government's preparedness to deal with these needs (policies, infrastructure, human capital, coordination).

3.1 Host organization

The project was implemented jointly with the Chilean Ministry of Health (MINSAL).

MINSAL's institutional mission is “contribute to improve health in the population; to develop a balanced health system centered on people; to strengthen the control of factors that influence health and; to support the national health provider's network, in order to meet timely individual, families and communities' needs”.

The DELTA project was carried out within the Minister's cabinet. This decision was made in order to ensure political support from the Ministry's authorities, expand access to information, and increase its potential impact. The option –versus, for example, working with a specific unit within the Ministry– is coherent with the problem previously described, i.e. the need to tackle the

issue from a more holistic perspective, instead of working from a specific trench (primary care, rehabilitation, elderly care). As shown in Figure 7, the Minister's cabinet is situated in a position that allows looking over the entire institutional structure, and particularly the two undersecretaries: public health and providers' network.

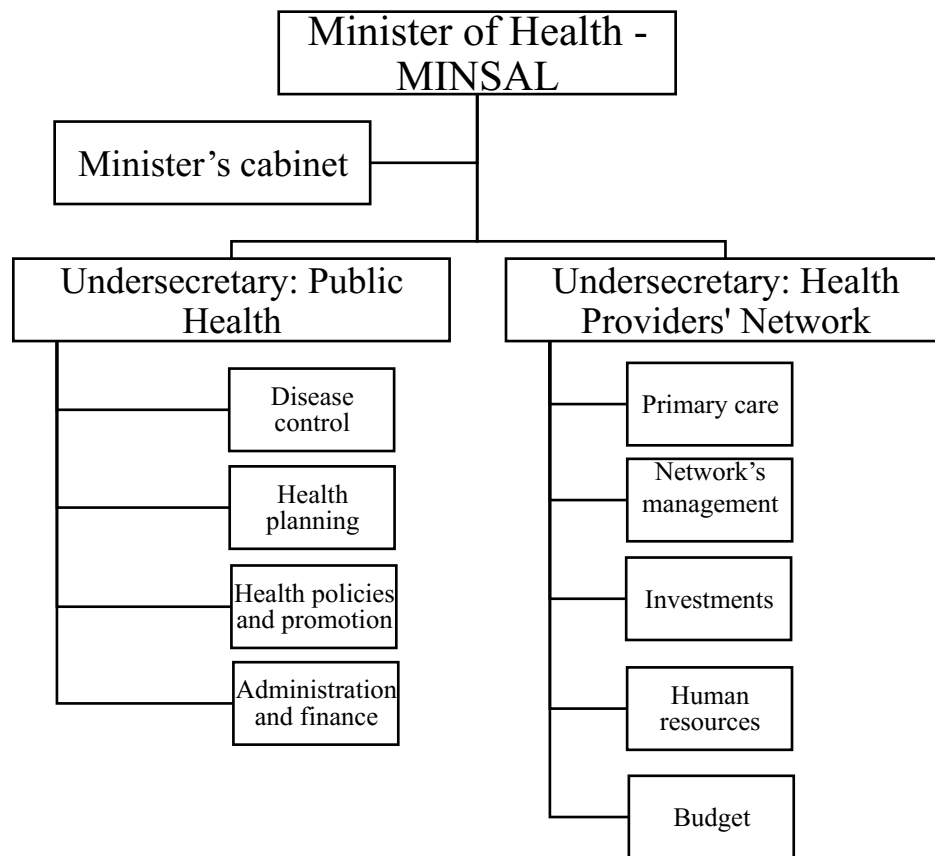


Figure 7. MINSAL's organigram

Source: Author's elaboration based on www.minsal.cl

Both undersecretaries are currently implementing LTC-related initiatives which reinforces the usefulness of placing the project at this level; since information (absence, differences) has been identified as key in understanding the problem and designing the project, putting the project outside the programs avoided potential biases (e.g. using a particular definition or approach), allowing to develop a diagnosis and propose solutions from a broad perspective. Additionally, a project generated from the cabinet ensures better access to information, improves communication and information diffusion within the organization, and gives it political support, a component identified as crucial in producing changes (Figure 4).

Furthermore, the project was supported by the Sociocultural Office of the Presidency (DSC), institution that teamed with MINSAL in the execution of this DELTA project. The DSC is a program that depends directly on the Presidency, whose goal is to coordinate and organize the work of the seven foundations under its tutelage. Its origins go back to 1954 and it has been customarily presided by the First Lady, who usually creates a foundation or program that is propelled through this institution^{*}. In 2015, the DSC launched its emblematic program *Chile Cuida*, a pilot initiative designed to bring support for elderly with dependency and their caregivers^{**}. The inclusion of the DSC as a support organization for the project was thought as a strategy to join forces and create a coordination instance within the government. The Office was intended to contribute by providing information and experience from its two years implementing a LTC program, but also as communication and coordination channel with other public institutions. Intersectoral coordination is also key in understanding the barriers to design and implement a LTC system since political and technical agreement is needed to move forward

^{*} <http://www.direccionsociocultural.gob.cl>

^{**} <http://www.gob.cl/2015/11/23/programa-chile-cuida-beneficios-para-los-adultos-mayores-y-sus-cuidadores/>

(Figure 4). As in the case of the Ministry of Health, help provided by DSC also contributes to give the project political support.

Finally, the project was financed by the Pan American Health Organization (PAHO) and the Inter-American Development Bank (IADB). These institutions were also considered as important stakeholders and were included in the design of the project and decision-making process. Besides financial support, both institutions were immensely relevant in helping with intersectoral coordination, as well as an important source of technical support. These institutions were also relevant in adding validity and political support to the project.

3.2 Activities and expected results

Considering the diagnosis and goals described in previous sections, the DELTA project was designed around three components, labeled as “Inputs: DELTA project activities” in Figure 6:

- a. Defining and measuring dependency: This first component is directly related to the definition of the problem as presented in Figure 4. Its purpose is to generate information on the relevance of LTC for the country, the current situation and future challenges, under the hypothesis that identifying problems is key for driving change (Kingdon 1995; Andrews et al 2015). As has been pointed out before, information has been key in developing LTC systems and solutions in other countries (Swartz et al 2012; Scheil-Adlung 2015; Butler 2016). Additionally, generating information on the magnitude and costs of dependency and long-term care needs is relevant since people tend to underestimate the likelihood of needing care, argument used to explain the low level of private LTC self-insurance and weak social pressure for implementing LTC systems (Barr 2010; De Donder and Leroux 2013; Caruso et al 2017; WHO 2017a).

In this case, the goal is not just creating awareness of an existing problem, but to connect a group of seemingly unrelated issues under the concept of long-term care (as depicted in Figure 5). This requires first working on generating a consensus definition and classifying these issues under this new label. An interesting parallel can be made with the research on neglected diseases, where a group of different stakeholders worked together in creating the label and agreeing on definitions as a way to articulate a coordinated response to the problem of lack of research for a particular group of diseases (Hotez et al 2007; Liese et al 2010; Hotez 2013).

This component requires, among other things, collecting information on LTC available at the Ministry of Health, including different definitions and estimations of dependency, meeting with MINSAL's personnel and people working in the implementation of LTC-related initiatives, listing other programs with LTC components within the government and looking at their definitions and instruments, and a literature review on international experiences.

The countries selected as examples to look at their definitions of LTC needs and dependency were Germany, the Netherlands and the Republic of Korea. All these countries have LTC systems already in place, are OECD countries, and recently went through reforms in their LTC systems, particularly in the way they understand and define dependency. Moreover, each system has particular features that make them interesting as benchmark for the Chilean case. Germany has a long tradition of social security and its LTC system has been prioritized within this system when defined as one of its pillars (instead of being nested within the health system as in many other countries); despite this long tradition, the country has undergone a series of important

changes, regarding the way in which LTC needs are defined and measured, serving as an example of the new trends in LTC systems around the world. The Netherlands, has one of the oldest LTC systems in the world that permits to draw lessons from a mature system that recently went into a major transformation; the Dutch LTC system is also interesting because it has also been prioritized within the social security and health system: the country devotes 30% of the health expenditure to LTC, meaning that the country invest 3% of its gross domestic product (GDP) (OECD 2016) in LTC exclusively. Finally, the Republic of Korea allows examining the experience of a recent reform in a country with an economic situation similar to Chile, which it is helpful in anticipating challenges and thinking about the design and implementation of a LTC system in the country.

The expected results of this stage are:

- State of the art of LTC and dependency in the Ministry of Health and Chile
 - Better understanding of the costs and benefits associated with a LTC system (versus one based on informal care)
 - Agreement on a ministerial definition of dependency. This result involves both agreeing on a theoretical definition (what dependency means) and a practical one (how to measure it)
- b. Designing a LTC system: As stated by Kingdon (1995), putting a topic on the agenda requires its recognition as a problem, but also having a reasonable set of alternatives to deal with it. In fact, Kingdon uses long-term care and mental health as examples of topics that have remained ignored in political agendas, “... not because participants

would not recognize real problems there but because they have little sense of alternatives...” (p. 208). The issue of consensus on solutions has also been highlighted as a key milestone in the discussion of a LTC system in the different contexts (Campbell and Ikegami 2000; Campbell et al 2009; Butler 2016).

LTC has been discussed for a long time in many countries, each one addressing the issue from diverse perspectives, but common trends and convergence in some policies has been observed in recent years (Swartz 2013; Norton 2016); the experience of other countries provides important lessons to be used in the design of the Chilean LTC system. The DELTA project is based on the idea that the problem needs to be addressed from a systemic perspective. The high degree of uncertainty, the large range of alternatives in financing and providing services, and constant need of reform, gives the rationale for the implementation of a LTC system. As described by Norton and Newhouse (1994) Colombo et al (2011), a LTC system comprises four main components: beneficiaries (who uses LTC services), benefit package (what services are provided), providers (who provides LTC), and financing (who pays for LTC, in what setting and at what cost). Consequently, this component is intended to produce:

- Proposal of alternatives for a LTC system: based on a literature review of LTC systems in other countries. The document aims to present alternatives for the Chilean system in terms of who should use it, what will be the benefits provided, who will provide these services, how much it would cost and how to finance the system. It will give a sense of the different alternatives available when designing a LTC system, and the many perspectives that are needed to address it

- Assessment of country's preparedness for launching a LTC system: in order to assess the best option for the Chilean context, information on the country's current situation is also required. The evaluation involves looking at the current initiatives on LTC being carried out in the program and compare them to other LTC systems, in order to establish where is the country today and what needs to be done in the future

The expected output of this component is a document with alternatives designs for a LTC system and lesson for the Chilean system.

- c. Dissemination and awareness: The first two components are focused on generating information regarding the needs of LTC in the country and the degree of preparedness in responding to these needs. This information is key to supply evidence that can support the existence of a problem and advocate for a particular solution. It also gives an idea of the many challenges to close the gap between conditions and responses. Following the scheme depicted in Figure 4, change also requires political support. The aim of the first two components is to create awareness of the challenges faced by the country in terms of LTC needs. Success and failure experiences in implementing LTC systems are useful in highlighting the need to consider the politics into the analysis, and emphasize the crucial role of decision-makers in generating policy changes (Harrington et al 1991; Norton and Newhouse 1994; Campbell et al 2009; Butler 2015; Maarse and Jeurissen 2016).

As stated previously (Figure 6) the DELTA project aims to set the conditions for implementing a LTC system in Chile. However, in the long run, the goal is to have this system in place. Accordingly, the project involves activities to increase awareness and

open a window of opportunity for the idea of a LTC system in Chile. The project considers the particular political environment in which was conceived: the project was developed during an election year, which potentially could reduce its support and relevance as election approaches. Even though this seems like an unsolvable problem, it also presents a valuable opportunity: if the idea is well implemented during the first months of the project, it could potentially be included in the agenda of the next government. Following Kingdon's model (Kingdon 1995), if the problem and solutions are well defined by the end of the project, the change in government can open an opportunity window to insert the issue in the political agenda. With this idea in mind, the third component was designed to be executed on two levels.

First, at MINSAL's level meetings with different stakeholders –including program managers and authorities– will be held in order to sensitize about the issue of LTC, present results, and advocate for changes. Second, at country level, meetings with different presidential candidates' teams were scheduled during 2017. The official list of candidates was defined in June 2017, right before the start of the DELTA; election (first round) was set for November 19th, with a potential *ballotage* on December 17th. The meetings were programmed for the first months of the project (September-October), period in which the different teams were discussing and elaborating the candidates' proposals. The goal of these meetings was to assess the priority given to LTC in the debate, to find the way in which the issue was incorporated in the presidential programs through concrete proposals, and to present the DELTA project and its main findings to the date.

As result of this component, a change in attitudes towards LTC is expected. In concrete, the project intends to increase awareness, provide inputs (definitions, statistics, frameworks) to better understand the topic, create a sense of urgency for action, and install the notion of a LTC system as a feasible, effective and efficient response for dealing with growing LTC needs in the country.

At government level, these changes should be reflected in concrete actions pointing toward increasing LTC relevance within the realm of the Chilean public policies.

On the other hand, the conversations with the representatives of different presidential candidates intend to secure these changes in a future government. The project acknowledges explicitly the differences between short and long-term actions and goals (Figure 6); this component aims to increase the sustainability of initiatives and changes introduced during the execution of the DELTA project. As in the case of the government level, actions carried out in this subcomponent also point toward changing attitudes and increasing the priority of the LTC issue for the next government. The short-term result is a change in the relevance gave to LTC in the presidential proposals, in order to secure it a place in the next government policies and reforms.

3.3 Project timeline

Broadly, the project was divided into two parts, although for many of the activities described in the previous section this division was merely formal (activities were carried out throughout the entire project). In order to deal with the project's uncertainty, a certain degree of flexibility was explicitly added to the plan, allowing for continuous monitoring and adjustment. The strategy was based on the iterative adaptation process proposed by Andrews et al (2015), which explicitly

looks for incorporating evidence-driven feedback for a project's real-time adaptation. The approach is based on four principles that guided the projects actions' (Andrews et al 2015):

- i. Local solutions to local problems: going from promoting standardized solutions to allowing local nomination, articulation and prioritization of concrete problems
- ii. Pushing problem-driven positive deviance: creating environments to encourage experimentation, and positive deviance
- iii. Try, learn, iterate, adapt: promote active experiential learning with evidence-driven feedback
- iv. Scale thorough diffusion: engage champions to ensure that reforms are viable, legitimate and relevant

The first part of the project (July 2017-October 2017) was mainly devoted to collect information and propose changes regarding LTC needs in the country. This was identified as the key piece of the project, an element required to understand the problem and design solutions, according to the framework presented in Figure 4. Following the project's activities described in section III.3.2 ("Activities and expected results"), this part is closely related to the first component, whose goal is understanding and quantifying the magnitude of the problems related to LTC growing needs. Consequently, the second part (November 2017-February 2018) was focused on the second component of the project, i.e. thinking about the way in which these challenges could be faced and identify how prepared the country is for giving a coordinated response to them. The timeline and activities for the second part of the project were defined and agreed between October and November 2017.

As shown in Table 1, both parts include activities linked to information collection and process, in order to: i) identify the data currently available in different institutions; ii) summarize and

structure the information collected; iii) evaluate information and; iv) draw conclusions, identify limitations and challenges, and propose actions. The goal was to build the project on information coming from the institutions and people working on the topic, in order to have a clear identification of the problem. This problem-driven approach acknowledges the difficulties of implementing complex policies and programs, and explicitly try to avoid the adoption of external well-known best-practice solutions and the risk of ending up coping a system that does not fit with the Chilean needs (Pritchett et al 2011; Andrews et al 2015).

The timetable presented below shows the original schedule of activities presented and approved by the host organization (MINSAL), except for the meetings with presidential candidates that formed part of the DELTA project, but was not part of the activities agreed with the Ministry. As explained before, the project explicitly incorporated evaluation-adaptation stages as a strategy to react to new information, unexpected delays and changes in priorities between different stakeholders (MINSAL, DSC, PAHO, IADB). Formally, these were set at the beginning of each part, in July and November 2017.

Table 1. Project timetable

Stage/Activity	Date
Part I: Understanding the problem – Defining an measuring dependency	
Project presentation	July 6 th
Meeting with MINSAL stakeholders and adjustments	July 3 rd – July 16 th
International experience in defining dependency: literature review	July 3 rd – July 23 rd
Meetings with MINSAL's employees: introducing the project and its scope. Data availability assessment	July 10 th – July 31 st
Elaboration report on measuring dependency in Chile	July 10 th – Aug 20 th
Data collection within MINSAL	July 17 th – Aug 20 th

Table 1 (Continued)

Preparing PAHO meeting on aging	Aug 7 th – Aug 20 th
Identification of indicators for measuring the impact of aging	Aug 7 th – Aug 27 th
Elaboration report on the impact on LTC for Chile	Aug 7 th – Sep 10 th
Data analysis. Measuring LTC indicators and its economic impact	Aug 7 th – Oct 22 nd
Interviews with MINSAL employees. MINSAL's views and state of the art on LTC and aging	Jul 17 th – Sep 24 th
Meetings with presidential candidates' teams	Sep 3 rd – Nov 3 rd
Elaboration report on costs of LTC needs for the health sector (use of hospital beds)	Sep 25 th – Oct 31 st
Part II: Looking for solutions – Designing a LTC system	
Defining goals and deliverables	Nov 6 th – Nov 17 th
Meeting with stakeholders (MINSAL, DSC, Ministry of Labor). Data collection and information availability	Nov 10 th – Nov 30 th
Literature review on indicators on aging and health systems	Nov 12 th – Nov 30 th
Selecting aging indicators for Chile	Nov 19 th – Nov 30 th
Data search and calculation of indicators	Nov 19 th – Dec 8 th
Meetings with presidential candidates' teams	Nov 20 th – Dec 14 th
Literature review: international experiences on LTC system design	Dec 11 th – Jan 12 th
Meetings with MINSAL stakeholders and program managers	Dec 11 th – Jan 12 th
Elaboration report on the alternatives for a LTC system in Chile	Jan 1 st – Jan 12 th
Data analysis MINTRAB information	Jan 14 th – Feb 16 th
Meetings and data validations	Jan 21 st – Feb 23 rd
Elaboration report on gaps in supply of human capital for LTC services	Jan 21 st – Feb 23 rd

Source: Author's elaboration.

Although the third component of the project – dissemination and awareness – was identified as key in promoting changes, actions were not explicitly included in the chronogram presented above. This decision was based on two main arguments. First, most of the activities were designed to increase awareness within the Ministry, and were seen more as a result of other activities than an activity itself. Again, this decision recognizes the several dimensions in which

the project was carried out: it needs to define not only the limits between short-term (developing an 8-months project) and long-term (developing a LTC system in the country) as shown by Figure 6 but also between the whole DELTA project and the more limited set of activities agreed with the host institution. Second, unlike the meetings with the presidential candidates' teams, there were no deadlines or well-defined counterparts at the beginning of the project. Specific proposals for action and strategies to implement them (e.g. key stakeholder to be convinced) were revealed jointly with the project's execution, according to new information available, results and conclusions reached, interpersonal relationships, and working and political environment. However, even though these activities were hard to plan in advance, they were considered as crucial for the goals of the project. This required a permanent effort in creating discussion spaces and being alert for new opportunity windows to open.

The whole project was designed taking into account the special timing in which it was supposed to be implemented. As described previously, even though the timing of the project was not changeable, the project's design incorporated this element in order to take advantage of potential opportunities arising during the period (influencing different candidates, Ministry's need to show results by the end of the period), understanding the limitations imposed by uncontrollable factors (election results, change in MINSAL's priorities and people).

III. RESULTS STATEMENT

This chapter presents the actions undertaken during the execution of the project and its results.

The first part is devoted to the identification of LTC in the country and explains the data collection process at MINSAL, and a summary of the information available at country level on dependency, delving in the issue of defining and measuring dependency, and presenting the efforts made in the past, a description of the current situation, and what can the country expect in the future. The second part proposes a framework to assess the impact of LTC needs from a social security perspective. It uses international experiences as well as Chilean data to explain why a LTC system is an effective and efficient response to the challenges of aging and increase in LTC needs. Finally, the third part present the activities aimed to ensure the continuation of the debate on LTC and the future implementation of a LTC system in the country; it describes the main changes generated by the project and contains a discussion regarding the design of LTC systems.

1. Identifying long-term care needs in Chile

All happy families are alike; each unhappy family is unhappy in its own way.

Leo Tolstoy

1.1 Collecting information at MINSAL

The first part of the project was devoted to understanding the way in which LTC was defined and to identify LTC (or LTC-related) initiatives within the Ministry.

The project was officially presented on July 6th. The first weeks were used to identify units, departments and people that could be interested in the project and/or could contribute in any way

to it. This recruitment period lasted a month, in which several meetings were scheduled with different stakeholders in order to explain the project, define its relevance for the unit/department, and identify collaboration opportunities. The list includes people working directly in LTC-related initiatives, such as the responsible of the home-based care program for severe dependents and the rehabilitation program, and other stakeholders at Ministry level (such the division of health planning, and the statistics and information department). The full list of meetings is presented in Appendix 1.

The goal of this first stage was to introduce people to the project, but also get key information to continue developing the activities of the component “Defining and measuring dependency” described in section III.3.2 (“Activities and expected results”). This stage comprised several activities, including meeting with stakeholders, data collection, and interviews with program managers.

As described before, meetings were mainly used to introduce people to the project, collect information, and identify collaboration opportunities. The main goals of this activity was to detect key project’s stakeholders within and outside the Ministry and assess the availability of information on long-term care and dependency (including statistics).

On the other hand, interviews were also used to identify the stakeholders’ network, but mostly to discover people’s understanding of LTC and the operational definition of dependency.

Interviews documents (consent forms and interview guides) are presented in Appendix 2. As shown by the forms, the interviews were designed to:

- Discern the (theoretical) concept of LTC used by different units within MINSAL and how LTC was seen (or not) as part of their day-to-day work
- Recognize the way in which dependency was operationalized, i.e. how it was measured

- Identify other sources of information

Three interviews were conducted during August with program managers of MINSAL's rehabilitation programs -one situated in the Disease Control Division of the Undersecretary of Public Health and the other being part of the Network's Management Division of the Undersecretary of Health Provider's Network- and the program of home care for severe dependents (Primary Care Division, APS) (see Figure 7).

The rationale for this strategy of starting the information collection with those involved closely with the issue of LTC and dependency, was to get first-hand information, identify differences between "real" and "official" definitions, and gain support from the people who were more likely to be interested in the project: if those working on LTC-related issues are truly concern about the topic, a project that intends to increase its visibility and priority is assumed to be well received.

These interviews proved to be very relevant in discovering new sources of information but also testing some of the project's initial hypothesis. As stated by Kingdon (1995) and Andrews et al (2015) problem identification is key in looking for a solution, but it is generally identified and constructed from the top down or determined by external experts, which usually leads to standardized interventions. In this case, the project gave the chance to define the problem to those working in direct contact with the beneficiaries of MINSAL's initiatives. One issue that clearly arose after the interviews was the lack of a definition of dependency, although the term was used by several units at MINSAL. Finally, interviews were also very relevant in identifying other LTC initiatives within and outside MINSAL.

Even though the information was collected intensively during the first months of the project, the process continued throughout its entire life, depending on the project's needs, the release of new

data, and availability of stakeholders/informants, following the problem-driven iterative approach described in section III.3.3 (“Project timeline”) (Andrews et al 2015).

1.2 What do we know about dependency in Chile?

1.2.1 Measuring dependency in Chile: Evolution 2000-2017

Using the information collected through meeting and interviews, an online search of studies on dependency in Chile and several statistics and databases, the project tried to address the question: How many people with dependency live in Chile? The objective was to have a crude estimation—an order of magnitude—of LTC needs in the country. In the process, I also present the several attempts to answer the question, “how many dependents are in Chile?”, and how the concept of dependency has evolved in the past years.

During the DELTA’s design stage, this issue was raised several times. After reviewing documents, looking for statistics, and talking to people working on LTC-related initiatives at MINSAL and other institutions, it became clear that there was no single answer to this question.

While searching for a number, many interesting issues came to light. First, the concept of long-term care is not well known or used until very recently; similarly, the discussion and use of the term “dependency” is relatively new. Second, the issue has been treated *vis-à-vis* with aging, as an elderly-exclusive problem.

The absence of the terms “long-term care” and “dependency” is evident when analyzing its evolution through time. In order to answer the question about the number of dependents in Chile, a search of documents was performed, looking for articles and studies containing “dependency Chile” and “dependency measurement Chile” published since 2000 to the date. This search was

complemented using a snowball sampling strategy, i.e. looking at the references of the articles already in the list, and through the meetings and interviews described in the previous section. The list only considered studies reporting dependency (or a related concept) at national level, including reports using data with national representativeness and excluding studies in specific populations, like the articles of Morrison and Pereira (2004) in two municipalities in the Metropolitan Region or the studies by Letelier and Yáñez (2009) and Muñoz et al (2015) on patients of specific health centers. The final list contains 15 documents published by different organizations, using different surveys and showing dissimilar results.

The complete list of studies, definitions used and results are presented in Appendix 3. The table shows different studies conducted in the country that measure the prevalence of dependency or dependency-related concepts.

In the first place, it is important to note that dependency has increased its importance throughout time, due to greater availability of studies and data, and a growing debate about the definition of dependency and the way to measure it (instruments), reflecting the increasing interest in the topic. This interest in defining and measuring concepts such as LTC needs, dependency or functional ability has resulted in the emergence of models, theoretical frameworks, instruments and statistics to quantify these issues in the country. Thus, for example, the first National Quality of Life Survey (ENCAVI) conducted by the Ministry of Health in 2000 (MINSAL 2000) begins by emphasizing the importance of demographic transition, including a series of questions regarding lifestyle, psychosocial and environmental factors that affect people's health, but does not contain a single indicator on LTC needs. However, this information was included in the following versions of the survey (MINSAL 2006, 2017), recognizing the need to advance in generating of information that allows quantifying some of the issues related to population aging.

This temporal evolution is clear when looking at the documents presented in Appendix 3. The first studies (early 2000s) were mainly focused on issues like aging and disability, concepts associated but not synonymous with dependency. This trend makes sense considering that the prevalence of dependency is higher in older adults and that disability is closely related to the loss of functionality in individuals. The WHO report on aging (WHO 2015) makes this distinction between intrinsic capacity –individual physical and mental capacities– and functional ability, a product of the interaction between individuals’ intrinsic capacity and the environment. Many studies have tried to approach this problem using different definitions of dependency, ranging from the existence of a caregiver, to the application of tests to measure functionality, mainly based on the concepts of basic activities of daily living (ADL) and instrumental activities of the daily life (IADL).

This evolution from aging and disability to a more complex concept of dependency is also present when looking at the National Socioeconomic Characterization Survey (CASEN), one of the most important sources of information in the country. The CASEN has been carried out since 1990, and its main goals are to describe the socioeconomic status of the Chilean families and assess the impact of social policy. The survey is coordinated by the Ministry of Social Development (MIDESO) and applied every two or three years.

Since its 2006 version, its questionnaire includes, as part of the survey’s health module, questions to identify disability. However, in subsequent editions, it has been moving towards the inclusion of questions that also allow identification of dependency (Table 2).

Table 2. Dependency identification in CASEN surveys (2006-2015)

Year	Question	Question number	Respondents	Concept	Addition
2006	Do you have any of the following long-term conditions?	t1	All	Disability	N/A
	What is the origin of this condition?	t2	All		
2009	Do you have any of the following long-term conditions?	t1	All	Disability Dependency (difficulty in performing activities – binary answer)	Questions on limitations to perform activities Questions by age
	What is the origin of this condition?	t2	All		
	Can you go out alone to the street?	t3a	> 6 years		
	Can you go shopping or to the doctor without help?	t3b	> 15 years		
	Can you?: Take a bath; brush your teeth; comb your hair and eat alone; move around inside the house; fully control your sphincter	t3c, t3d, t3e	> 6 years with some difficulty		
2011	Do you have any of the following permanent or long-term conditions?	s37	All	Disability Dependency (difficulty in performing activities – binary answer)	Distinction between ADL and IADL
	What is the origin of this condition?	s38	All		
	Difficulty for: bathing; brushing teeth; combing hair; eating alone	s39	> 6 years with some difficulty and > 60 years		
	Difficulty to: concentrate, learn, social relationships, recreational activities, move	s40	> 6 years with some difficulty and > 60 years		
	Difficulty to: going out without help, shopping or going to the doctor alone	s41	> 6 years with some difficulty and > 60 years		

Table 2 (Continued)

2013	Do you have any of the following permanent or long-term conditions?	s34	All	Disability Dependency (difficulty in performing activities and need for help)	Need for help
	What is the origin of this condition?	s35	All		
	Difficulty for: eating, bathing, move around the house, go to the bathroom, lie down/get up, get dressed	s36	> 6 years		
	Difficulty to: concentrate, learn, social relationships, recreational activities, move	s37	> 6 years		
	Difficulty to: going out on the street, shopping or going to the doctor alone, housework	s38	> 15 years		
2015	Do you have any of the following permanent or long-term conditions?	s31	All	Disability Dependency (difficulty to perform activities and need of help, different degrees)	Questions by age New activities Levels of difficulty Separates difficulty to perform activities and need for help
	Difficulty to: concentrate, recreational activities, learn, move, social relationships	s32	> 6 years		
	Difficulty for: eating, bathing, moving around the house, going to the bathroom, going to bed/getting up, getting dressed	s33	Between 6 and 14 years		
	Difficulty for: eating, bathing, moving around the house, going to the bathroom, going to bed, getting dressed, going out, shopping, going to the doctor, housework, making calls	s34.1	> 15 years		
		s34.2	> 15 years		
	How often do you get help from someone else?	s35.a	> 15 years who declare receiving help		
	Does someone at home help you to carry out these activities?	s35.c	> 15 years who declare receiving help		
	Does someone outside the home help you to carry out these activities?				

Source: Author's elaboration using CASEN's questionnaires.

The evolution of the CASEN survey reflects the path followed by several institutions in trying to understand, define and measure the concept of dependency as happened, for example, with the MINSAL's ENCAVI survey. In its latest version, CASEN 2015 uses the definitions established in the National Study of Dependency in the Elderly (SENAMA 2010), which shows an intention to measure this variable with greater accuracy, using a clear and previously validated methodology.

Second, despite a greater availability of data, there is still a high degree of heterogeneity in the information. As shown in Appendix 3, studies use different sources of information to obtain their results; they also focus on different populations and what is more complex, use different definitions and instruments to measure dependency. This imposes immense challenges in terms of comparability of results, revealing a lack of consensus regarding the meaning of dependency and its measurement.

For example, disability surveys conducted by the National Disability Service (FONADIS 2004, MIDESO 2015b) provide an overview of disability in the country, which can be considered an upper bound for the estimation of dependency in the country. According to these statistics, the percentage of disabled people is between 13% and 17% of the population, a percentage that increases with age, being close to 40% in elderly. In line with the previously presented evolution in the surveys and studies, the second version of the survey (MIDESO 2015b) includes specific measures of dependency, showing that only a subset of the disabled (40.4%) have some degree of dependency, representing roughly 8% of the country's total population.

The National Health Survey (ENS) (MINSAL 2003, 2010) also provides figures on the prevalence of disability at the country level. Using a set of definitions and different instruments, it finds that the share of people with disabilities is close to 7% (MINSAL 2010); when adding

cognitive impairment as part of the definition, studies show that the percentage of people over 60 years of age in this condition is higher than 10% (using the Mini-Mental State Examination, MMSE) and between 4% and 8% using a more strict definition (MSSE plus Pfeffer test). The SABE study (OPS 2005) finds similar results using the same instruments in a sample of elderly in the Greater Santiago.

Another group of studies tried to advance in the measurement of dependency, using difficulty to perform ADL and IADL as metrics. The SABE study (OPS) finds that 19% of the population over 60 years report having difficulties to perform at least one ADL, while 28% have problems with some IADL. Using a similar approach, the Second Survey of Quality of Life and Health, ENCAVI (MINSAL 2006) found that the share of people reporting difficulties in performing activities such as traveling, handling objects, eating or going to the bathroom varies between 5% and 15%, depending on the kind of activity assessed. The study also highlights that these figures increase with age: for example, while 7% of the population between 15 and 19 years reports problems when using public transportation, this number is 36% for those older than 75 years. Difficulty to perform ADL and IADL is also greater among people with lower income, emphasizing the interaction between health conditions and environment. The CASEN 2013 survey (MIDESO 2015a) finds that 16% of the population over 15 years have difficulties in performing some ADL.

Finally, the CASEN survey has incorporated questions to characterize dependency based on ADL and IADL. Unlike other studies, the survey collects data from the whole population (not only elderly), which permit conduct analysis for the general population. However, the documents published by MIDESO analyzing the results of the last two surveys (España 2016, MIDESO 2017a) restrict the analysis to elders exclusively. Using data from CASEN 2013, España (2016)

finds that 19% of the population has some degree of functional dependency –using a combination of responses regarding difficulties to perform ADL and IADL that cannot be applied to previous surveys–, distributed evenly among different levels (mild, moderate and severe). The analysis of the 2015 survey (MIDESO 2017a) indicates that the percentage of the elderly population with dependency reaches 14%, with half of them classified as moderate. As in the 2013 survey, the measurement is based on the definitions used in the National Survey of Dependency (SENAMA 2010), but the new version includes changes that take into account the experience of the II National Study on Disability (MIDESO 2015b)), in particular it incorporates scales to assess the degrees of difficulty in carrying out activities, the inclusion of questions regarding frequency in receiving help, questions for caregivers, and the inclusion of new categories of activities, changes that they help to better define the concept of dependency, but they do not allow comparison between both surveys (MIDESO 2017a).

In summary, the concept of dependency has been slowly introduced into the public debate, and nowadays there are several sources of information that use the term explicitly. The concept has arisen during the last 15 years, becoming independent from concepts that dominated the debate in the early 2000s, such as “disability” and “elderly”. Despite this important progress, consensus is still scarce around the definition of dependency and the way to measure it. The National Study of Dependency in the Elderly (SENAMA 2010) represents an inflection point in the debate; the report proposes a specific methodology that measures dependency, based on a well-defined conceptual framework. It is not surprising that many programs focused on dependent population are using this study as reference to estimate their demand for services –for example, *Tránsito a la vida independiente* (MIDESO), *Más adultos mayores autovalentes* (MINSAL) or *Envejecimiento activo* (SENAMA)–, and that CASEN ended up adopting its definition to design

its questionnaire. However, the question “how many dependents are in Chile?” is still hard to answer. We have more and better information now than ten years ago but need to invest in generating consensus about its conceptual definition and the instrument to measure it, since this lack of agreement has shown to be an important barrier for defining LTC as a problem in the country.

1.2.2 How many dependents are in Chile? Dependency profile

The previous section showed the efforts in answering this question, and the journey towards understanding, defining and measuring dependency in Chile. As shown in Appendix 3, several studies have contributed enormously to this endeavor, but very few allow the establishment of a methodologically sound and complete estimation of the number of people living in situation of dependency in the country: some estimations do not measure dependency, but related concepts, while others are focused on measuring dependency, but restraining the estimations to specific populations.

One of the few databases available to estimate the prevalence of dependency in the Chilean population is the CASEN 2015 survey^{*}. As described before, CASEN 2015 includes questions and uses the methodology proposed by SENAMA (2010) for measuring dependency, but also other information that can be useful in identifying people with LTC needs in the country; Table 3 shows these definitions and the numbers obtained:

^{*} Dependency can also be estimated with the Second National Study of Disability in Chile (MIDESO 2015b), using the same methodology than CASEN 2015 (SENAMA 2010).

Table 3. Dependency definitions using CASEN 2015

Concept	Question number	Population	Definition
Difficulties performing activities	s33, s34.1	> 6 years	People between 6 and 14 years who declare having any difficulty to perform ADL and people older than 15 years with some difficulty to perform ADL or IADL
Functional dependency (CASEN 2015 definition)	s34.1, s34.2	> 15 years	Persons over 15 years reporting: a) having extreme difficulties or being unable to perform ADL or IADL or; b) receiving help with high frequency (many times or always) to perform activities or; c) having moderate or severe difficulties in at least one ADL or two IADL
Presence of caregivers	s35a, s35c	> 15 years	People over 15 years who declare to receive help from a third party in carrying out activities

Source: Author's elaboration based on survey questionnaires and MIDESO (2017a).

Note: ADL: eating, bathing, moving inside the house, using the restroom, laying down and getting out of bed, getting dressed; IADL: going out to the street, shopping or going to the doctor, doing housework, making or receiving calls.

Figure 8 shows the prevalence of dependency for different age groups using the three definitions presented in Table 3. In the first place, it is observed that, regardless of the definition used, prevalence (percentage of dependents in each age group) increases with age, exceeding 10% of the population for people over 70 years.

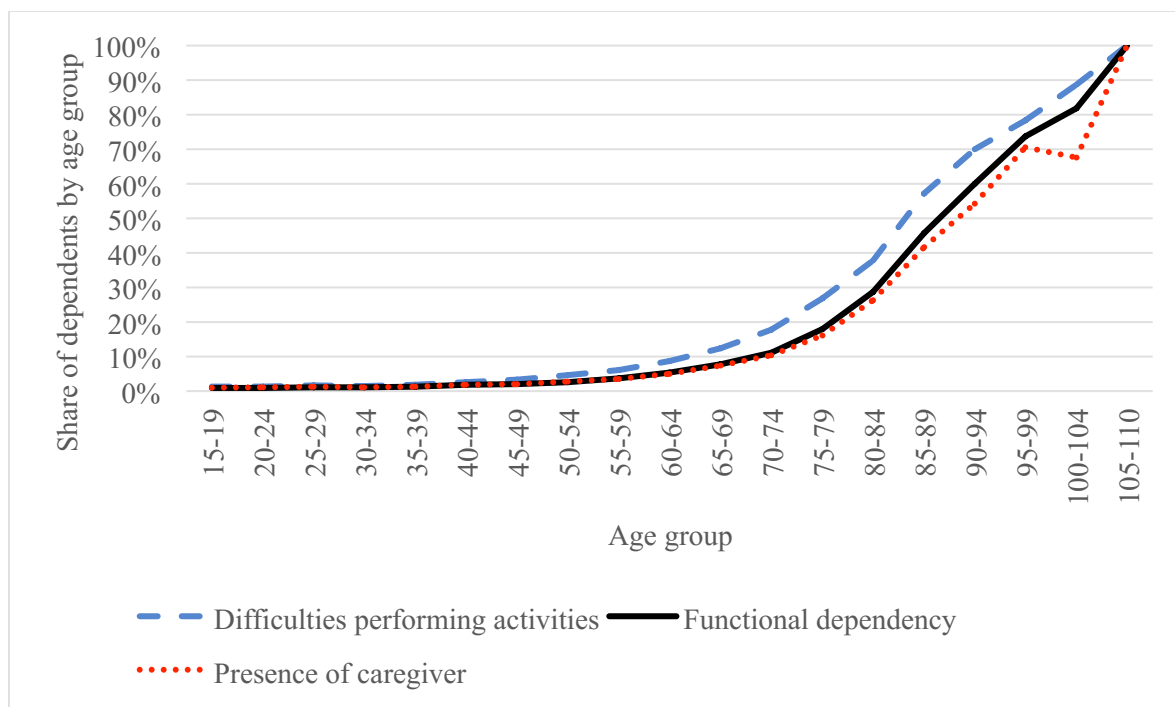


Figure 8. Dependency prevalence by age group (different definitions)

Source: Author's elaboration based on CASEN 2015.

Second, differences in prevalence levels are observed using different definitions. The first definition can be considered an upper bound since it includes all those who present some difficulty (not necessarily all dependents). At the other extreme, the definition based on the presence of a caregiver is closely linked to the concept of dependency and results in smaller numbers than those obtained using a definition based on difficulties in carrying out activities. In spite of this, it is difficult to consider it as a lower bound for the dependents: although it is a subset of people reporting difficulties, it could also include other people who receive help without being dependent. Finally, the definition of functional dependency (MIDESO 2017a) is based on the one used by the National Study of Dependency in the Elderly (SENAMA 2010) and offers a more specific definition, situated between the other two estimations.

Table 4. Number and percentage of dependents in different populations (different dependency definitions)

Variable/Dependency definition	Difficulties performing activities	Functional dependency	Presence of caregivers
Number of dependents	970,279	625,484	598,066
Prevalence in the population ^a	5.53	3.56	3.41
Prevalence in people older than 15 years ^b	6.54	4.47	4.28
Prevalence in people older than 65 years ^c	25.12	18.00	16.61
Share of dependents older than 65 years ^d	57.44	63.83	61.59

Source: Author's elaboration based on CASEN 2015.

Notes:

a Total dependent/total population

b Dependents over 15 years old/population over 15 years old

c Dependents over 65 years old/population over 65 years old

d Dependents over 65 years/total dependents

As shown in Table 4 and Figure 8, dependency is particularly prevalent in older adults, which has justified the prioritization of this group in different studies and policies, as a way to focus the analysis on the group that presents the greatest burden. However, from a LTC system perspective, it is important to point out that even though dependency is more prevalent in elderly population, an important portion of dependents is under 65 years of age. As shown in Figure 9, although the prevalence is low in the group of people under 65, they represent almost 90% of the total population. This is an issue that needs to be considered when discussing the topic of LTC

and dependency in the country: an analysis or policy focused exclusively on elderly excludes almost 40% of the country's dependents.

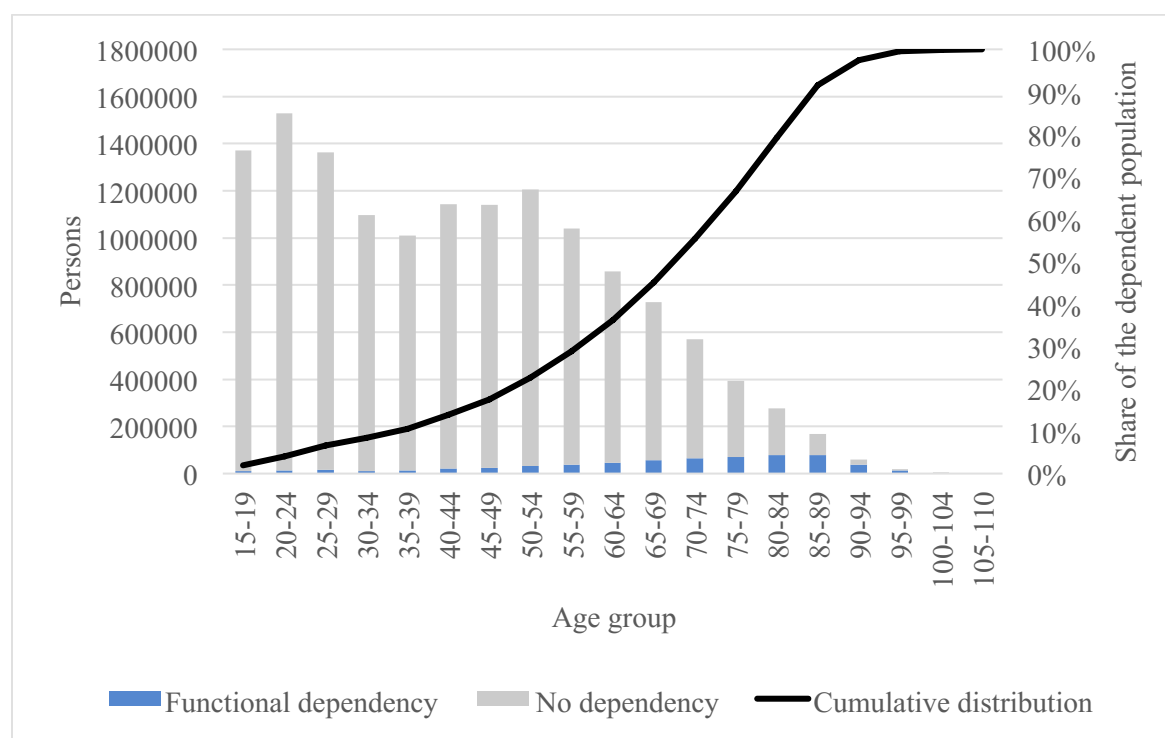


Figure 9. Population by age group and cumulative distribution of dependents, Chile (2015)

Source: Author's elaboration based on CASEN 2015.

Regarding the prevalence by sex, data shows not only that the total number of dependents are mainly women, but also that dependency prevalence is higher for this group: while 3.53% of men over 15 years of age is classified as functional dependent, this number is 5.29% for women.

The larger (total) dependency prevalence among women, this is explained by two facts. First, the ratio women/men is larger at older ages, where the prevalence of dependency is higher (Figures 8

and 9): while 11.17% of men are over 65 years old, this number is 13.87% among women; the share of the population over 85 years is 0.99% and 1.82%, respectively. Second, not only there is a larger population of older adults among women, but also the dependency prevalence is greater in each age group, compared to men (Figure 10).

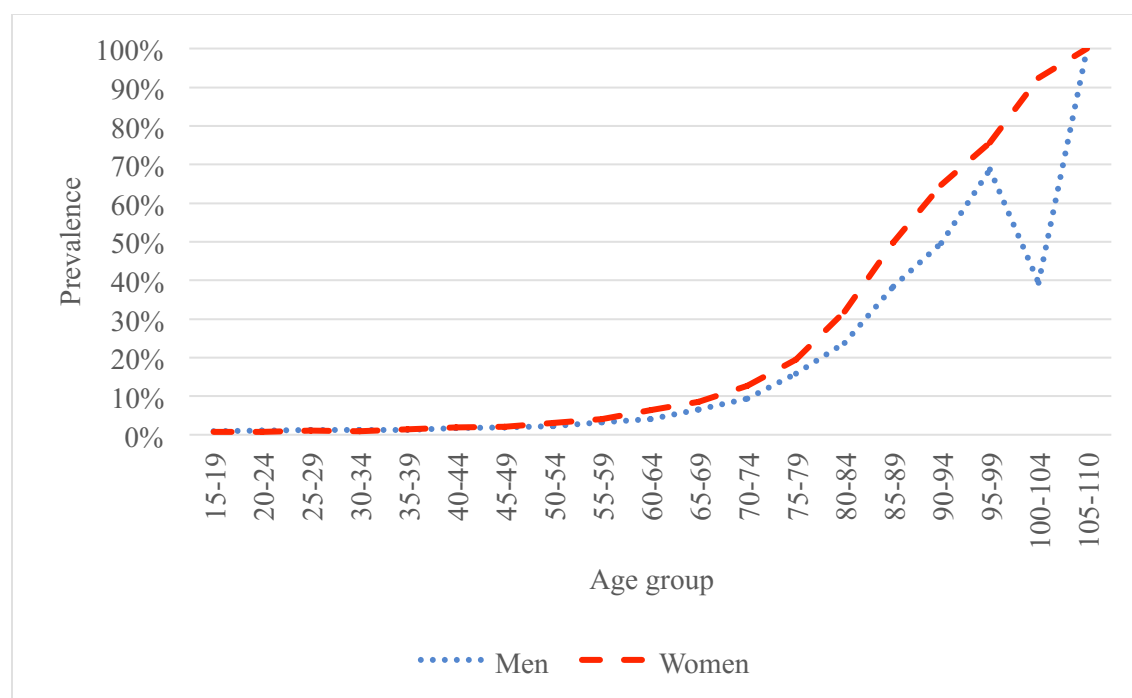


Figure 10. Dependency prevalence by age and sex, Chile (2015)

Source: Author's elaboration based on CASEN 2015.

Now, looking at dependency by severity levels, CASEN also allows classifying dependents into mild, moderate and severe, using the methodology described in MIDESO (2017a) and SENAMA (2010). Considering severity, 32.7% of the dependents are classified as moderate, while 42.9% are moderate, and 24.5% severe. These figures remain relatively stable until population reaches

80 years: from this point, severe dependency increases considerably representing almost half of the dependents. The share of moderate dependents fluctuates around 40% for all ages, which implies that the increase in severity in older ages is compensated with a decrease in the share of mild dependents, as shown in Figure 11:

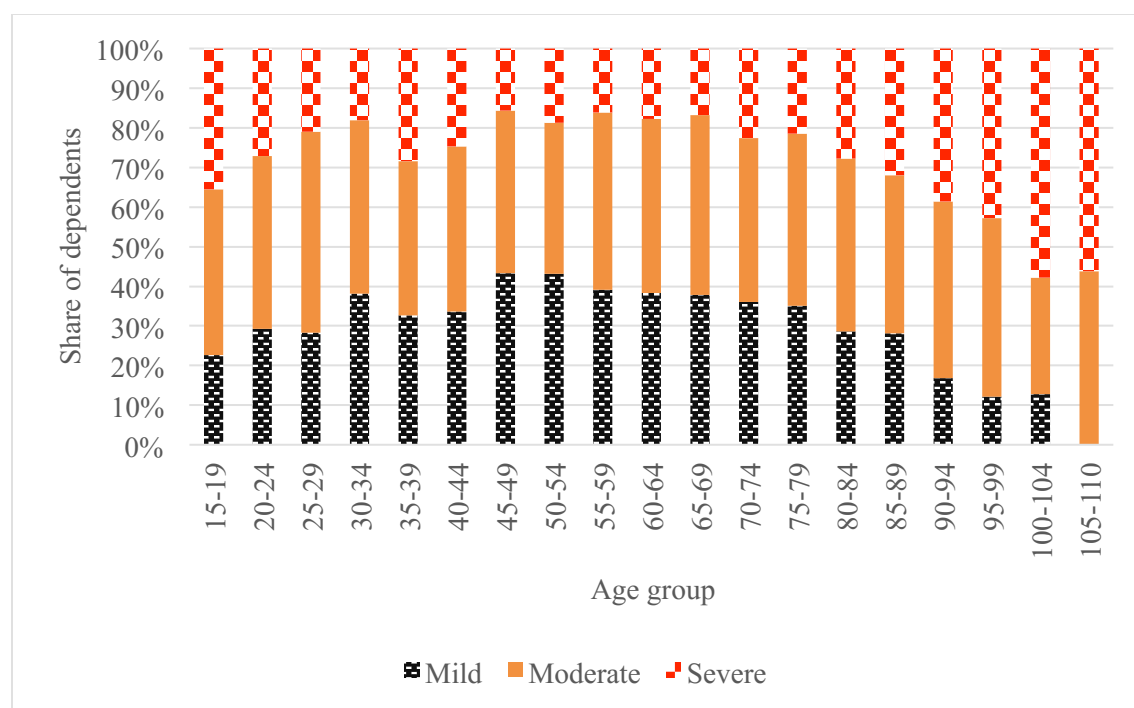


Figure 11. Dependency by level and age group, Chile (2015)

Source: Author's elaboration based on CASEN 2015.

In summary, the CASEN survey shows that more than 625,000 persons can be classified as dependents, with most of them being elderly. Data indicates that dependency prevalence increases progressively with age, growing abruptly after the 70 years threshold. From this point, severity also increases.

These numbers are extremely useful and give a rough estimate of the long-term care needs in the country, but they must be interpreted carefully. First, it is necessary to consider that the survey uses the definitions and methodologies proposed in the Dependency Survey conducted by SENAMA (2010), but excludes people with dementia, which implies an underestimation of the dependents in the country, especially those with severe dependency^{*}. On the other hand, the survey data are self-reported, which generates a second source of potential measurement error.

Other sources of information, such as the monthly statistical summary (*Resúmenes Estadísticos Mensuales*, REM) collected by MINSAL also contains information on the number of dependents in the country. Despite the high frequency of the data (monthly), the information is incomplete, because it only includes people covered by the public health insurance (FONASA), registered in a health center, and attending health controls during the year. Using the estimations from CASEN 2015 (N=625,484), only 15% of the dependents in the country are in control in the public network.

Even though useful for monitoring population in control and production, it is inadequate to design national-level policies. Because data is collected “from the supply” and not “from the demand”, i.e. it only registers people who end up participating in one or more of MINSAL’s initiatives, it is not only incomplete but also biased. In fact, the REM also classifies dependents according to level of severity. Data shows that 31% of the dependents are classified as mild, 16% as moderate, and 53% as severe; these figures differ from those found using CASEN 2015 (33%, 43%, 24%, respectively). This over-representation of severe dependents in the REM database is explained by the presence of several programs targeting severe dependency at MINSAL.

^{*} SENAMA (2010) study classifies people living with dementia as with severe dependency.

Lastly, the fact that information is collected at aggregated level makes it difficult to interpret the data and restricts its analysis. The system collects valuable information in different areas, but since individual identification is not possible, cross-check validations are impossible and identification of particular populations is complex. This limitation greatly reduces the usefulness of this data source to perform different analyzes, in particular, to identify and measure LTC needs in the country's population.

Finally, it is relevant to acknowledge some important steps that have been given in the last years. One of the initiatives that need to be highlighted because of its relevance for the whole project, and particularly because of its effort in progressing in the area of measuring dependency and evaluating LTC needs is the National System for Care (SNAC). The system, originated at MIDESO, started its design phase in 2014 and began implementing pilots in some municipalities during 2016. The system is intended to cover needs dependents and disabled people (Berner 2015). As stated before, the subject of evaluation and measurement of dependency has been central for the SNAC (Instituto de Sociología PUC 2016, MIDESO n.d. a, b, 2017b). As in the case of the statistics coming from the REM-MINSAL, dependency is likely to be measured with some error by the SNAC, because it takes a “supply side” approach, i.e. it collects data from people participating in public programs. In this sense, it is important to move towards the establishment of an instrument to measure LTC needs for the entire population and not just the application of a questionnaire to select beneficiaries. The current instrument proposed by MIDESO to be SNAC’s entry point has this problem, by establishing an entry requirement based on level of dependency (only moderate or severe) and socioeconomic level (60% most vulnerable of the population), which allows having a practical instrument to select beneficiaries, but not to calculate dependency needs in the country. Similarly, the strategy is based on

information from the Social Household Registry (MIDESO 2017b), which necessarily provides a partial view of the supply of public sector initiatives, ignoring the needs of the wider population. Additionally, it is necessary to move towards the inclusion of mental illnesses and a concrete definition regarding their identification in the context of dependency. For example, the calculations of Stallard (2008) in the United States show that almost 38% of people over 65 who would end up being classified with some degree of loss of functionality would fall into this classification exclusively based on some cognitive impairment (defined as a score in the MMSE test between 0 and 23, senility or Alzheimer's) and 35% would have both cognitive impairment and difficulties in performing ADL or IADL; only the remaining 27% of the potential beneficiaries of the system would be eligible based exclusively on difficulties in carrying out activities, definition actually used by most of the instruments measuring dependency in the country. This is an element to consider since cognitive impairment is particularly relevant in elderly people, a group in which the prevalence of dependency is also higher. Ignoring mental illness, particularly dementia, means ignoring an important part of the problem, especially considering that dementia has been identified as the main cause of dependency in older adults in the world and an important contributor to the loss of functionality in Chile and is expected to increase considerably in the coming years (Gajardo and Monsalves 2013; Fuentes and Albala 2014). It should be noted that this combination of physical and cognitive factors in the identification of dependency is not new and it is already being used by the Elderly Functionality Exam (EFAM), applied through the primary care system (MINSAL n.d.). Several countries have recognized this need to use broader definitions of dependency, including dementia, embarking on –often and complex– reforms of their LTC systems, in order to expand their eligibility criteria (Federal Ministry of Health 2009; Jeon and Kwon 2017). Chile has the opportunity to include

these conditions from the beginning, revealing the true dimension of the problem, focusing policies on solving problems, not restricting the current offer, and avoiding future complex and costly reforms.

Finally, the proposed instrument assumes dependency as a dynamic situation, identifying "people in a situation of dependency" instead of "dependents", combining a disability-based approach (permanent difficulties), functionality (problems to perform ADL and IADL), and environmental conditions; the strategy allows detecting people with some degree of dependency and also its cause. The experience of other countries shows the usefulness of implementing an evaluation carried out *in situ* by professionals, which allows evaluating the person and its context, in line with the definition of functionality as a product of the intrinsic capacity and the environment, proposed by WHO (WHO 2015). In spite of this, it is necessary to include an evaluation that allows not only recognizing a combination of difficulties to perform ADL and IADL but also to evaluate its "long-term" nature. As Stallard (2008) shows in estimates for the United States, dependency prevalence calculations are usually biased when they do not include the time dimension: according to his estimates, dependent population would be 15% lower if all the cases in which disability last for less than three months are eliminated

In this line it is necessary, on the one hand, to advance on the formalization of a dependency measure that allows identifying the population of people with dependency in the country and that, additionally, can be used as an instrument for the selection and classification of beneficiaries in a future LTC system and, on the other hand, working in a process that allows the use of existing instruments and information to initiate a transition towards the measurement of dependency in the country.

1.2.3 Projecting LTC needs: Dependency in Chile, 2015-2100

Finally, and aiming to add a temporary dimension to the topic, this section shows projections for the number of dependents in the country in the next 70 years. The exercise seeks not only to raise awareness of the magnitude of the problem today but also to stress that LTC needs and the number of dependents in the country will continue growing at a high rate in the coming years.

The calculations are based on dependency prevalence rates by age and sex obtained from the CASEN 2015 survey (Figure 10). Data on population projections were obtained from CEPAL (2017). The number of dependents for each year was calculated assuming that dependency prevalence rates would remain constant for the period of analysis, implying that estimations reflect exclusively the effect of demographic change (age-sex composition of the population). As shown by Eggink et al (2017) for the Netherlands and Nozaki et al (2017) for Japan, demographic change is the main driver behind changes in demand for long-term care services.

Table 5 shows these estimates. It is observed that the number of dependents increases over time, an increase explained by the growth of the population, the change in the sex composition, and the change in the age composition. In the first place, the country's population will continue to grow until the middle of the century (2055) and then it will begin to diminish. In the case of the population over 65, their number will continue increasing for another 30 years (until 2080). In terms of the number of dependents, it is expected that they will double in a period of just over 20 years (to 2040).

On the other hand, the dependency prevalence is higher in men than in women (Figure 10). The ratio of women to men will decrease in the population: by 2080, there will be more men than women in Chile. This effect attenuates the growth of the dependent population in the country.

Table 5. Evolution of the number of dependents and dependency prevalence in the general population and over 65 years, Chile (2015-2100)

Year	Total population			Elderly population (> 65 years)			% dependents > 65years
	Total	Dependent	Prevalence	Total	Dependent	Prevalence	
2015	17,552,505	625,4844	3.81%	2,218,368	399,268	18.00%	59.66%
2020	18,621,991	648,196	3.48%	2,254,144	403,584	17.90%	62.26%
2025	19,250,535	748,695	3.89%	2,730,545	493,326	18.07%	65.89%
2030	19,785,083	865,597	4.37%	3,253,935	603,638	18.55%	69.74%
2035	20,209,963	996,501	4.93%	3,801,064	733,324	19.29%	73.59%
2040	20,522,038	1,138,382	5.55%	4,257,821	872,732	20.50%	76.66%
2045	20,725,222	1,282,495	6.19%	4,630,621	1,012,618	21.87%	78.96%
2050	20,828,161	1,419,957	6.82%	5,003,324	1,149,157	22.97%	80.93%
2055	20,842,906	1,541,994	7.40%	5,429,533	1,278,944	23.56%	82.94%
2060	20,783,463	1,645,070	7.92%	5,786,905	1,392,117	24.06%	84.62%
2065	20,662,306	1,734,869	8.40%	6,016,062	1,489,793	24.76%	85.87%
2070	20,491,212	1,817,684	8.87%	6,135,319	1,578,132	25.72%	86.82%
2075	20,280,320	1,892,666	9.33%	6,208,009	1,659,526	26.73%	87.68%
2080	20,036,507	1,946,010	9.71%	6,212,564	1,718,665	27.66%	88.32%
2085	19,770,221	1,967,556	9.95%	6,141,657	1,743,959	28.40%	88.64%
2090	19,499,862	1,960,700	10.05%	6,054,071	1,741,011	28.76%	88.80%
2095	19,246,715	1,941,591	10.09%	5,967,527	1,725,828	28.92%	88.89%
2100	19,021,680	1,921,035	10.10%	5,884,205	1,708,662	29.04%	88.94%

Source: Author's elaboration based on CASEN 2015 and CEPAL (2017).

The aging effect is important in elucidating the data presented in Table 5: population over 65 years old will increase rapidly in the coming years, which explains why the prevalence of dependency in this population will almost reach 30% by the end of the century. This growth is mainly driven by the increase in the older among the elders, i.e. people over 80 years old, the population with the highest prevalence of dependency and who will experience high growth rates during the coming years. Figure 12 shows that the number of dependents will double between 2015 and 2045; in the same period, the number of dependents over 65 years old will increase 2.5 and triple in the population over 80 years old. By 2075, the number of dependents in this population (over 80 years old) will be almost six times what exists today.

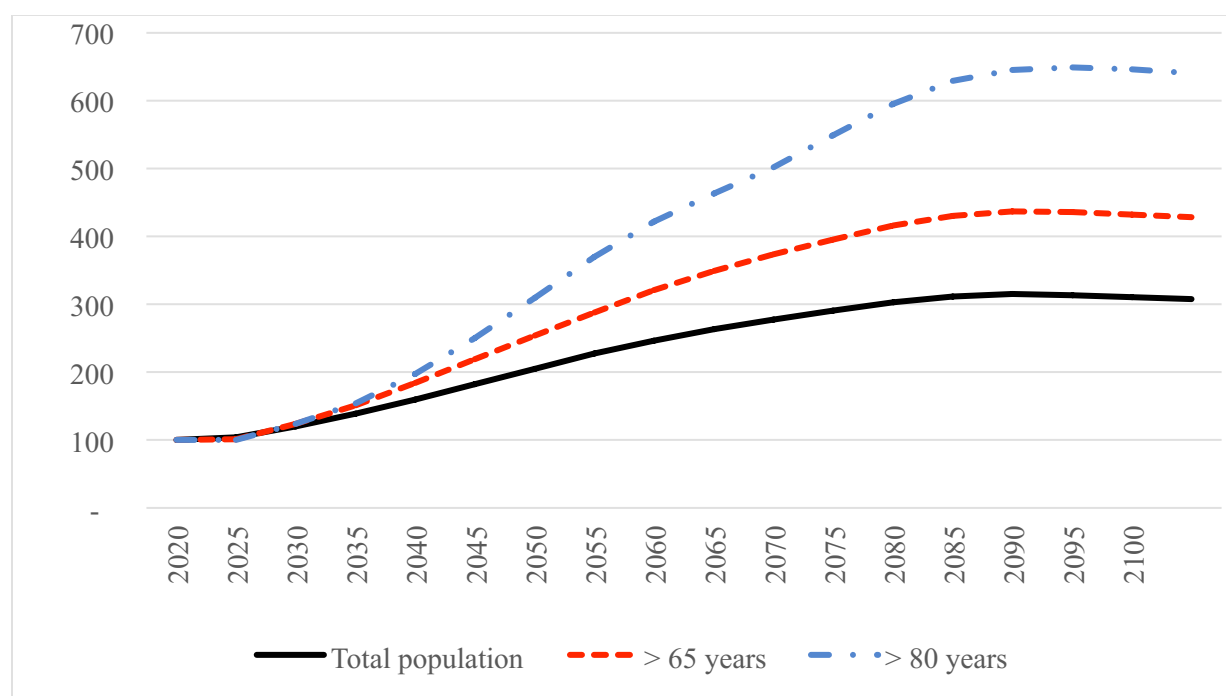


Figure 12. Index of the evolution of the number of dependents for different populations in Chile (2015=100)

Source: Author's elaboration based on CASEN 2015 and CEPAL (2017).

These numbers should turn on the alerts regarding the need to establish a coordinated LTC system to face the challenges of aging and increasing dependency. The estimations shown reflect only the growth due to change in the population age composition, assuming that prevalence rates will remain the same in the future. The figures could be even higher if considering an increasing prevalence of dependency, as reported recently by countries like United Kingdom (Kingston et al 2017).

The section reveals the path traveled by Chile in understanding, recognizing, defining and measuring dependency. The results presented reveals that that country is in a better position than ten years ago to carry out a discussion about the importance of LTC needs in the country, but some consensus is still required. Regardless the differences in the way in which dependency is measured, data shows that dependency prevalence is a 4%, with higher prevalence rates among women and elderly. Projections confirm that dependency and LTC needs will grow at an accelerated path in the following years, highlighting the importance of having a LTC system in place and the need for rapid action.

2. Making the case for long-term care

Hell is truth seen too late.

Thomas Hobbes

2.1 The impact of (not having) a LTC system

2.1.1 Rationale for implementing LTC systems: International evidence

Although there are multiple justifications for the implementation of a LTC system –political (Campbell et al 2009), ethical (WHO 2002), economic (Bloom et al 2015) or legal^{*}–, its economic impact is usually relevant from a public policy perspective, mainly because the implementation of a LTC assumes the need to increase public spending, an item usually controversial for governments. This emphasis on controlling and decreasing spending (mainly on health), together with a focus on the provision of specialized medical services and the fact that LTC has historically been carried out within families have contributed to the slow introduction of LTC systems in the world (Brosdsky and Clarfield 2008; EU 2016). With this idea in mind, this section presents arguments used by other countries in their debate about the implementation of a LTC system.

In general, the economic impact –at the macro level– of a LTC system has two main components (Muiser and Carrin 2007; Rodrigues et al 2013; Rhee et al 2015; Bloom et al 2015; WHO 2015; Norton 2016):

- i. Increase in labor participation and employment: on the one hand, it allows informal caregivers to opt for paid work in the formal sector and, on the other hand, it generates a

^{*} For example, in Chile, Law 20,422 (Establishes equal opportunities and social inclusion for people with disabilities) declares the right to equal opportunities for people with disabilities, as well as the duty of the State in its promotion (BCN 2017b).

new sector in the economy –formal care services– which also creates new opportunities and jobs.

ii. Increased efficiency in the allocation and use of resources for care activities: the LTC system offers more alternatives to respond to population needs, which can be more cost-effective than those traditionally comprised in a social security system. For example, in the case of Germany, Schneider (1999) and Campbell et al (2009) show that this type of problems triggered the appearance of the issue of care in the public agenda: the lack of LTC programs' supply and poverty in adults elderly put an enormous pressure on local budgets for social benefits. Other argument commonly found in the literature is the substitution of beds in hospitals for places in LTC institutions or home care (Brodsky et al 2000).

Regarding the first point, three potential impacts are identified: increase in labor participation, increase in productivity, and creation of new jobs. In the first place, the existence of a system based on informal care means that the entire burden of LTC needs falls on the group of caregivers who usually, and given the characteristics of the caregiver activity, cannot choose another job. The assessment of the economic impact from a labor supply point of view requires an approximation of the number of informal caregivers in the economy as well as an estimation of their economic value in the labor market. As indicated by Arno et al (1999), it is important to bear in mind that there are two approaches to calculate this value: i) opportunity costs and; ii) replacement costs. The first approach measures the loss of income generated to caregivers as result of their care responsibilities, i.e. the salary they could earn by working in a paid job work instead of providing care. The second approach measures the cost of replacing informal caregivers with formal caregivers, based on the market wage for care services. Arno et al (1999)

use the replacement cost approach to calculate the economic value of informal care services in the United States. The decision is based on the fact that many caregivers exceed the retirement age and because this strategy gives a better estimation of the costs of implementing a LTC system. The authors find that the size of the informal care sector in 1997 was US\$196 billion (for about 26 million caregivers), far larger than the size of the formal sector (US\$32 billion in home care and US\$83 billion in institutional care), representing about 18% of the country's health expenditure. Updates of this figure show that the value of informal care increased to US\$450 billion in 2009, reaching US\$470 billion in 2013 (Reinhard et al 2015), a number that considers the existence of 40 million caregivers in the country. A recent report on care in the United States indicates that the number of informal caregivers who do not receive remuneration would be 43.5 million (AARP 2015), about 650 times the estimated number of paid caregivers (roughly 67,000 according to CDC (2016)).

These figures show how a big problem is rendered invisible. As stated in section III.2 (“The inaction problem”), the (perceived) existence of a problem is required to advance in its solution (Kingdon 1995); in this case, numbers like those presented for the US and the underestimation of the number of dependents in the country –as shown in section IV.1.2 (“What do we know about dependency in Chile?”) for Chile– creates the sensation that the probability of dependency and its costs are negligible, which explains the low level LTC services coverage and the low level of population demand for a better system (De Donder and Leroux 2013; Caruso et al 2017).

Although the economic value of informal care is difficult to estimate, the estimations for developed countries show that even considering potential underestimation problems, the numbers are huge (Norton 2016).

In addition to reducing the likelihood of employment, informal care can also have an impact on productivity. This means that caregivers who work in the formal sector end up receiving lower wages than those who do not have care responsibilities (Rodrigues et al 2013). The impact of being a caregiver on productivity can be explained by a lower accumulation of human capital (less education, fewer years of work experience, worse health condition). Informal caregivers may also have more problems finding a job (especially women) and a larger probability early retirement, which impacts not only their current salaries, but also their future income and social protection coverage, particularly in systems where coverage is linked to contribution or working condition (Lilly et al 2007; Norton 2016).

Finally, a LTC system also creates new markets and jobs. Given that the system requires professionals and firms providing the services established in the benefit package, its implementation increases the demand for workers who develop these activities in the formal labor market. For example, in the case of Republic of Korea, a marked proliferation in job demand for LTC workers was noted after the implementation of its LTC system: the number of workers in health services increased from 37,684 in 2008 to almost 252,000 in 2013 (Choi 2015) and has continued growing in recent years (Jeon and Kwon 2017). Additionally, many countries have taken advantage of the injection of new resources to fill the gaps in the country's infrastructure in terms of care, which also generates an impact on job demand services (Geraedts et al 2010; Schultz and Tompkins 2010; Choi 2015).

Regarding the second point –increase in allocative efficiency of resources– different arguments can be found in the literature. First, the direct impact of a greater expenditure made by the social security system (substitution). In this regard, anti-poverty policies for dependents (social benefits) and the use of health resources (hospital beds) in providing (non-medical) services to

patients requiring long-term care are usually pointed out as relevant costs of not having a LTC system (EU 2016). A good example of the first type of allocative distortion (coming from social expenditures) is the case of Germany; the country uses the pressure that dependent older adults placed on the local budget earmarked for social benefits as its main argument for the implementation of a LTC system in the mid-1990s (Schneider 1999). On the other hand, one of the most emblematic cases regarding the use of health resources as the rationale for a LTC system is Japan (Rhee et al 2015). As Campbell and Ikegami (2000) point out, population aging rapidly led to an increase in health sector expenditures: between 1963 and 1993, the number of hospitalized elderly persons multiplied by ten. By that time, elders used half of the hospital beds and one third of these patients ended up living in the hospital for more than a year. All the expenses were financed by health insurance, even when the patients did not require medical supervision. This was also the argument used by the United States when, in 1965, it began to finance nursing homes for poor elderly, in order to reduce the financing of more complex care centers (Norton 2016). Similar discussion was held in South Korea, where the main concern was the high health system costs: given the rapid aging and a family care system in crisis, there was a concern that unnecessary medical expenses in elderly people would increase greatly, idea that gave support to the implementation of the LTC system (Choi 2015). In the case of Korea, these were the arguments used by the Ministry of Health and Welfare to convince the Ministry of Finance and Economy. The LTC system has several objectives: from the social point of view, it seeks to reduce the financial burden on the elderly, while also reducing the burden on the health system by reducing admissions to intensive care hospitals (Kwon et al 2015; Kim and Lim 2015). These arguments also justify the application of universal rather than focused programs (Brosdsky and Clarfield 2008). The rationale in the German case was similar. As stated by

Geraedts et al (2010) the lack of social support creates incentives for caregivers to stop working, which deteriorates their financial situation and motivation to continue providing care. This situation encourages families to send patients to nursing homes before nursing services were required, implying an overuse of these facilities, which translated into a greater cost for the country.

A different line of argument has to do with the justification for government intervention based on the existence of market failures. As in the case of health (Arrow 1963), LTC has a series of characteristics that make it an imperfect market and, therefore, enhance the role of government in its design and implementation (Norton 2000; 2016). LTC services are not only affected by the traditional problems of adverse selection and moral hazard, but also present additional problems: longer periods of time increase the uncertainty, existence of crowding-out between public and private insurance, and inability of people to determine their risk of dependency, generates under provision of private services in these markets (Brown and Finkelstein 2007; Coe et al 2015; Norton 2016).

Despite these arguments, the example of many countries that have implemented LTC systems shows that the discussion does not revolve around implementing or not implementing the system, but the way to do it. Countries incorporate the economic dimension into the debate as an important issue, but the decision is not based exclusively on a cost-benefit analysis. In their analysis of five LTC systems, Brodsky et al (2000) show that these countries have introduced the LTC issue into their social security systems not only by changing laws but also devoting resources. As Norton (2016) points out, the demographic change triggered a change in the vision regarding the responsibility of care, from a paradigm in which families were the exclusive responsible to one where the government assumes a preponderant role which explains why currently all developed

countries provide some type of LTC service with public financing. For example, in Germany, the debate about implementing a LTC included the economic argument based on the need to reduce the local social expenditure, but was mainly grounded on the idea that paying for LTC services usually exceeds the payment capacity of the families which constitutes a risk that, according to the principles of the German welfare state, must be covered by the social security system (Geraedts et al 2010). Similar discourse appears in the Dutch case, in a system that includes elderly and everyone with chronic diseases, under the premise that expenses are so disproportionate that cannot be covered by the private market: the system's philosophy is that every person in the country must be insured against the high expenses of basic care (Mot et al 2010). Finally, the report made by the European Commission (EU 2016) shows that while most countries share concerns regarding the financial sustainability of their LTC systems, they perceive cost containment investment in LTC systems (including allocating more funds) as equally relevant.

This fact raises the need to consider the approach taken by other countries that have made progress in the topic of LTC: LTC systems are an integral part of the social security system and should be considered from an entitlement approach. The discussion regarding the cost containment in the system is important but has to be part of the debate on the system's design, not as the sole argument to start the conversation.

2.1.2 An approach to evaluate the impact of a LTC system in Chile

Using the ideas presented above, Figure 13 presents a scheme to understand the response of society to LTC needs from the perspective of the Chilean social security system. The structure includes the arguments wielded in other countries regarding the need of a LTC system, as well as

the features of the Chilean social security system. According to the Undersecretary of Social Welfare, the Chilean social security system is composed by four components (SPS 2017):

- i. Pension system
- ii. Health system
- iii. Insurance for work accidents and occupational diseases
- iv. Unemployment insurance

These components aim to provide protection against different contingencies, related to the generation and availability of income and health status. On the one hand, the goal of the pension system and unemployment insurance, together with another series of programs and social benefits, is to ensure an income that allows families to exercise their rights (MIDESO 2017c). On the other hand, the health system aims to provide rights and deliver services to the population in the face of the contingencies of illness and pregnancy. Finally, the occupational safety system combines both objectives, aiming to prevent and protect workers from accidents and occupational diseases, caring for both their health and income. In this scheme, a LTC system is also located at the intersection of the social/labor and the health system^{*}.

Figure 13 presents a structure to identify flows in the Chilean social security system, in order to better understand the impact of a LTC system from a financial perspective. The scheme starts with the existence of LTC needs in the country and the way in which these needs are addressed by the current social security system. The black box at the left of the picture contains the

^{*} Additionally, the LTC system has another particular feature –the long-term dimension–that gives it a special category. Thus, for example, the social/ labor protection system explicitly distinguishes between transitory benefits (unemployment insurance) and those where the flow of benefits is uncertain over time, presumably from an extended period (such as pensions).

estimation of LTC needs, a box that, as discussed in sections III.1 (“The overarching problem”) and IV.1.2.3 (“Projecting LTC needs”) is expected to grow in the coming years. In a context in which a LTC system is in place, these needs could be addressed by the system, represented by arrow A. In the absence of this option, LTC needs are channeled through different ways.

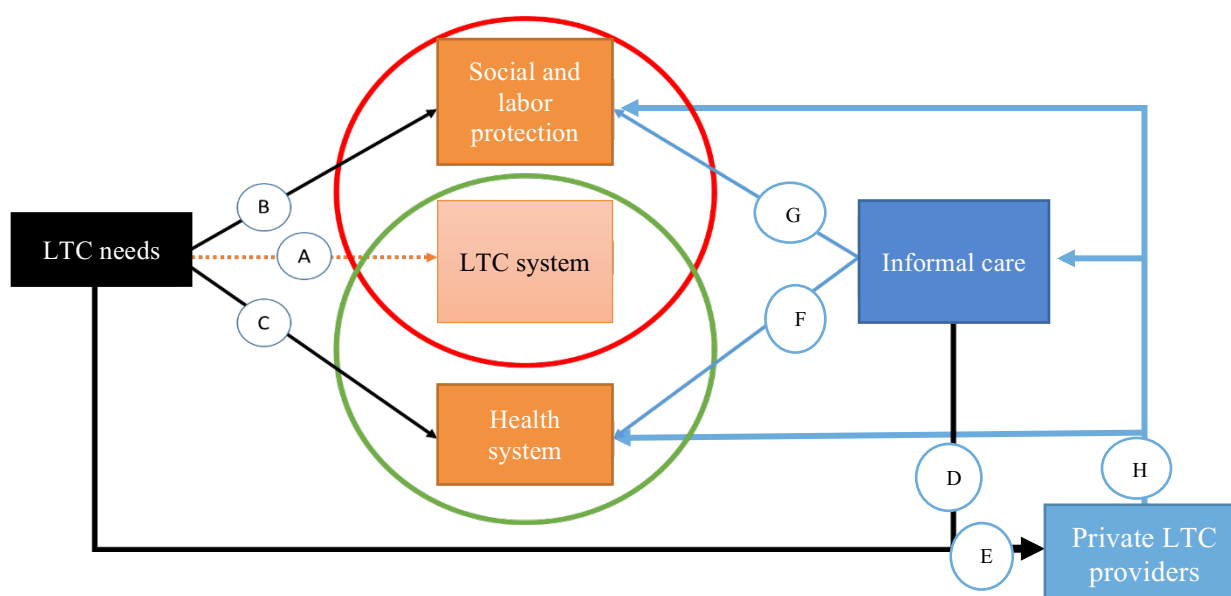


Figure 13. A scheme to assess the impact of LTC from a social security perspective

Source: Author’s elaboration.

In the first place, part of these needs is absorbed by the social security. On the one hand, the social and labor protection system generates actions and uses its apparatus to respond to some of these needs, for example, through subsidies to families and financing long-term care facilities (arrow B). On the other hand, the health system receives people with LTC needs that do not require healthcare services. As in the case of the social protection system, the health system uses its already installed capacity to respond to these demands (arrow C).

However, as in many countries, most of these needs move outside the social security system, ending up in the private realm (Colombo et al 2011). On the one hand, a big portion of these needs is expected to be assumed by informal caregivers (arrow D), while some demands will be met by private providers outside the social security system (arrow E). The fact that social security in Chile does not include a component of LTC means that part of the problem does not enter directly into the social security system, apparently reducing the burden for the government. However, as shown by the blue arrows in the figure, these initial savings are likely to re-enter the system in a different way: because provision of LTC services is carried out by informal caregivers, they bear its costs in terms of time, physical, psychological and emotional health (Rogero-García 2010; Adelman et al 2014). As the literature shows (Colombo et al 2011; Rodrigues et al 2013; Norton 2016), this translates into a decrease in labor supply and income-generating capacity, increasing the risk of poverty (arrow G), and a greater burden of disease in caregivers (arrow F). The foregoing implies that the social security system receives, indirectly, the burden generated by the demand for LTC services. Because the private market of LTC services is unregulated, extra resources will also need to be devoted to solving situations generated by the provision of low-quality services (Matus-López and Cid 2015; WHO 2017a), situation depicted in arrows H, coming from the “Private providers” box. These flows would not exist or would be lower with a LTC system in place.

In summary, in a context where there are LTC needs but no LTC system, the social security system ends up adapting the problem to the solution. In terms of the described "direct impact" (arrows B and C), this means that the system takes those problems and tries to solve them with its available tools. In the case of Chile, this is done through a set of public programs with LTC components, as well as subsidies for elderly and disabled people (in the case of social programs)

and healthcare services (in the case of the health system). In terms of the "indirect impact" (arrows F and G), the system "translates" these demands for which it has no answer, in a problem that it can solve with its capacities and experience (subsidies, healthcare services).

Finally, it is necessary to discuss the magnitude of these flows in a scenario with and without a LTC system, which requires an economic analysis of the problem. As described by Drummond et al (2015), this type of analysis is important since it allows identifying relevant alternatives, including different perspectives, quantifying and approximating orders of magnitude, and increasing the transparency of decision-making processes.

On the one hand, the existence of a LTC system, in which the elements presented in Figure 13 are included as part of the social security system^{*}, eliminates black and blue arrows but requires investments in its design and operation, including the establishment of institutions to govern the system and deliver services. The system can also generate other benefits, such as creation of new markets and innovations, and promotion of employment (Rhee et al 2015; Scheil-Adlung 2015; WHO 2015).

On the other hand, addressing LTC needs through informal care generates both benefits and costs (Knapp and Somani 2008; Rogero-García 2010; Adelman et al 2014; WHO 2015) that need to be considered. First, it generates saving by using part of the capacity already installed to respond to these demands. Informal care can have positive effects on patients and caregivers, in terms of their personal satisfaction and contribution to the care of a loved one: it can be emotionally rewarding because it affirms family ties, honors past service the caregiver received

^{*} The implementation of a LTC system within the social security system does not imply the extinction of informal care of private LTC providers, but its inclusion as part of a larger system in which, for example, informal caregivers and private providers can opt to benefits coming from the system and where quality of service can be monitored and enforced.

from the person in need of care, and save family resources. However, this option is not costless: there are direct and indirect costs assumed today by families that provide informal care services, such as spending on supplies for care and opportunity costs for caregivers (for example, in terms of education and job opportunities). Second, it generates costs in terms of efficiency when using the social security system and its institutional framework to cover these demands (Rhee et al 2015). These costs can be explained by:

- i. Coordination: the existence of several instances decreases the effectiveness and efficiency of the response. On the one hand, current programs do not focus on people with LTC needs. On the other hand, lack of coordination also generates overlap between different initiatives.
- ii. Specialization: the current system was not designed to meet LTC needs. Similarly, informal caregivers do not have training and tools to deliver the services required by their patients; additionally, their own health problems result in a deterioration of the quality of care provided. This implies a lower efficacy and efficiency in the provision of services (Arechalaba et al 2011; Ejem et al 2015; WHO 2017a).
- iii. Opportunity: because part of the LTC needs is not solved timely, and because the informal system generates a new flow of needs in the medium-term, the flow of LTC needs increases from one period to another. This is particularly important in the case of dependency, understood as a condition in which prevention and rehabilitation strategies can be applied (WHO 2015, 2017).
- iv. Evolution: LTC needs will increase, which will also increase the efficiency and efficiency problems described above. Additionally, the combination of a formal system of small size and growing demand increases the costs of care (increase in both price and

quantity), which generates incentives to substitute formal care for informal care (EU 2016; Eggink et al 2017; Nozaki et al 2017; Caruso et al 2017), generating a vicious circle that can exacerbate these problems.

The proposed framework it is useful to structure the debate about the effects of a LTC system. As stressed by WHO (2017a), “...few regional or national frameworks exist to guide more specific action. Focused debate has been largely absent, reflecting the low policy and political priority accorded to long-term care, combined with a belief that the issue has little impact on economic development.” In this sense, this framework can be used to identify different costs and benefits of a LTC system, helping stakeholders in advocating for LTC policies in Chile and other countries.

2.1.3 Impact of a LTC system in the health system: Direct and indirect costs

As proposed in the previous section, there are several costs associated with not having a LTC system. This section uses the scheme presented in Figure 13 to identify some of these costs. The analysis is divided in direct and indirect costs, i.e. those that are currently assumed by the social security system, particularly the health system (arrow C) and those that reenter to the system via informal care (arrow F).

a. Direct costs

First, the figure proposes the existence of flows coming from LTC needs that enter directly into the social security system (arrows B and C), representing resources currently used in trying to respond to population's LTC needs. As discussed in section IV.2.1.1 (“Rationale for

implementing LTC systems”) one of the main concerns and arguments utilized by countries when deciding about the convenience of having a LTC system is related to the potential savings this can bring to the healthcare sector. The assumption behind these savings is the existence of patients using the health system without requiring healthcare services (the so called “social patients”), and the fact that other services, such as LTC services, are cheaper.

The topic has been identified as relevant in Chile. In 2015 the Ministry of Health (MINSAL) launched the program “*Camas Sociosanitarias*” whose goal was to reduce hospital stay and encourage the use of home-based care. The program was designed under the assumption that many patients in hospitals were “socio-sanitary patients” (or were using “socio-sanitary beds”), i.e. people that remain at hospitals after being discharged or, equivalently, keep using health resources without needing healthcare services. The program estimates that 36% of the long-stay cases (longer than a month) of elderly in hospitals are socio-sanitary patients (MIDESO 2016). In 2017, it has a budget of CLP\$824 million (US\$1.2 million).

A recent study by MINSAL (Figuerola 2017) addresses the issue and provides estimates of the number and costs of using the so-called “socio-sanitary beds”. The study indicates that, to date, there was no estimate of socio-sanitary demand in the country, despite the fact that this has been identified as a relevant issue, with important economic and health consequences. The study uses the concept of “biosocial dependency risk” –a scale based on both the risk of social dependency and the need for care– to identify socio-sanitary users in the country's health system. Information was collected in two stages (September-December 2016 and January-April 2017) at the national level. Data shows that approximately 60% of socio-sanitary patients are elderly, with an average age 65 years. Although there is variability with respect to the average stay of these patients in the different health services, the second stage of the study concludes that, on average, socio-sanitary

patients stay 69 days in the hospital, with ranges that vary from one day up to more than six years. This information was obtained from 4,600 records and a total of 3,782 socio-sanitary patients. From these data, the study made estimations to approximate the cost that these patients impose to the Chilean health system. Costing is based on the number of socio-sanitary users and the number of bed days used by them in a given month. The study finds that on average (using the period September 2016-April 2017), there are 702 socio-sanitary patients per month occupying a bed in the public network. The analysis concludes that the total cost of these patients is CLP\$19,000 million per month (approximately US\$29 million).

In order to complement the results presented by Figueroa (2017), an additional analysis was made using hospital discharge data from MINSAL. Contrary to the strategy adopted by Figueroa (2017), this analysis used information on total hospital discharges for the period 2005-2015, instead of samples from different patients in certain periods of time. It also uses a different definition for socio-sanitary patients based on the identification of statistical outliers, i.e. patients outside a certain range of normality with respect to a standard length of stay. Standard time of stay was defined using the average length of stay of patients admitted to a hospital with the same health condition, using International Classification of Diseases, version 10 (ICD-10) codes.

The analysis used different definitions of outliers to identify potential socio-sanitary patients. First, results show that although the number of discharges has remained stable during the past 10 years, the number of bed days has increased in the hospital system, driven by increases in the length of stay of long-stay patients (outliers). Second, using different estimations for the cost of a day bed in public and private hospitals, it finds that the annual cost of these patients ranges from US\$81-265 million, i.e. between US\$1,000 and US\$1,800 per person. Finally, the study estimates the cost differential of the patients being in a hospital versus receiving LTC services.

Using several estimations for the cost of a home-based care model, the results show that the extra cost of caring these patients in a hospital versus providing services through a LTC system ranges from US\$689-19,600 million per year (see a description of the methodology and sources used in Appendix 4).

Although the analysis has several limitations, it gives an order of magnitude for the cost of socio-sanitary patients in the Chilean health system, which constitutes a portion of the resources depicted by arrow C in Figure 13. The study highlights the relevance of considering LTC as an alternative to provide better services to people with LTC needs and as a strategy for cost reduction in the health system. The figures are high compared, for example, with the current public expenditure in LTC programs: while the extra cost born by the health system reaches almost US\$1,000 million in a year, the total budget of the National Elderly Office, SENAMA – considering all its programs, activities and administrative expenses– was US\$29 million in 2016.

b. Indirect costs

One of the main differences between a formal and informal LTC system refers to the role played by caregivers as central providers of LTC services. In this context, they assume most of the direct and indirect costs of care. From this perspective, the main impact of lacking a LTC system are those depicted in Figure 13 as flows coming from arrows F and G, i.e. effect on health and the change in labor participation and the consequent effect on income for informal caregivers.

Who are these caregivers? First, it is necessary to consider the existence of different definitions of caregivers and the fact that these differences give different results when trying to establish the “caregiver profile” (Schultz and Tompkins 2010, Colombo et al 2011, WHO 2015). With this

caveat in mind, the literature shows that caregivers are mostly women –wives, daughters or daughters-in-law– over 45 years of age. Colombo et al (2011) show that in OECD countries more than 10% of adults are involved in some kind of informal care. In general, caregivers have some kinship relationship with the dependent. These patterns are also observed in low and medium-income-countries: caregivers are women, usually children or spouses (Mayston et al 2014; WHO 2017a). In the OECD context, Colombo et al (2011) also found that most informal caregivers devote a limited amount of hours to caregiving, with more than 50% of caregivers reporting spending less than 10 hours a week, which is explained by the existence of a formal LTC system; this pattern changes in countries such as Korea, which implemented its LTC system in 2008, but have a long tradition of informal care.

In terms of caregivers' profile, Chile exhibits a situation similar to that found in other countries. As stated before, it is important to consider that there is no single definition of caregiver and that adopting a definition is crucial to compare profiles between different studies. As shown by Riquelme et al (2007), Arriagada (2011), and Chacón and Rojas (2016), caregivers can be classified according to: education and level of training (formal and informal), responsibility level (main and secondary), type of service provided (direct or indirect), remuneration scheme (paid and unpaid) and relationship with the patient (relatives and non-relatives).

Several studies in different contexts and populations (Riquelme et al 2007; Albala et al 2007; CCI 2007; Jofré and Sanhueza 2010; Arechabala et al 2011; Espinoza and Jofré 2012; Flores et al 2012; Benavides et al 2013; Rosson et al 2013; Slachevsky et al 2013; Aporto 2014; Orta et al 2016) as well as statistics from national surveys (MINSAL 2006; SENAMA 2010; MIDESO 2015b; MIDESO 2017a) show that features of caregivers in Chile are similar to those highlighted by the literature, using experiences from other countries. Despite the different definitions of

caregiver, context of care (children, elderly, different degrees of dependency, different health problems) and definitions used in the studies presented (disability, dependency), there are some patterns that clearly emerge from the data.

Table 6. Caregiver profile in Chile

Variable	Studies in specific populations	National surveys
Women (%)	65-91	67-96
Older than 55 years (%)	50-60	7-45
Age (average)	40-59	51-54
Daughter/son (%)	18-51	20-38
Spouse (%)	11-76	28-53
Daily hours of work (average)	17-21	16
More than 15 hours per day (%)	71-83	n.d.
Years as caregiver (average)	5-9	n.d.
More than 5 years as caregiver (%)	39-69	n.d.

Source: Author's elaboration based on results reported by studies listed in section IV.2.1.3.b.

First, studies confirm that in Chile care labor is mainly carried out by women, revealing a gender bias explained by the traditional role of women in the Chilean society but, at the same, showing how informal care contribute in perpetuating these inequalities (Vaquiro and Stiepovich 2010; Arriagada 2011; Hardy 2017). In general, the role of women as caregivers is predominant, similar to what is observed in other countries. Similar to what is exhibited by international data, the average age of caregivers is close to 50 years, with most of them being offspring or spouses.

Finally, the caregivers use a large part of their day in tasks related to care, and most of them have been in this role for several years. Caregivers differ from people with LTC needs, both in terms of demographic profile and their needs and demands, reinforcing the idea that the social security system "transforms" one problem into another, and adapts it in order to respond to these needs through its current institutions and capabilities.

From a health perspective, the indirect effect of lacking a LTC system in Chile (arrow F in Figure 13) comes from the growth in the demand for healthcare services coming from caregivers and increases in utilization rates from people with LTC needs.

In general, it is possible to argue the existence of positive and negative effects of informal care (Rogero-García 2010; Adelman et al 2014): on the one hand, and as indicated above, families often choose home-based care, which undoubtedly constitutes a positive element factor in emotional and psychological terms. However, this decision also entails a series of negative effects on health, related to the workload borne by caregivers, which reduces their physical and mental health. These problems are manifested as a result of several factors, among others that the caregiver neglects his own health and social life, the existence of family deterioration as a result of the relationship between caregiver and the relative being cared, and frustration due to lack of preparation and technical knowledge (Breinbauer et al 2009; Chacón and Rojas 2016). If the issue of LTC is imperceptible, problems faced by caregivers are even harder to see, making them invisible patients in the health system (Adelman et al 2014).

Some of these effects have been operationalized through the concept of caregiver overload, usually measured using the Zarit scale. The instrument was validated for Chile (Breinbauer et al 2009) and has been extensively used in studies on caregivers in Chile (Riquelme et al 2007; Albala et al 2007; CCI 2007; Jofré and Sanhueza 2010; Vaquiro and Stiepovich 2010; Espinoza

and Jofré 2012; Flores et al 2012; Benavides et al 2013; Rosson et al 2013; Slachevsky et al 2013). As described previously, the impact on caregivers' condition also affects people receiving care, since deterioration in the caregiver's health decreases the quality of care provided (Arechalaba et al 2011; Ejem et al 2015). Several studies for Chile show the effects of the care tasks on caregiver's health (Riquelme et al 2007; Albala et al 2007; CCI 2007; Jofré and Sanhueza 2010; Arechabala et al 2011; Espinoza and Jofré 2012; Benavides et al 2013; Rosson et al 2013; Slachevsky et al 2013; Aporto 2014; Centro Estudios de Vejez y Envejecimiento UC 2015; Orta et al 2016; Chacón and Rojas 2016). Although evidence differs according to the type of patient and care provided, all caregivers report significant levels of overload, as well as negative effects on health status, including physical problems and depression, similar to results reported in other countries (Colombo et al 2011; Rodrigues et al 2013). Table 7 presents a summary of results for studies on caregivers burden and health problems for Chile.

Table 7. Health effects on caregivers: Studies in Chilean populations

Health condition	Sever burden (Zarit)	Risk factors	Protective factors
Severe dependency	28%-75%	Care time (years)	Monetary allowance Human help (respite) Institutional support
		Intensity of care (hours/day)	
Parkinson/dementia	35%-63%	Level of dependency	
		Women caregiver	
Dependents (general)	11%-55%	Lack of support	

Source: Author's elaboration based on results reported by studies listed in section IV.2.1.3.b.

Regarding protective and risk factors, results for Chile are also similar to those found in other countries, with care home-based care and age of patients showing the greatest negative effects on health perception and depression, and income appearing as a protective factor in all cases (Rodrigues et al 2013). Similarly, the existence of a support system for care work (for example, a LTC system) shows important effects in reducing the overload of caregivers. For example, studies in Japan show favorable effects in terms of emotional burden and satisfaction after the introduction of the LTC system (Tamiya et al 2011; Umegaki et al 2014).

Finally, indirect costs can also be identified in terms of income. As shown in Figure 13 (arrow G), LTC needs that do not enter into the social security system are solved in an informal care setting; care tasks generates not only health effects on caregivers and families, but also important economic impacts. This means that some of these families will require government support (social and labor policies) in the future. As in the case of health effects, several studies have compiled the economic impact of informal caregiving in the Chilean families (FONADIS 2004; MINSAL 2006; Riquelme et al 2007; Albala et al 2007; Bravo and Puentes 2012; Espinoza and Jofré 2012; Aporta 2014; Centro Estudios de Vejez y Envejecimiento UC 2015; MIDESO 2015a; MIDESO 2017a; Hojman et al 2017). All the studies show an effect in terms of decisions regarding labor market participation, which usually generates an impact on family income. Studies show that caregivers report not having many options when deciding what to do with their time, with a majority indicating that becoming a caregiver (and opting out from the labor market) was not a choice, which clearly represents not only a restriction on labor participation and families' income generating capacity but a broader restriction on their opportunities and capacities (Sen 1985).

It is important to note that because of this lower participation in the formal market, many households with LTC needs also report not being covered by the social security system which adds an extra factor to their precarious economic situation, exposing them to financial risk related to health status, a risk that is greater in homes with elderly (Cid and Prieto 2012). This issue is particularly important for this population since they also face higher direct costs related to LTC needs, which are usually paid out-of-pocket (Scheil-Adlung 2015).

Using information from CASEN 2015, it is found that most caregivers in the country (93%) are unpaid. As shown in Figure 14, only 2% of people with LTC needs pay for a “formal” caregiver (labeled as “external paid”); the remaining 98% uses home-based care provided by a relative (labeled as “home”), friends (labeled as “external unpaid”) or a combination of these options in which the primary caregiver (a relative) receives part-time help from another person in performing care tasks.

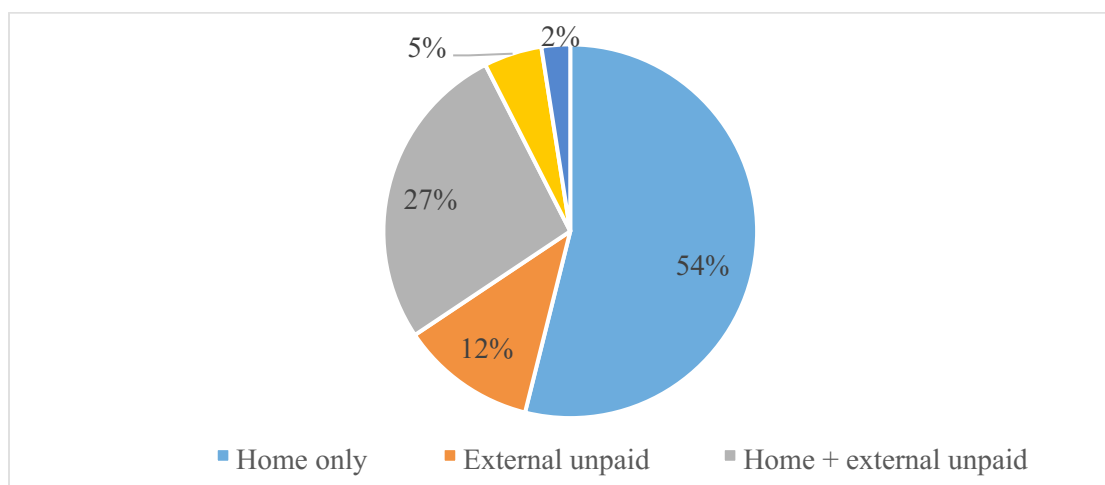


Figure 14. Type of caregivers in Chile (2015)

Source: Author's elaboration based on CASEN 2015.

Regarding labor participation, primary caregivers are much less likely to participate in paid jobs than the other people (the difference is statistically significant between both groups). Both groups also differ regarding willingness to work: while among caregivers 80% answered that they would be willing to work if a job is offered, this figure only reaches 35% for those who are not caregivers, in line with the idea that the caregivers marginalization from the labor market is, to some extent, non-voluntary.

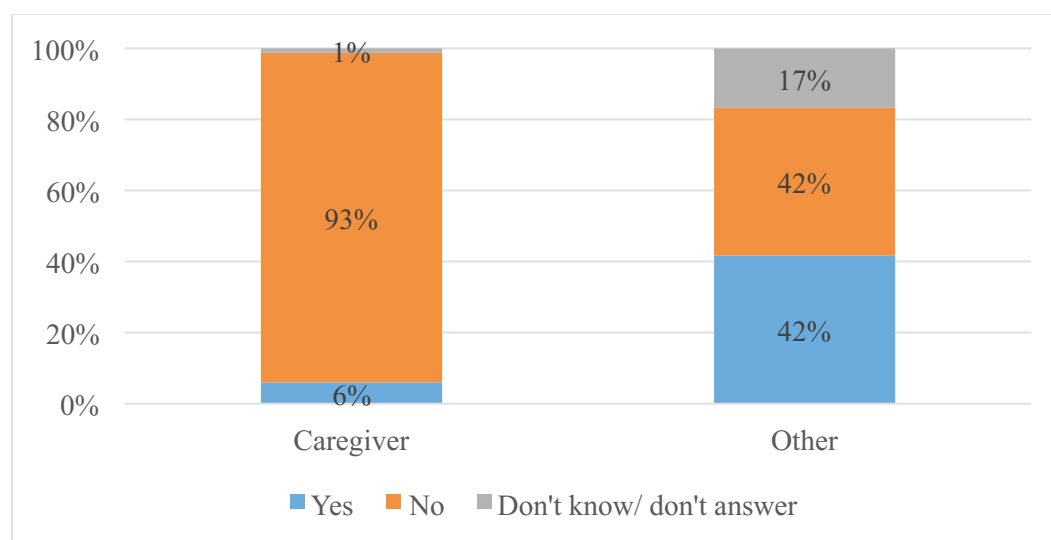


Figure 15. Caregivers' labor market participation: Last week, did you work at least one hour in a paid occupation?, Chile (2015)

Source: Author's elaboration based on CASEN 2015.

When inquiring into the reasons for low labor participation, data shows that this decision is related to their responsibilities as caregivers and that many of them would want to have a paid job but they feel that they cannot stop providing care. In both groups –caregivers and others–, the main reason for not looking for a job is related to having another activity or income. However,

when analyzing figures in detail, important differences are observed between the two groups: in the case of the caregivers, the majority are retired and homeowners, while non-caregivers are mainly students. This shows the need to be careful about the interpretation these results since, although there is a relationship between the role of caregiver and work condition, this relationship is not necessarily causal: higher prevalence of unemployment among caregivers can also be explained because people who decide not to participate in the labor market (or those with health problems) are more likely to stay in their homes and provide care services (reverse causality) (Rodrigues et al 2013). In any case, Figure 16 shows that family issues –mostly related to proving care for a relative– are much more important in the case of caregivers, with “not having another person to care for an elderly” declared as the main reason to stay out of the labor market.

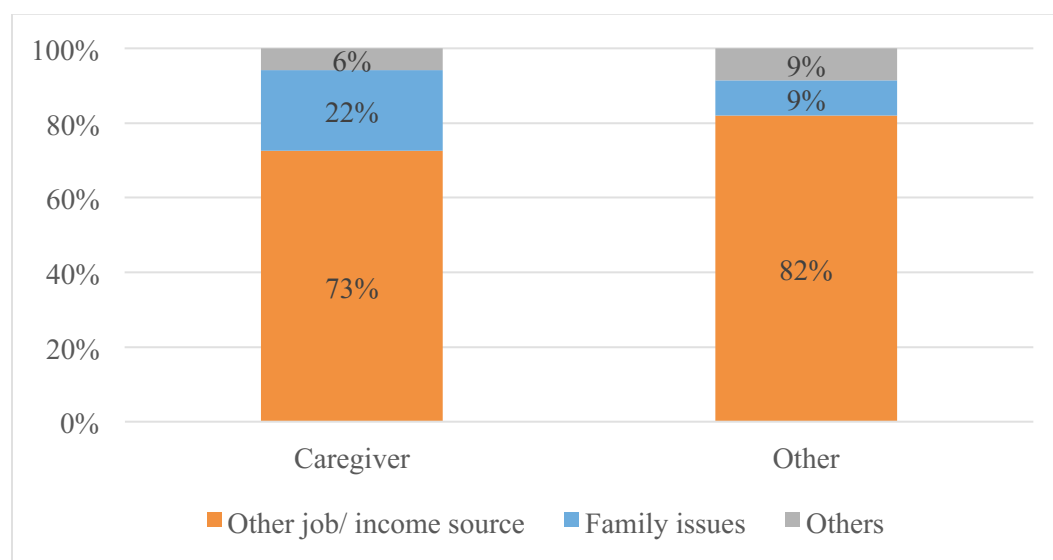


Figure 16. Reasons for not searching a job in the last month, Chile (2015)

Source: Author’s elaboration based on CASEN 2015.

These results, as expected, translate into higher levels of poverty in households with dependent persons, adding a new dimension of analysis to the problem: income inequality. As exhibited in Figure 17, the percentage of households in poverty is almost twice for households with dependents versus households without dependents.

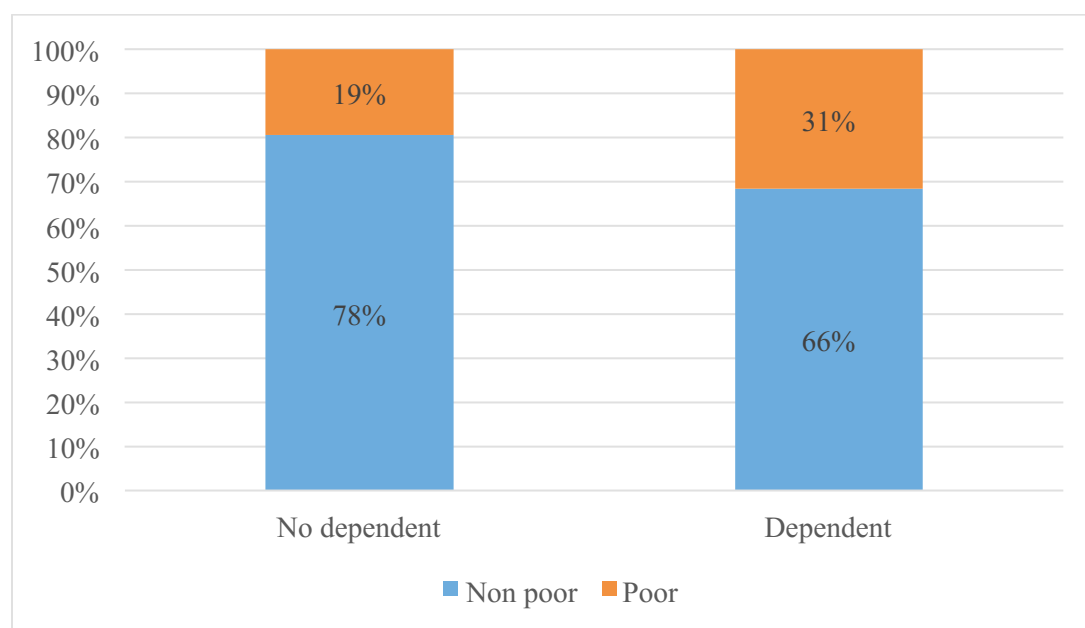


Figure 17. Poverty in households with and without dependents, Chile (2015)

Source: Author's elaboration based on CASEN 2015.

In general, results show that informal caregiving has important effects on labor participation and income generation in Chile. International studies illustrate that these effects can manifest in different ways (working versus not working, working full time versus part time, wage differences, poverty) and can be explained by different factors (type and intensity of care, labor regulations, LTC policies). It is important to note that these effects can be reduced through

policies that encourage participation of caregivers in the formal market (such as caregiver leaves) and the existence of formal care systems (Rodrigues et al 2013).

Finally, the system must respond not only to needs generated in the short-term, like unemployment among caregivers, but also requires consider its long-term impacts: given that the care-caregiver dyad does not participate in the labor market, nor does they contribute to the social security system, becoming “social (non-contributing) beneficiaries” –first pillar in the pension system and FONASA A (indigents) in the health system–, adding extra financial pressure to it.

2.2 How prepared is Chile today?

This section presents information on the current situation of the country regarding LTC and the government’s response to LTC needs for the Chilean population. It takes two approaches and present different pieces of information.

A first step into answering the question of how prepared is Chile to face the challenges of growing LTC demands in the country is to identify what are the LTC initiatives currently in place. This was done by carrying out a search and analysis of public programs and initiatives with LTC components. Section IV.3.3.2 (“Designing a LTC system in Chile) presents more information regarding the current efforts undertook by the country in terms of giving responses to the growing demands for LTC system, particularly by analyzing the recent experience of the design and implementation of the National System for Care (SNAC).

The goal of the section is two-fold. First, a message of hope, highlighting the fact that even though LTC is absent from the Chilean public policy vocabulary, there are several LTC-related

initiatives already in place: Chile does not need to start building a LTC system from zero.

Second, encouraging a sense of urgency. Even though there are several initiatives in place, these need to be adapted using a LTC approach, and there are important challenges to be addressed and a long way to go before establishing a LTC system in the country.

2.2.1 LTC-related government programs in 2017

The social security system currently has multiple programs that aim to cover, in part, the needs of this specific population (dependents and caregivers). In order to have an overview of these initiatives, a search of LTC-related public programs and initiatives currently in operation was performed.

The starting point is the report prepared by the World Bank (2015) for MIDESO as part of the initial analysis for the design of the National System for Care (SNAC). The document uses the Integrated Registry of Social Programs (BIPS) between 2013 and 2014, finding 43 programs with focus on aging and disability.

The information in this report was updated and completed using the BIPS in 2016. In the process, new programs and initiatives not included in the World Bank report were incorporated, also reviewing those that were reformulated or eliminated from 2015 to date. The programs identified by MIDESO (2017c) were also included in the elaboration of the framework for the SNAC. Finally, the list was complemented by a consultation process with professionals from the Ministry of Health and DSC working on issues related to long-term care. The summary of the search and selection process is explained in Figure 18:

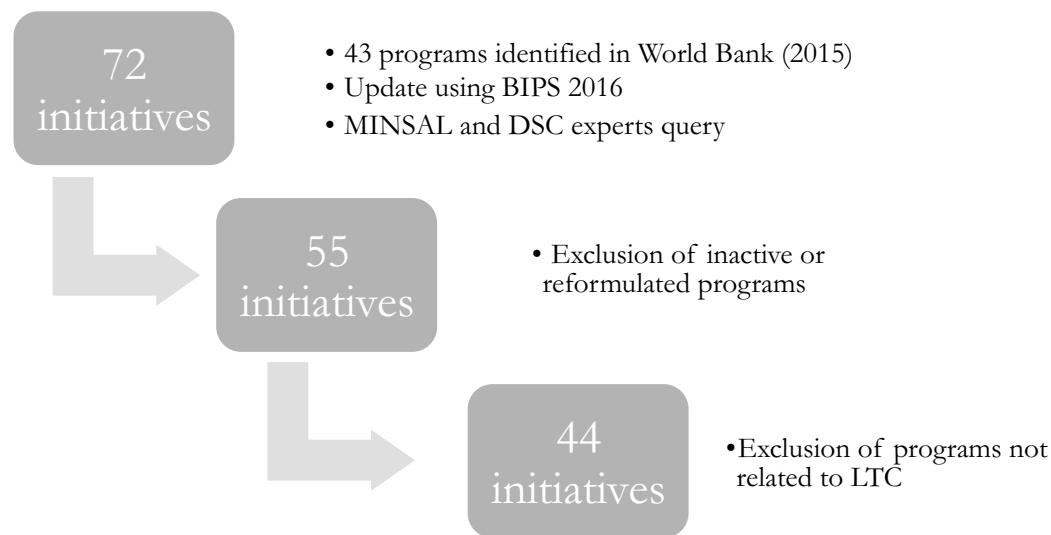


Figure 18. Flowchart: Selection of government LTC-related initiatives, Chile (2017)

Source: Author's elaboration.

After adding all the new programs, the final list comprised 72 programs in six ministries. Out of these, only 55 remain active to date (in five ministries). The update of the original list of 43 programs was made using a different criterion from the original study. The World Bank report focused on identifying programs based on who were the beneficiaries, particularly constraining the search to programs for elderly and disabled populations. This strategy generates errors of inclusion and exclusion when trying to generate a list of LTC-related programs. In order to include this perspective, the new list includes information on the population of each program (eligibility criteria), as well as characteristics of the programs (long-term care component).

Eligibility criteria/target population were grouped according to:

- i. Age: if the program establishes explicit age ranges for its beneficiaries

- ii. Condition: if the program focuses on people with certain health or socio-sanitary conditions related to LTC, such as disability, dependency or mental health issues
- iii. Socioeconomic status (SES): if the program uses income or other measure of vulnerability to allocate benefits
- iv. Geography: if the program restricts its action to a particular geographical location
- v. Others: if the program defines other requirements for being beneficiary

On the other hand, a program was classified as LTC-related if includes at least one of the following LTC components:

- i. Diagnosis: the program has activities that intends to identify/certify LTC-related health conditions of the beneficiaries (exams, certificates)
- ii. Prevention/rehabilitation: the program has components designed to prevent or reduce the level of dependency in its population
- iii. Care services: the program delivers specific care services to people in situation of dependency (visits, nursing services, etc.)
- iv. Support for caregivers: the program has components designed to support the caregiver's tasks (respite, monetary compensation, training, etc.)

This perspective of trying to identify LTC-related initiatives instead of specific populations allowed the inclusion of new programs not considered in the previous study. The full list of (active) LTC-related initiatives is presented in Appendix 6.

Adding up all the initiatives presented in the appendix, in 2017 the Chilean government allocated CLP\$1,350,488 million (roughly US\$2,000 million) to programs containing LTC components (DIPRES 2016). Of course, many of these programs devote only part of their budget to LTC goods and services, implying that the effective budget allocated to this type of activities is lower.

Similarly, it is difficult to obtain an estimate of beneficiaries using this information, because it is not possible (for all programs) to identify who benefits from LTC-related activities or overlapping between programs. In any case, it is interesting to note that the country is currently investing resources in LTC activities, which means that there is a base of resources (financial, human, and institutional) already allocated to the subject.

The previous point is relevant because one of the main concerns of governments regarding the implementation of a LTC system is the (apparent) enormous fiscal effort necessary to launch it. Governments that have implemented LTC systems face without exception the challenge of meeting population needs population and keeping the system's costs under control; this factor explains the slow introduction of LTC systems around the world (Brosdsky and Clarfield 2008; EU 2016). However, this fiscal effort is not as titanic when the country is already spending resources in facing the demand generated by aging and the increase in LTC needs. For example, Campbell et al (2010) compare LTC spending for older adults in Germany, Japan, and the United States, finding that expenditures are similar (Germany being the lowest-cost system), despite the fact that both Japan and Germany has universal LTC systems (covering 13.5% and 10.5% of the population over 65, respectively), while the US system, with a similar expenditure, only offers benefits to 4.5% of the population over 65 years. The authors show that having a formal LTC system is not synonymous of higher expenditure.

3. Long-term care beyond the DELTA

*Progressive improvement beats delayed perfection.
Mark Twain*

3.1 Towards a common definition of dependency for MINSAL

One of the most relevant issues presented in the previous sections is the importance of identifying a concrete problem in order to generate actions (Kingdon 1995; Andrews et al 2015). As described in sections III.2 (“The inaction problem”) and III.3 (“Designing a project for enabling change”), defining the problem was a key part of this project and considered the cornerstone for building a LTC system in the future.

The work at MINSAL was focused in generating conditions for the design and implementation of a LTC system in the country, which required collecting and structuring information, building consensus about the relevance of the issue among stakeholders, and convincing policymakers on taking actions to start the process (Figure 6).

After an initial stage of data collection and assembling stakeholders’ perspectives on LTC it was clear that the issue of defining and measuring dependency in Chile was a bottleneck in trying to move forward in the discussion: the inexistence of an official definition of dependency translated into difficulties to measure the extent of the problem in the country which, in turn, diminished the topic’s priority in the public policy debate. The difficulty in defining and computing the size of LTC needs in the country was present everywhere. As presented in Appendix 3, studies at national level used different concepts when trying to identify LTC needs and even though during the last years a consensus is observed around the use of “dependency” as the concept for

measuring these needs, this agreement generated new dimensions over which consensus is needed: what does dependency means and how can it be measured.

This confusion identified at the national level was also present in the Ministry of Health (MINSAL). Within MINSAL, several stakeholders were identified; they all work on issues in which the term “dependency” was used, and recognized it as a fundamental concept in their day-to-day labor. However, when asked about the definition they had in mind (Appendix 2), it was clear that they were talking about related but not the same concept. As described in section IV.1.2.2 (“How many dependents are in Chile”), MINSAL registers information on dependency, but different programs use different instruments for measuring it. Additionally, several stakeholders reported feeling identified with the topic of LTC and dependency but being excluded or misrepresented by the current definitions and instruments.

This was the situation when in October an opportunity to discuss the project and other issues related to aging with the Minister of Health came out. The meeting was coordinated through the Minister’s cabinet and the Office for International Cooperation (OCAI) and triggered by the visit of a PAHO delegation to the country. Since the first part of the project was funded and supervised by PAHO, they showed interest in including the results and conclusions of the DELTA project as part of the meeting’s outline. The meeting was scheduled for October 17th, 2017 (see Appendix 1) and participants included the Minister of Health and her cabinet’s chief, the head MINSAL’s Office for International Cooperation (OCAI), PAHO representatives, and myself. During the meeting, PAHO representatives insisted on the relevance of the topic of aging and the role that MINSAL should play in putting it on the political agenda. I presented the main results of the project to the date, reinforcing the idea that aging is a key issue that should be incorporated by MINSAL in its planning and policies, and highlighting the need of better

information in order to design evidence-based policies in the area. I discussed some figures related to aging, dependency, and LTC in the country –section IV.1.2 (“What do we know about dependency in Chile”)–, emphasizing how the lack of definitions and data prevents a better diagnosis, problem identification, and search for solutions. The Minister agreed that this was a top-priority issue for the Ministry, and asked about actions that could be taken before the end of the presidential period in March 2018. This was an excellent opportunity since I had been working on formulating a plan for concrete actions to be taken by MINSAL jointly with the chief of the Minister’s cabinet; being in that meeting and drawing the attention of the Minister allowed me to accelerate a process that could have taken several weeks.

When asked by the Minister about the main problem and solution (to be implemented in the next months) regarding the topic of LTC in Chile, I had a clear answer: MINSAL needs a single definition for dependency and has to agree on an instrument to measure it. The Minister was surprised by the fact that there were multiple definitions and statistics regarding dependency at the Ministry and agreed that was not only a good, but also a necessary starting point. The rest of the participants also agreed that this was a problem that required a quick solution and could be addressed within the limited time available. We decided to create a working group to work on these issues, which should present results by the end of the year (December 2017), and I took responsibility in coordinating this group.

The dependency group was formed by several professionals working in the health sector with the concept of dependency. Many of them had been previously contacted or interviewed during the first months of the projects, but invitations were sent to anyone potentially interested, in order to convene different perspectives and information. The final group was constituted by professionals coming from the primary care division (APS), people working on disability and rehabilitation

from both of MINSAL's undersecretaries, people working on mental health, elderly and aging, and the OCAI. Invitations were sent during the first week of November, and the first meeting was scheduled for November 13th, 2017. The group's formation was justified based on several arguments:

- i. Country's context
 - a. Aging: expected increase in dependency and LTC needs
 - b. Some populations –such children and people with mental health problems– have been traditionally excluded from analysis and policies
 - c. Creation of National System of Care (SNAC) by MIDESO raises questions about MINSAL's role in the system and ability to contribute to intersectoral efforts
- ii. Lack of a ministerial definition and single instrument for measuring dependency at MINSAL
- iii. Lack of consensus hinders the information-generation process for policymaking

The group's goal was to propose a ministerial definition of dependency and agree on an instrument to measure it. A deadline was set for mid-December, and it was decided that the working strategy will be to hold monthly (two-hours) meetings in which people will share information and debate perspectives, in order to reach consensus. The final schedule is presented in Table 8:

Table 8. MINSAL dependency group timeline

Meeting	Date	Topic
1	November 13 th	What is the problem? Information availability/assessment
2	November 21 th	Defining dependency
3	November 28 th	Choosing an instrument
4	December 6 th	Conclusions and proposals

Source: Author's elaboration.

The work started by gathering all the information available and sharing it with the group. This step allowed us to acknowledge the differences in the way people understood dependency. It was key to identify agreement spaces, clarify points of view, and define areas that required building consensus. Based on this information, several conclusions were reached and used as criteria for guiding the rest of the work:

- i. There is no a single way to define dependency, which highlights the need to create a consensus definition
- ii. Lack of consensus is not synonym to lack of inputs. The new definition should take into account the existing ones. It is not necessary to create something completely new but to adjust what already exists in order to incorporate different approaches
- iii. Definition should explicitly consider groups traditionally ignored: children and people with mental health disorders

During the second meeting, a definition was proposed and approved by all participants:

dependency is a state associated to a health condition –physical, sensorial or mental– that entails loss of functionality, associated to need of assistance in performing activities of daily living (basic, instrumental, and advanced), according to their age.

The objective of the third meeting was to agree on a single instrument to measure dependency, aligned with the proposed definition. Following the criteria previously defined, the participants performed a critical assessment of the instruments currently used by MINSAL and other institutions, identifying their advantages and disadvantages. The task proved to be more challenging than expected and the group decided that it will be very hard to either agree on a single instrument or define a new one in the assigned time. Considering time constraints, the group resolved to work on short and medium-run actions. In the short run, the decision was to continue working with the instruments already available, particularly using the one used by APS in evaluating elderly. The Elderly Functionality Exam (EFAM) is based on the Barthel index. The index was designed to measure functionality in elders, based on difficulty to perform activities of daily living. The instrument is too narrow to be used in children or to classify people with mental health disorders, reason why it is currently used together with a medical certificate issued by a physician. The use of Barthel was criticized by almost every participant as incomplete and biased towards a physical notion of dependency. The use of medical certificate helps in including other populations that Barthel does not consider, but requires a standardization process; participants also raised concerns about the potential “medicalization” of conditions (particular mental health issues) that require a more holistic view.

In order to deal with these drawbacks, a medium-term strategy was also proposed. Taking into account the need of advancing towards a better instrument to measure dependency and the time constraints imposed to the group, it was decided that in the medium-run the Ministry should evaluate the adoption of a different instrument (or set of instruments) that allow to better identify and classify dependents, considering the proposed definition. It was also stated that MINSAL should start a joint effort with other public institutions, such as MIDESO, SENAMA, and

SENADIS, aiming to elaborate a national definition and instrument for dependency, as well as a collaborative work with other countries, in order to scale-up the Chilean experience and potentially adopt regional definitions.

Proposals were presented to the Minister on December 20th, 2017. In that meeting, the definition was discussed again, and participants agreed on including a lifecourse approach to the definition (WHO 2000), in line with recent strategies adopted by MINSAL. The Minister valued the proposal and suggested it should be presented and discussed by the whole Ministry before becoming official.

MINSAL's definition of dependency is: "Dependency a state associated to a health condition – physical, sensorial or mental– that entails loss of functionality, associated to need of assistance in performing activities of daily living (basic, instrumental, and advanced), according to their age, and considering a lifecourse approach.

Agreeing on an institutional definition for dependency will help MINSAL to better structure its programs and policies around this concept and organize the intersectoral debate. The next challenge is move towards a national definition that will constitute the cornerstone of the future LTC system in the country.

3.2 Long-term care in the agenda: Ensuring sustainability

One of the main concerns of the project was how to give it continuity after the end of the DELTA and the current administration in March 2018. A first concern was about the way MINSAL should use the results produced by the project and how to promote its future involvement in the topic of LTC in the country. As explained in the previous section, one of the

main outputs of the project was the adoption of an institutional definition of dependency at MINSAL. The process also involved other proposals that should be addressed in the medium and long run, i.e. after March 2018. The project got support from different people at MINSAL, but ensuring sustainability required institutionalization. This issue was presented to the Ministry, and discussed in a meeting held on November 17th, 2017. The meeting was coordinated jointly with DSC and its main topic was how to prioritize and visualize the issues of aging and LTC in MINSAL, and how to ensure some continuity in the next presidential period, regardless who ended up winning the election. During the meeting, we insisted that MINSAL should have a preponderant role in a future LTC system, and for that, defining dependency was key. It was also proposed that, in order to increase sustainability for these initiatives, an institutional change was needed. Changing the Minister's organigram will also help in sending a signal that the topic of aging was priority for the health sector. Currently, aging and LTC are not a priority for the Ministry: the topic does not show up as one of the institution's main areas, it is led by a small team –the Elderly unit– within the Division of Disease Control and the Life-Cycle Department; the head of the unit works part-time for the Ministry (see Figure 7).

In order to highlight the relevance of aging and LTC within the Ministry, the creation of a ministerial committee was proposed. The idea of a committee was adopted because it allowed introducing modifications in MINSAL's organigram within a short span of time. The “Advisory Committee for Aging and Long-Term Care” introduces an important institutional change to spur the future work on the area after the change in MINSAL's authorities (March 2018). It also becomes a coordination space within the Ministry, since it was situated at the Minister's level, and includes representatives of both Undersecretaries (Public Health and Networks). The Committee was created by decree as a permanent body, whose goal is to advise the Ministry of

Health in the articulation of a national policy that responds to the needs arising from population aging and the increase in LTC needs.

The process of creating this committee started after the November 17th meeting, and included establishing the rationale, goals and description of the committee, formatting the document to comply with standards as a legal official document, and present it to different stakeholders at MINSAL. It was finally signed by the Minister on March 9th 2018, and sent to the Comptroller General of the Republic, the government's auditor, for its official approval (see Appendix 6).

Finally, as described in section III.3.2.c ("Activities and expected results"), the project included a component of dissemination and awareness intended to gain popular and political support for the idea of implementing a LTC system in the country. Many activities described in Appendix 1 had a dissemination and awareness component, but additional initiatives were also planned with this goal in mind. Appendix 7 shows a list of presentations and publications related to the project.

Besides the activities carried out at MINSAL, the project also considered the goal of putting the topic of LTC in the country's political agenda. As explained in the section on activities and expected results, the fact that the project was implemented during the last months of Michelle Bachelet's government posed several risks, but also many opportunities. The project's timeline allowed interaction with presidential candidates while they were designing their campaigns, discuss the relevance of LTC, and inquire them about their thoughts on this issue. The main milestones of the election and the project's activities are presented in Figure 19:

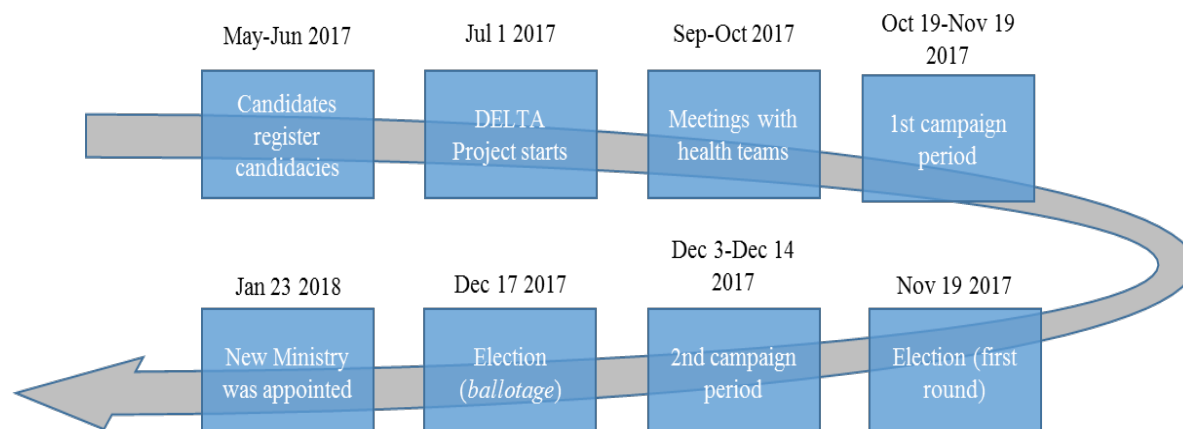


Figure 19. Milestones in the presidential election

Source: Author's elaboration.

Table 9 shows the schedule of meetings with four out of the seven candidates that ran for President in November's election. Unfortunately, for time reasons it was not possible to meet with all the candidates' teams, but as shown in the table, meetings included interviews with the teams of the three candidates that obtained most votes and the two that went to the *ballotage* in December*.

* After Piñera, Guiller and Sánchez (who obtained almost 80% of the votes), the fourth candidate was José Antonio Kast with 7.93% of the votes, followed by Carolina Goic (5.88%), Marco Enriquez-Ominami (5.71%), Eduardo Artés (0.51%), and Alejandro Navarro (0.36%).

Table 9. Meetings with presidential candidates' health teams

Candidate	Party/Coalition	Meeting date	% votes
Beatriz Sánchez	Independent/Frente Amplio	Sep 4 th	20.27
Alejandro Guillier	Independent/La Fuerza de la Mayoría	Sep 7 th	22.70*
Carolina Goic	Democracia Cristiana/Convergencia Democrática	Sep 29 th	5.88
Sebastián Piñera	Independent/Chile Vamos	Oct 3 rd	36.64*

Source: Author's elaboration.

* Candidate made it to the *ballotage*.

All meetings lasted between 60 and 90 minutes and were conducted as semi-structured interviews. Interviews were not recorded and discussion was set as an informal chat, although people were informed they were part of a project being developed at MINSAL. The first part was used to ask about the candidate's ideas on long-term care and initiatives in the area proposed for a future government. In the second part, I presented the DELTA project and the work done so far at the Ministry. The third part was a summary of the discussion, devoted to advocate for the incorporation of LTC or LTC-related policies and initiatives in the government's program and the campaign. After each meeting, a brief document –explaining some concepts and the importance of LTC for Chile– was sent to the interviewees.

In general, all interviewees agreed on the relevance of the topic, even though they differed in the way it was addressed. The concept of LTC was absent of the proposals, although some people were familiar with it. All teams considered the topic was closely linked to aging and elderly policies, consistent with what was found in the written proposals submitted by the candidates at the moment they officially registered their candidacies: as shown in Appendix 8 most of the

LTC-related proposals were included in a section on policies for elderly, just a couple proposed policies related to the concept of dependency, and none used the term “long-term care”. Several candidates also proposed the creation of a mental health law, as well as the need to advance in the establishment of a National System for Care.

Four candidates (Goic, Piñera, Guillier, and Sánchez) launched new versions of their programs during the campaign period (October 19-November 16). These new documents were issued as a way to incorporate ideas generated between June and October 2017. Appendix 8 presents the differences between the initial and final proposals, as a way to capture changes in emphasis as well as inclusion of new topics and proposals. These documents were the main source of information of the candidacies and were used as references in news, analyses, seminars, and debates. The four candidates that presented new programs were the same presented in Table 9. In general, the new proposals built on the previous ones, explaining some initiatives, as well as adding details and new initiatives.

Carolina Goic’s included explicitly support for dependents, people with disabilities and caregivers in both versions of the program, although the second version also encompasses prevention and rehabilitation programs for dependents, in line with the idea of a continuum of care usually present in the LTC discussion (Norton 2000; Brodsky et al 2000; Borrayo et al 2002; Colombo et al 2011). Following the debate about financing LTC (Norton and Newhouse 1994; Brown and Finkelstein 2007; Muiser and Carrin 2007; Barr 2010; Colombo et al 2011; Costa-Font and Courbage 2012; Favreault et al 2015; Villalobos 2017; Costa-Font et al 2017), Sebastián Piñera proposed the creation of a National Care System, including the establishment of an insurance for dependency, both proposals absent in the first version of his program. Like Goic, Alejandro Guillier included in his second wave of proposals the need to strengthen the

National System for Care as well as “promoting autonomy and preventing dependency”; the program moves further and advises the creation of a “Dependency Law” and labor market policies to encourage inclusion of caregivers in the labor force. Finally, Beatriz Sánchez had a set of initial proposals mostly focused on the issue of aging and pensions; in its second version, the program included some of the other candidates’ suggestions, such as the mental health law and the creation of a National System for Care, but also explicitly adds the creation of a LTC system working together (or within) the SNAC.

Although a causal relationship between the meetings with the candidates’ teams and the change in the proposals cannot be established, the result, i.e. incorporation of LTC into the agenda, was achieved. Not only because the final proposals included more LTC-related initiatives but also because a consensus over certain issues is noticed (mental health law, National System for Care, adding prevention and rehabilitation strategies) and policymakers started using concepts and words –such as “dependency” and “long-term care”– that are fundamental to establish the existence of the “problem”.

As shown in Figure 19, the new Minister of Health was appointed on January 23th, 2018, and took office on March 11th, 2018. In order to discuss the continuation of LTC related initiatives at MINSAL, the new Minister was contacted by an email sent on January 23th. Unfortunately, to this day I have not received an answer, and any future event in this line is not registered in this document.

3.3 Alternatives for designing a LTC system: Elements to consider

The document presented the state of the art in terms of information, programs and policies related to LTC in Chile. The proposal was built based on the concept of LTC system as a feasible

solution to the problems posed by the increasing in LTC needs in the country. In this section, the concept of LTC is discussed, using international experiences to propose a structure for analysis and looking at the recent attempts to design a LTC system in Chile.

As previously stated, due to demographic transition many countries around the world have had to face the challenges posed by aging and increase in LTC needs. Similar to the case of health systems, the emergence of this new component of social security has generated a debate about which is the best design to meet these needs (Colombo et al 2011; Swartz et al 2012; Carrera et al 2013; Swartz 2013). Like in healthcare, the definition of indicators to measure performance has been a difficult task and no particular design performs systematically better than others do; as result, there are as many LTC systems as countries that have implemented them (Brodsky and Clarfield 2008; Joumard et al 2010; Weiner 2011; Pot et al 2017; WHO 2017a). Despite this wide range of alternatives, there are common elements in all the systems that allow analyzing their design; likewise, recent experiences in LTC allows to observe some convergence that is very important when thinking about the design of a system for Chile (Norton and Newhouse 1994; Colombo et al 2011; Swartz 2013).

3.3.1 Designing a LTC system: Elements and interactions

As described in section III.3.2 (“Activities and expected results”) a LTC is comprised by four components (Norton and Newhouse 1994; Colombo et 2011):

- i. Beneficiaries, i.e. who uses the LTC services
- ii. Benefits, i.e. what are the services offered to the beneficiaries
- iii. Suppliers, i.e. who provides these services
- iv. Financing, i.e. who pays for LTC services, in what form and at what cost

A LTC system is designed by selecting different alternatives for each one of these components. It is necessary to bear in mind that these classifications are arbitrary and the boundaries proposed, diffuse. For each component, several alternatives are available and decisions about their particularities need to be made. Beyond the list of options for each of component in the system, it is important to remember the core concept embedded in term "LTC system", i.e. that the system is more than the sum of the parts. In this sense, it is crucial to consider not only the elements of each component, but also the way in which they interact with each other. More than choosing between different alternatives for the different components of the system, the important thing is to understand that these alternatives are closely related and determined simultaneously. For example, when defining the beneficiaries of the system is crucial to have a diagnosis of LTC needs in the population and, therefore, what are the services required and the best way to provide them, which in turn determines the system's cost.

Any of the alternatives proposed for the components of the LTC system can be analyzed on its own merit, but quickly finds an equivalent or impact on another element. For example, if when discussing the system's coverage, we can immediately think that this relates exclusively to the definition of beneficiaries. However, the definition of who receives the benefit is closely linked to the package of benefits offered. According to the European Union report on health and long-term care (EU 2016), the coverage of the system should be defined taking into account both, beneficiaries and services provided, as presented by the scheme outlined in Figure 20:

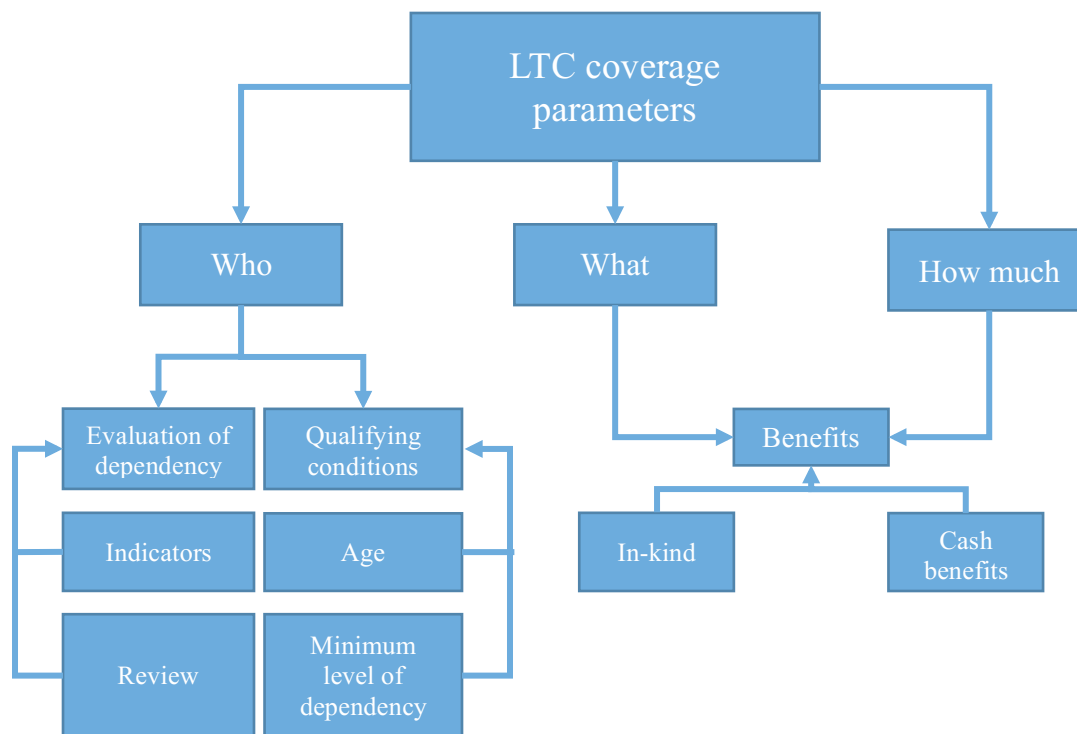


Figure 20. Long-term care coverage parameters

Source: EU (2016).

Similarly, following the scheme proposed by the World Health Organization (WHO 2010b) to define coverage, this can be understood in terms of (Figure 21): i) percentage of population covered (width); ii) percentage of covered services (depth); iii) percentage of the cost of services covered (height). In this sense, a cost dimension is added, implicitly considered in the previous scheme, which relates beneficiaries (width) and benefits (depth) directly to the issue of suppliers and financing (height).

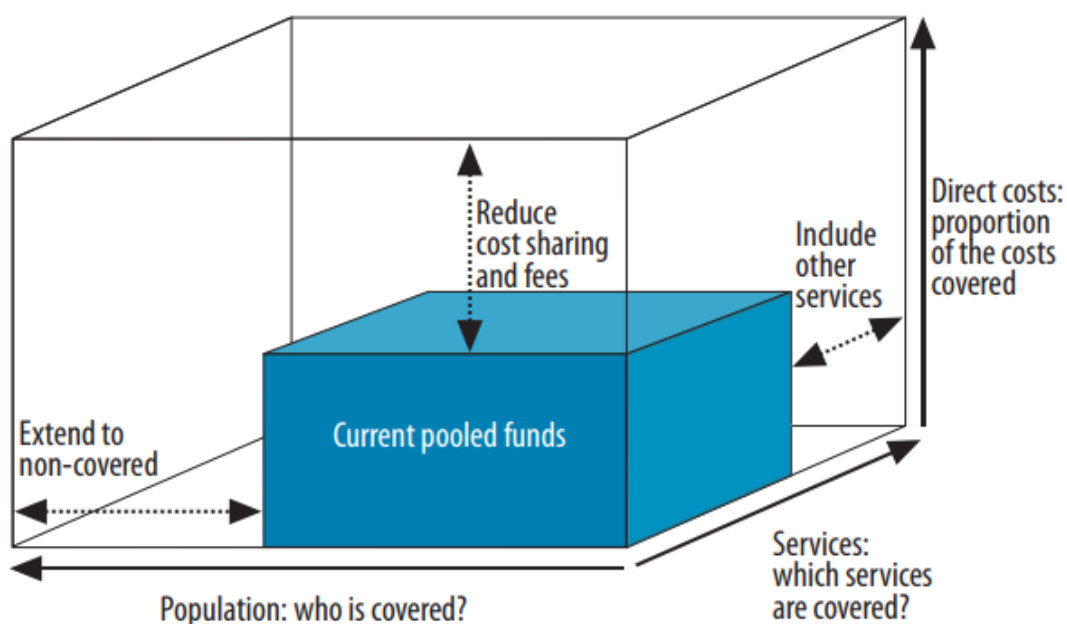


Figure 21. Coverage dimensions and universal health coverage

Source: WHO (2010b).

These schemes exemplify the way in which different components of a LTC system interact and why, since they are determined simultaneously, it is necessary to adopt a systemic vision for their analysis.

As explained above each one of the four components of a LTC system require adopting several design decisions. As well as the separation of the LTC system into four components is arbitrary, options presented for each of the elements are not intended to be complete, exhaustive or exclusive. The analysis aims to illustrate the multiple complexities, options and interactions involved in the design of a LTC system, under the precept that there is no single paradigm or model (Brodsky and Clarfield 2008; Weiner 2011; Pot et al 2017; WHO 2017a). The

alternatives, often presented as binary and mutually exclusive, represent rather points of a continuum where gray areas are the rule, and where countries have usually chosen to combine instead of selecting options. Taking into account these particularities, the exercise of disentangling the LTC system into components and defining choices for each one is still useful for structuring the discussion, as well as serve to facilitate the exposition of diverse topics, making explicit the multiple links between these elements, and exposing the fuzziness of their definitions. The section also discusses the way in which these trade-offs have been faced in practice, using the previously selected countries –Germany, Netherlands, and Republic of Korea– as concrete examples of the difficulties posed by the design of a LTC system.

a. Beneficiaries

A first element in the LTC system refers to the definition of who will be the users of the services provided by the system. This subsection presents some alternatives that countries have faced, regarding ways to define and select their beneficiaries. The identification and selection of beneficiaries is key to any LTC system and countries have used different approaches and instruments to achieve this. However, despite this heterogeneity, countries have focused on the standardization and assurance of objectivity in the eligibility criteria, key to ensuring transparency in the system (Brodsky et al 2000). Some of the trade-offs present in this component are:

- *Universal versus targeted coverage? Eligibility criteria:* As shown in Figures 20 and 21, the first questions that need to be answered regarding the beneficiaries are who they are and how they will be identified.

In terms of system coverage, the issue requires making a series of decisions regarding: i) how to identify people with LTC needs?; ii) how to define the beneficiaries of the system? While at first glance these seem as the same question, they contain fundamental differences that need to be understood. The first question is related to the identification of LTC needs in the population. Traditionally, LTC literature and systems have operationalized the idea of LTC needs through the concept of dependency, linked, in turn, to difficulties in carrying out activities of daily life. As shown in Figure 20, this process requires having a definition and an instrument to measure dependency, usually a *sine qua non* condition to be eligible for the system. In turn, selecting the instrument to measure dependency implies other decisions, for example, the use of a standardized instrument versus individual evaluations.

In this sense, the lack of an official definition of dependency has pushed several countries to adopt national definitions, with numerous ways of operationalizing them. For example, the Netherlands base its evaluation on standardized instruments –specifically the International Classification of Functioning, Disability and Health, ICF (WHO 2001)– to determine eligibility (Government of the Netherlands 2017), while others, such as Germany or the Republic of Korea, have generated their own instruments (Kang et al 2012; Won 2013; Federal Ministry of Health 2014). On the other hand, while the latter have standardized dependency classification systems based on their instruments, the Netherlands uses an individual evaluation to define the needs and services provided by the system (MPHWS 2016; Kroneman et al 2016).

On the other hand, Figure 20 also shows that beneficiaries selection is different from LTC needs identification (dependency evaluation), which requires new eligibility criteria that may be based on dependency or other factors such as age, income, or family situation (Brodsky et al 2000; Colombo et al 2011). For example, while the Dutch and German systems are exclusively based on LTC needs, the Korean system adds age (people over 65 years of age) as an eligibility criterion (NHIS 2014; 2017).

Both processes (identification of dependents and selection of beneficiaries) can be understood as a trade-off between universality and targeting: in the first case, one must decide on a definition to identify dependents, while in the second case the decision refers to whether the system will consider all dependents or a portion of them as beneficiaries. Both alternatives have pros and cons: on the one hand, targeting is useful as a control containment strategy, increasing the system's financial sustainability; on the other hand, universal programs decrease the risk of fraud in the system (e.g. beneficiaries selection) and some problems commonly associated with targeted programs (mainly in low-income populations), such as delivery of low-quality services (Brodsky and Clarfield 2008).

- *How to define LTC needs? Dependency, autonomy or need for help:* A related issue is the way on how to classify dependents. The previous point raised the dilemma regarding the selection of definitions and instruments for measuring dependency from a coverage perspective: definitions that allow inclusion or determine exclusion of certain people as dependents. The problem raised here also refers to the definition of dependency, but from a more general perspective.

In this case, the emphasis is on the perspective adopted to define the concept of LTC needs. When choosing a definition and an instrument, will it be used to identify dependency? To identify independent people? To identify and measure help needs? Again, the alternatives may

seem equivalent, but they have proven to be fundamental, for example, in the discussion of how to include new population groups as beneficiaries of LTC systems (e.g., people with dementia or children) and how to focus interventions (e.g., treatment versus prevention approach).

Germany is an interesting example to illustrate this point. In 1995, the country established the basis for its current LTC system (*Pflegeversicherung*) by implementing a compulsory LTC insurance as complement for the health insurance. The initiative came into operation in July 1996. The government decided to integrate LTC into the social security system, making it the fifth pillar of its system (Geraedts et al 2000).

Initially, the system established eligibility criteria based on the demonstration of LTC needs. Benefits depended on whether the beneficiary required frequent or substantial help with daily living activities for an extended period, presumably more than six months (Geraedts et al 2000). According to Arntz et al (2007), the key concept in identifying beneficiaries was "frailty"; the Social Security Code (*Sozialgesetzbuch XI, SGB XI*) defines a person as "frail" if he or she requires permanent, frequent or substantial help to perform at least two ADL and an additional IADL, due to illness or physical, mental or psychological disability, for a minimum period of approximately six months. This constituted the definition of need for LTC in the old German system (Arntz et al 2007; Schultz 2010).

The needs assessment was the responsibility of the health insurers (medical teams), and sought to determine if the services were necessary and what kind of services were required. The evaluation was carried out in the house of the potential beneficiary and was a requirement to access to the system's benefit package (Geraedts et al 2000; Arntz et al 2007). The system classified beneficiaries in three levels, based on four categories:

- i. Personal care (*Körperpflege*): includes activities such as washing, showering, taking a bath, washing teeth, shaving, combing, urinating and defecating
- ii. Food (*Ernährung*): help with food preparation and intake
- iii. Mobility (*Mobilität*): activities such as getting in and out of bed, dressing and undressing, standing and climbing stairs, moving from one place to another
- iv. Household chores (*hauswirtschaftliche Versorgung*): for example, shopping, cooking, washing, ordering and house cleaning

The levels of care were defined as:

Table 10. Care levels and definitions in the old German LTC system

	Level I	Level II	Level III
Need definition	Considerable need for care	Severe need for care	Extreme need for care
Operational definition	Needs help at least once a day with personal hygiene, eating, or at least two of these types of activities and additional help in IADL several times a week	Needs help for at least two ADL at least three times a day, and additional help in IADL several times a week	Needs help at least with two ADL 24-hours every day, and additional help in IADL several times a week.
Time required	On average, 90 minutes per day on basic care and help with household chores (more 45 minutes should be spend in providing basic care)	On average, at least three hours per day; two out of these three hours must be devoted to basic care	At least five hours per day, and four of these must be devoted to basic care

Source: Geraedts et al (2000), Arntz et al (2007) and Schultz (2010).

Additionally, there was a category for "severe cases", that is, people in Level III that require an even higher level of care. To qualify in this category, ADL assistance was required for at least

seven hours a day, with at least two of these hours during the night, or assistance in basic needs that can only be provided by several people at the same time (Schultz 2010).

The reform of the system began in 2005, based on a series of critiques regarding the way in which the LTC needs were defined in the German social security system. Critics mainly pointed to the fact that the definition ignored problems and needs of a growing group of people who had limited competence to develop ADL due to mental problems (dementia), as well as the system's inability to assess LTC needs in children (Federal Ministry of Health 2009). From here, an advisory commission was created, in order to establish a new definition for LTC and a new (reliable and unique) instrument to determine LTC needs in the country. The main modification consisted in shifting from a three-level system (*Pflegestufen*) to one with five levels (*Pflegegrade*), aiming to better reflect the needs of the beneficiaries, including people with physical and mental disabilities (especially people with dementia). In this new system with a five-levels scale, physical, mental and psychological impediments have equal weight in the evaluation of LTC needs. The assessment scheme measures the degree of independence of a person in six areas –mobility, cognitive and communication abilities, psychological and behavioral problems, self-confidence, ability to deal independently with the demands and pressures caused by illness or the need for therapy, organization of daily activities and social contacts– which combined give a general score (Federal Ministry of Health 2014).

A summary of the definitions used in both systems is presented in Table 11:

Table 11. Comparisons between old and new German LTC systems

	Old system	New system
LTC needs definition	Estimated time required in help with ADL for an extended period of time (more than six months) (needs approach)	Degree of Independence to perform ADL and manage aspect of the daily living (capabilities approach)
Measurement instrument	Three-levels scale Areas: personal care, eating, mobility, household tasks	Five-levels scale Areas: mobility, cognitive and communication abilities, psychological and behavioral problems, self-confidence, ability to deal independently with the demands and pressures caused by illness or the need for therapy, organization of daily activities and social contacts

Source: Author's elaboration based on Federal Ministry of Health (2014).

The Dutch system is grounded on the concept of need for care as a gateway and guide to define the services to be delivered: the basic requirement to access the benefits is the need for constant care or supervision (24/7) (Government of the Netherlands 2017). After this diagnosis, the health services administration office defines jointly with the client, the services to be delivered based on a needs assessment.

Finally, the Republic of Korea adopts a definition focused on the traditional concept of dependency, considering as beneficiaries people with difficulties in performing ADL for at least six months (NHIS 2014; 2017). The evaluation process is based on a home visit in which the individual needs are evaluated, using a standardized instrument that combines the dependency and needs approach. The questionnaire has 52 questions and evaluates five dimensions (Kang et al 2012; Won 2013): i) development of daily activities (12 questions); ii) cognitive function (7 questions); iii) behavioral problems (14 questions); iv) need for nursing care (9 questions); v) rehabilitation needs (10 questions). According to NHIS (2016) the target population of long-term

care insurance are all residents, the eligible population (those who can apply) are those over 65 with geriatric diseases, while the beneficiaries are people (over 65 years) with difficulties to perform daily tasks for a period of at least 6 months. In 2011, approximately 5.8% of the population over 65 years old was a beneficiary of the system (Won 2013).

- *The dyad issue: Considering caregivers:* Additionally, the system must consider an important addition element: not only dependents are part of the system, so are caregivers. The foregoing implies that all decisions regarding the design of the LTC are multiplied by two; the system must take decisions not only about the "patients" beneficiaries of the system, but also about those who provide care services. All the elements proposed also apply to caregivers:
 - i. Beneficiaries: How to define a caregiver? Which should receive benefits through the system? All caregivers? Family members? Primary caregivers? Those who dedicate more time to care work? Those with the least socioeconomic conditions? The ones with the greatest burden? Or those with weak social networks?
 - ii. Benefits: What will be the goods and services delivered to this group? As in the case of dependents, there are different types of benefits that LTC systems can offer to caregivers. Among these are salaries, monetary and non-monetary compensations, tax benefits, labor flexibility, training, respite, counseling, among others.
 - iii. Provision: Provision is closely linked to the type of benefits delivered. Caregivers add a decision on who and how to deliver these services (e.g. through government programs, private providers, peers, etc.)
 - iv. Financing: Finally, it is necessary to decide how much and how to pay for these benefits, including the decision on who pays for them (public/private, health/social).

b. Benefit package

As in the case of the definition of beneficiaries, there is no LTC benefit package that can be considered as "standard" around the world (Brosdsky and Clarfield 2008). The type of service offered is closely related to the needs of the beneficiaries, but also the type of provider in the market. For example, Norton (2000) indicates that in the United States, even if looking at the residential services market only, there is a high heterogeneity in the benefits offered: for example, while board and care homes provide, in general, more services than boarding and rooming houses, these offer less medical services than nursing homes. This section presents options regarding the type of benefits that a LTC system could offer, as well as examples of countries that have adopted one or another alternative.

- *Health or social? Type of benefits delivered by the system:* LTC spending can be divided into expenditure in health and social services; the first includes benefits such as palliative care, nursing services, care services and health services to support families, while in the second are initiatives such as domestic help, support in carrying out activities and residential services. In general, LTC systems include benefits from both areas (Brodsky et al 2000; Colombo et al 2011; Weiner 2011; Aguilar n.d.). For example, Aguilar (n.d.) identifies six types of LTC services: i) medical and nursing care; ii) personal care, iii) personal assistance; iv) other social services; v) lodging; vi) maintenance.

The author classifies the first three as health services, while the last three would be eminently social. It also notes that the last two types of services are more about living conditions than care itself. The author argues that although many of these services can be classified in one of the two areas (health and social), they generally contain elements of both.

As discussed before, the kind of service delivered is directly related to the type of providers (Brodsky et al 2000). For example, while in institutional care housing is considered as the main service, the range of alternatives in home and community care is very broad, including nursing visits, home adaptations, vacations for caregivers, technical aids, respite programs, night care, among others. Brodsky and Clarfield (2008) identify the following services associated with home care:

- i. Home health services: including nursing services, health promotion, prevention, education, self-care strategies, and palliative care.
- ii. Personal care: mainly services related to basic activities of daily living, such as bathing, dressing, eating and going to the bathroom.
- iii. Homemaking: mainly services related to instrumental activities of daily living, such as meal preparation, cleaning and shopping.
- iv. Technical aids: including assistive devices, adaptations of the home, and special technologies.

The authors also identify a wide range of services that can be classified both in the health and social areas and that are delivered on an outpatient basis or through institutional care, including health status monitoring, rehabilitation, or opportunities for recreation and socialization. As illustrated by the cases of the Netherlands and the Republic of Korea, fragmentation of services is an unsolved problem for many LTC systems, with this lack of integration being crucial for the quality and efficiency of the services delivered (Brodsky and Clarfield 2008; Pot et al 2017).

For example, in the Dutch case, the LTC system has different services that can be used according to the individual specific needs. Some of the services that can be financed through the system are: i) stay in long-term care institutions; ii) personal care (assistance with bathing, dressing,

going to the bathroom and feeding); iii) services to increase autonomy, such as organizing the day's activities or learning to perform certain tasks in the home; iv) nursing care, for example, management of injuries or injections; v) medical treatment; vi) transportation services (MHWS 2016).

Unlike the Dutch case, LTC insurance in Korea is mainly focused on social rather than health benefits. In fact, health professionals are not allowed to deliver medical services in long-term care institutions. The insurance provides assistance in daily activities (home services): care visits, nursing, bath, day/night care, equipment; services in long-term care institutions; and monetary benefits (food purchase, dental health), depending on the individual level of limitation (Kang et al 2012; Won 2013).

- *In-kind, in-cash, and caregiver compensation: Nature of the benefits:* In general, there is a trade-off regarding the way in which services are delivered by a LTC system. Broadly speaking, the literature identifies two major options: delivery of direct benefits (in-kind) and delivery of money to beneficiaries (in-cash) (with and without restrictions on how this money can be used), so that they can buy the required services directly (Brodsky et al 2000; Brodsky and Clarfield 2008; Colombo et al 2011; EU 2016). From a government's point of view, these options pose a trade-off between freedom to choose (and better match between LTC services and needs) and control over the use of the benefit (fraud).

Other important issues arising from this decision refer to the definition of the primary caregiver, the involvement of family members in care, distortions and incentives to work, and working conditions of caregivers (Colombo et al 2011). Monetary compensation to informal caregivers – understood as a compensation to the effort and opportunity cost of the caregivers–, is an interesting initiative because it recognizes the value of informal care for society, but it presents a

series of challenges in terms of design. Despite its advantages, financial support should not be the only policy for caregivers; given it generates incentives, mainly in the labor market (disincentive formality, creation of unregulated markets), these benefits should be combined with in-kind services, such as respite and labor policies to allow participation of caregivers in the formal labor market (Brodsky et al 2000; Colombo et al 2011).

In the German case, starting in 2015 the benefits are granted according to a five-level scale (*Pflegegrade*). The system provides both in-cash and in-kind benefits like: nursing training for volunteer and family caregivers, subsidy for caregivers, day and night care services, supplies and equipment (Colombo et al 2011; Federal Ministry of Health 2016).

In 2015, the Netherlands underwent an important reform of its LTC system. The main goal of the reform was to situate the patient in the center of the system. In order to achieve this goal, the reform encouraged the use of home-based care over institutional care, as well as the use of in-cash benefits instead of in-kind benefits (MHWS 2016; Maarse and Jeurissen 2016).

Finally, the Korean LTC benefit package is mostly comprised by in-kind services, although the LTC insurance allows for some exceptions (NHIS 2014; Won 2013).

- *Generous or limited? Standard or customized? Interaction between beneficiaries, needs, services and financing:* A key element influencing the cost of the system and its financial stability is the degree of generosity of the benefits. Depending on resources availability, infrastructure, providers' capacity, the system may choose to deliver a limited package of benefits or a broad set of services. As indicated above, this variable, as well as the eligibility criteria of the beneficiaries, can be used to control cost in the system (Figures 20 and 21). As Brodsky et al (2000) point out, most countries set maximum and minimum levels for their benefits, balancing coverage and sustainability. In addition, many countries offer different levels of benefits to

different types of beneficiaries. The Dutch case is an excellent example of a personalized system, in which the person is at the center of the system. In this case, benefits are delivered to a subgroup of the population: those most vulnerable, such as elderly people in advanced stages of dementia, people with significant physical or mental disabilities, and people with long-term psychiatric disorders. Each case is evaluated by the Agency of Evaluation of the Care (*Centrum Indicatiestelling Zorg*, CIZ), based on a standardized format. The system is comprised by individuals, government agencies and managers, and they decide what is the best way to address people's LTC needs, selecting providers and quality of services (MHWS 2016).

Finally, as stated in Figure 21, the cost of the services is related to a broad definition of coverage in the system. Coverage can be seen from a financing perspective (who pays what?) or from a benefits point of view (what services are included?). In this logic, the design of the LTC system has to consider not only what services to offer (depth), but also how much to finance (height) and who finances the rest. As previously explained, this decision is linked to the rest of the elements of the system:

- i. Financing: if the LTC offers only partial financial coverage, how to cover the rest of the cost? For example, the system could establish that services are paid out-of-pocket or could include an insurance scheme
- ii. Beneficiaries: Is the coverage the same for everyone? For example, coverage could varies for different beneficiaries (e.g., by income group)?
- iii. Benefits: Is coverage the same for all services? For example, the system could opt for a "zero copayment" scheme for "basic" services

As indicated by Colombo et al (2011), copayment, out-of-pocket expenses and deductibles are present in all LTC systems, including those defined as with universal coverage. In these cases,

payments are generally set according to people's income. In some systems, copayment is the general rule for accessing the system, while in others, it exists for some benefits only, and is used both as a financing mechanism and as a cost containment strategy via reduction of demand for services (Brodsky et al 2000).

c. Providers

LTC needs can be addressed using a formal LTC system of formal care or through informal care. Traditionally, formal care has been provided in nursing homes but recently many countries have been experiencing with new ways of providing care, such as cash benefits, counseling strategies and home-based care (Colombo et al, 2011; Swartz 2013; Norton 2000; 2016). On the other hand, informal care is usually an unpaid activity, often provided by family members (Knapp and Somani 2008; Norton 2016). People demand different services offered by different types of providers according to their physical and mental health condition, as well as their economic and family situation, but also on individual and social preferences (Norton 2000; Brodsky and Clarfield 2008; Colombo et al 2011; Rhee et al 2015; Gentili et al 2017). This subsection discusses these and other design challenges related to providers of LTC services within a LTC system.

- *Formal or informal? Basic dilemmas in a LTC system:* As many authors point out, provision of LTC services includes a continuum of alternatives ranging from sporadic and informal care provided by a neighbor to institutional care (Norton 2000; Borrayo et al 2002; Brodsky and Clarfield 2008; Colombo et al 2011). One of the main characteristics of LTC services, compared for example with healthcare services, is that it is mainly provided by unpaid informal caregivers (Norton 2000; Colombo et al 2011). The size of this activity is difficult to quantify, since it does

not exist within the limits of a formal market; paid (non-family) caregivers constitutes a space in the middle between informal unpaid services and services provided by professional/paid caregivers.

Although many countries have incorporated formal LTC systems, informal care remains critical in the provision of LTC everywhere; in spite of this, countries need a system of formal services provision that allows to cover LTC needs, in order to avoid that these end up being assumed exclusively by families (Colombo et al 2011).

LTC systems face a dilemma between promoting labor formalization and encouraging labor participation of informal caregivers and/or family members. On the one hand, as presented in section 2.1 (“The impact of (not having) a LTC system”), informal care has important effects on the labor market, income generating capacity of families, and health of caregivers but, on the other hand, patients with dependency often prefer to be taken care by relatives and friends and, given their economic value, informal caregivers help keep system costs controlled. This trade-off justifies the existence of a mixed system, in which the responsibility of care does not rely exclusively on formal caregivers, but where informal caregivers may also have access to support and help to perform their tasks and relieve their burden (Colombo et al 2011).

The proper mix between formality and informality arises, again, from the interaction of the elements of the system and its objectives: what kind of needs exist in the population and what kind of services are demanded? How to take into account families’ preferences? How much money is available to finance the system? How does the design of the LTC system affect caregivers’ behaviors? As shown by Colombo et al (2011) there is a high degree of heterogeneity regarding formality in LTC systems in OECD countries: the percentage of the population

reporting performing informal care activities varies from 8% in Sweden to more than 16% in Italy.

- *Institutional or home-based care? Individual or community services? Decisions regarding setting in which services are delivered:* Several authors have proposed the existence of a continuum of care alternatives in LTC, going from institutional to home-based care, and offering a diverse set of alternatives in between (Norton 2000; Brodsky et al 2000; Borrayo et al 2002; Colombo et al 2011; Aguilera n.d.). Regardless of this continuum, discussion has usually revolved around the two extreme alternatives: nursing homes and home-based care. These alternatives are also linked to formal and informal care although formality, as discussed above, constitutes a different dimension of the provision of services. This paradigm –linking home-based care to informal care– is debatable, especially considering the trend observed recently in which many countries have opted for home-based services as part of their formal LTC systems (Colombo et al 2011; Swartz et al 2012; Swartz 2013; MHWS 2016). Colombo et al (2011) show this trend for OECD countries: although there is variety in the mix of institutional and home care between different countries, most users of LTC systems receive services at home instead of getting it from institutions, such as nursing homes.

In the German system, services are delivered in both modalities: more than 70% of the total beneficiaries opt for home-based care, both in public and private insurance. In this case, they can choose to receive a payment in money that goes from 120 to 700 euros, depending on the level of care. The system also includes benefits for caregivers, such as a payment for services, as well as a pension and an accident insurance, valid for the duration of their care activities (subject to compliance with a minimum number of hours providing services) (Federal Ministry of Health 2014).

As noted above, the Dutch system was recently redesigned to encourage change in the method of providing services, from a system based mainly on institutional care to one that promotes home care (MHWS 2016).

Finally, the Korean system also separates services between those provided in specialized institutions and home care, which includes help with household chores and tasks of daily living, nursing services, as well as day and night care. In 2013, LTC expenditure was almost evenly distributed between care in institutional (49%) and home care (46%), with the remaining 5% corresponding to administrative expenses (NHIS 2014).

- *Centralized or locally managed? Integrated or atomized? Private (with or without profit) or public? Organizing the system's administration:* Colombo et al (2011) distinguish three types of systems according to the way in which services are provided: i) single system (centralized); ii) multiple benefits and; iii) services and programs. This classification has to do with the way in which the service is provided but mainly with the way in which the system is managed and its decision-making process.

The first type of scheme (centralized system) has the advantage of ensuring broad access to services, guaranteeing coverage and facilitating coordination in the provision; its main disadvantage is its cost: because coverage is greater, these schemes are typically more expensive.

The three countries chosen as examples (Germany, the Netherlands and the Republic of Korea) fall into this category, with services provided through a single, well-defined LTC system.

Mixed systems provide services through different programs, including some with universal coverage and others with a limited coverage. In this case, countries do not have a single service delivery system, but multiple benefits, programs and entitlements, according to their target

populations and the type of service offered. These schemes can be, in turn, divided into three groups (in decreasing order according to their universality):

- i. Universal parallel schemes: this category includes countries where different schemes provide universal coverage for different services. For example in Scotland, nursing services are universal and provided by the health system, while personal care services are also universal but provided through a different scheme (social benefits system).
- ii. Income-related universal benefits: in this case, there is a single system in which the beneficiaries are chosen based on their care needs, but benefits are adjusted according to their income (as in France or Australia).
- iii. Mix of universal and mean-tested (or no) benefits: these systems usually offer universality in some benefits (such as access to home-based or institutional care) with others in which access is restricted according to socioeconomic status (for example, monetary subsidies).

Finally, there are countries where there is no central coordination for the delivery of LTC services; instead, benefits are provided through a series of programs and initiatives. This is the case of Chile, in which there is no LTC system, but several programs designed for people with LTC needs.

d. Financing

The discussion on financing LTC can be done from different angles. On the one hand, there is a distinction between sources and uses of resources, i.e. how money is collected and allocated.

This perspective poses a dilemma, typically, between public and private resources. Although the

discussion regarding the origin of resources can be seen as irrelevant (money always come from households), as in the case of health spending, the focus of the analysis has been traditionally put on the way in which resources are collected (taxes, voluntary contributions/mandatory, private pocket expense). Additionally, in the case of LTC, a different dimension is added: here not only the debate about public versus private matters, but also the discussion regarding LTC as health or social expenditure (in the case of public expenditure).

- *Private versus public? Central or local government? General taxes or social insurance? Compulsory or voluntary contributions? Sources of financing:* Although in general LTC systems are financed through public expenditure (*via* taxes), recently a group of countries has implemented special financing schemes to deal with the financial risk of the LTC system. Currently, there are six countries in the world with a compulsory insurance system for LTC: Netherlands, Japan, Republic of Korea, Germany, Israel and Luxembourg (Colombo et al 2011).

As with the rest of the components of the LTC already discussed, financing alternatives are multiple and, just like in the case of the other components, what is important is to assure coherence between the financing option chosen and the rest of the elements of the system. For example, the United States tried to implement a LTC insurance, as part of the health reform (Affordable Care Act, ACA) carried out in 2010. The initiative –known as CLASS Act (Community Living Assistance Services and Supports Act)– sought to create a market for LTC insurance, in a market traditionally identified as small (Brown and Finkelstein 2007; 2009). CLASS was designed as a voluntary LTC insurance, where people would contribute to the system during their working years and then could access LTC services (institutional or home-based care). This design was identified as weak, since it wanted to fulfill two opposing objectives: being non-mandatory and self-financing. The design was subject to problems of

adverse selection (given its voluntary nature) and moral hazard (since the benefits could be used in different ways), threatening its financial sustainability (Gleckman 2011; Norton 2016). These problems explain why this initiative was deleted from the budget and finally repealed in 2013.

Germany has a LTC insurance scheme (*Pflegeversicherung*) that is part of the country's social security system. The scheme was established in 1995 (Long Term-Care Act) and establishes a compulsory insurance for all residents of the country, in order to cover the needs of people who cannot live independently for a period of at least 6 months. Prior to this scheme, LTC was financed directly by the beneficiaries via out-of-pocket expenditure. Although LTC insurance is not formally part of the health financing system (it is an independent branch of the social security system), they are closely related: participation in this scheme is mandatory for all those with health coverage. The system is financed through compulsory contributions, corresponding to 2.35% of the salary; paid in equal parts between employee and employer (people without children pay an extra premium of 0.25% and specific regulations apply to the state of Saxony), and is administered by LTC funds, linked to health insurers. The system works as a pay-as-you-go scheme, where today's contributions are used for the expenses of the same period. As in the case of health benefits, funds negotiate with providers on the services conditions (quality) and prices; the Ministry of Health is legally responsible and regulator of the system (Colombo et al 2011; Federal Ministry of Health 2016).

Long-term care insurance (*Wet Langdurige Zorg*, WLZ) is part of the Dutch health insurance scheme. The LTC services entitlements are supported by different legal bodies, such as the Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten*, AWBZ) of 1968. The current system is governed by the Long-Term Care Act (WLZ) of 2015. LTC funds are collected and deposited in the Long Term Care Fund, administered by the National Institute of

Health Care. The fund is financed through contributions (mandatory) and public funds: i) 9.65% of taxable income (top of 33,589 euros); ii) contribution based on income; iii) public funds (if necessary). The funds administration and payments are carried out at central level through health insurers (for institutional care), while payment for home care is made through the municipalities (Schäfer et al 2010; MHWS 2016; Government of the Netherlands 2016).

Like the Netherlands, the Republic of Korea established a specific fund for long-term care (Long Term Care Insurance Act of 2008), with the aim of preserving and improving the quality of life of older adults and their caregivers, promoting better health and a stable life, and reduce the burden of care for the elderly in families (Kang et al 2012). The fund is managed by the National Health Insurance Corporation, while the services are delivered by private providers. The fund is financed by a combination of: i) mandatory contribution to long-term care insurance, corresponding to 6.55% of contributions made to compulsory health insurance (6.12% of salary) (68% of financing) ; ii) contributions from the government and municipalities (12% of financing); iii) copays of beneficiaries (20% of financing) (NHIS 2014).

- *Health or social (or other) expenditure? Labeling the money:* Just like discussed in the section about benefit package, the health-social divide reemerges when analyzing LTC financing. The debate regarding the “institutional ownership” of LTC is directly related to the administration of its budget and if LTC spending should be considered as health expenditure, social spending or something else, trying to answer the question: who should pay for what? For example, Colombo et al (2011) make explicit this tension when classifying LTC schemes between those financed with taxes, systems with LTC insurance, and systems in which services are financed through the health system.

Regardless whether the services offered are classified as health or social (point discussed in subsection b), a decision about who should manage the system is also needed. This choice is relevant, because it ties the LTC system to not only the budget, but also the rules and organizational culture (definitions, access to information, intervention strategy, regulations) of the hosting institution. In many cases, LTC systems end up hosted within the health system; the debate is relevant in the Chilean case, since the main endeavor to implement a LTC system, the SNAC, is being designed, implemented and managed by Ministry of Social Development (MIDESO).

Of the selected countries, Germany represents an interesting case, since it has allocated its LTC as an independent pillar of the social security system, along with health, pensions, unemployment and accidents (Federal Ministry of Health 2016). In the case of the Netherlands, the LTC system is part of the health system; the Dutch health system explicitly divides curative care, long-term care and public health, with separate legal bodies, financing and provision (MHWS, 2016). The Korean LTC system separates the social and health functions of LTC, with two separate financing schemes (National Health Insurance and Long-Term Care insurance), but a single administration body: the National Health Insurance Services (Kim et al 2015).

3.3.2 Designing a LTC system in Chile: The SNAC experience

The National System for Care (SNAC) is an initiative developed in recent years that seeks to complement the country's current social protection system. The Chilean social protection system is composed of a series of social programs, coordinated by the Ministry of Social Development (MIDESO). In the past years, these programs have evolved towards greater coordination in order to improve quality, timeliness, and equity social services (Robles 2011). In 2009, the

Intersectoral System of Social Protection was created, establishing a management structure for several government's social benefits, coordinated by MIDESO. The system includes the subsystems: Opportunities (former *Chile Solidario*), Childhood Protection (*Chile Crece Contigo*), and Support and Care (Berner 2015; World Bank 2017).

The SNAC's design process started in 2014, and its implementation began in 2016 with a pilot in 12 municipalities, which will increase gradually until cover the 345 municipalities of the country in 2021, reaching a regime status in 2023. Its origins date back to the 2013 presidential campaign, in which several promises were made in order to deal with issues related to aging, gender inequality and the increase of dependency in the country (MIDESO 2017b).

In terms of beneficiaries, the target population was defined as people with dependency/disability and their caregivers; socioeconomic vulnerability and age (over 60 years) were also proposed as inclusion criteria in a first stage (Berner 2015; MIDESO n.d. a). In summary, the system's potential beneficiaries were households belonging to the 60% most vulnerable according to socioeconomic classification, with at least one person in a situation of moderate or severe dependency^{*}. Using data from the Social Registry of Households (RSH), the National Registry of Disability, and the Social Security Institute, MIDESO estimated the SNAC potential populations in 314,166 people, almost half of what was obtained using the CASEN 2013 survey, according to which 12% of households in the country (637,373 households) would have at least one person with dependency. As shown before, estimations using CASEN 2015 and the dependency definitions proposed by SENAMA (2010) and MIDESO (2017a), the number of dependents in the country reaches 625,484 people (including all dependency levels and excluding people with dementia), and 421,094 only considering moderate and severe

^{*} Initially, people with mild dependency were also considered as beneficiaries, but this inclusion criterion was removed.

dependents; the figure is reduced to 306,282 people when applying the age criterion, showing that estimations are similar in terms of magnitude. Recently, the SNAC decided to expand its target population, eliminating the age criterion, and defining potential beneficiaries as "... households with one or more members in a situation of dependency due to age (elderly) or disability, including the caregivers." (World Bank 2017).

Regarding the definition and measurement of dependency, it is defined as "the state or situation of lack or loss of personal autonomy in the performance of essential activities of daily life. It assumes the need for help and care provided by other people, and may also imply requiring devices (technical or other aids) and/or environmental adaptations" (MIDESO 2017b). MIDESO proposes using the RSH to identify beneficiaries and their dependency situation. The RSH classifies people into non-dependent, mild dependency, moderate dependency, and severe dependency (MIDESO 2017b; 2017 n.d. a).

The SNAC adopted various alternatives discussed in the previous section. First, it proposes a targeted system instead of universal benefits, with dependency (excludes people with mild dependency), and income (considers the 60% most vulnerable) as eligibility criteria.

Regarding the way in which SNAC operationalize the concept of LTC needs, the system embraces an approach based on dependency defined as difficulty in performing activities of daily living (MIDESO n.d. b). Following the strategies previously used in the CASEN survey when defining and measuring dependency (MIDESO 2017a), the SNAC do not consider people with mental diseases (particularly dementia) as dependents. Implications of this strategy were discussed in section III.1.2.2 ("How many dependents are in Chile?"). Finally, the identification strategy for beneficiaries is based on information from the Social Registry of Households (MIDESO 2017 n.d. a, 2017 n.d. b). As presented in section III.1.2.2 ("How many dependents

are in Chile?") when analyzing the data available in MINSAL-REM, there is a risk of underestimating the number of dependents, and leaving out the population with the greatest needs, when using administrative records from government's programs, since information is collected with a supply-side, instead of a demand-side approach.

In terms of caregivers' identification, the instrument utilizes the concept of "primary caregiver", defined as "the person... who provides more hours of unpaid daily care services, help or permanent assistance to at least one person with moderate or severe dependency (belonging to the 60% most vulnerable), with respect to the rest of the people who perform these tasks, whether or not they are linked by kinship ties." (MIDESO 2017b). The proposed instrument also collects information on the tasks performed and assistance provided to dependents, asking about hours dedicated to these labors and the presence of other caregivers (MIDESO n.d. b). Using these definitions and data from the CASEN 2015 survey, it is estimated that primary caregivers belonging to the 60% most vulnerable of the population would be 78,417 people (MIDESO 2017b).

When looking at the benefits package offered by the system, it is clear that the SNAC combines different types of services for its beneficiaries (Berner 2015, MIDESO 2017b, World Bank 2017). These include:

- i. Home-based care
- ii. Dependency prevention
- iii. Caregiver training
- iv. Respite
- v. Home modifications

vi. Institutional care

vii. Income subsidies

As discussed before, the list includes a wide range of services, which can be considered as social (for example, home modifications), health (like dependency prevention) or a mixture of both (such as home-based care services). Moreover, most of the benefits are delivered as in-kind services, but the system also comprises in-cash benefits (income subsidies). Finally, the system is explicitly defined as one that delivers "social care services", although it recognizes the need for intersectoral coordination delivering of benefits (MIDESO 2017b).

Using the information available, it is not possible to conclude whether this package of benefits is limited or generous, or if it provides personalized or standardized benefits. However, as previously discussed, these are crucial decisions that a LTC system must take and that can be crucial for its effectiveness (interaction between the needs and services provided) and efficiency (interaction between beneficiaries, benefits, and cost). In this regard, the information allows venturing the existence of a certain degree of individualization in the services. This customization is carried out through a process of identification of care and support needs (MIDESO n.d. b) and the elaboration of a "care plan" for each household in the system (MIDESO 2017b).

On the provision of services, SNAC defines its mission as "... to accompany, promote and support dependent persons and their support network. It includes public and private actions, considering different levels of dependency and people's life cycle "(MIDESO 2017b). The foregoing makes explicit the participation of private entities in the provision of services within the system. In this sense, the role of the SNAC is established in term of coordinating the existing offer of care services, either public or private (MIDESO 2017b).

Regarding the dilemma between formal and informal services, the SNAC aims primarily to formalize the supply of services currently provided by informal caregivers within households. On the other hand, it proposes the implementation of a system with atomized provision and the SNAC acting as coordinator, not provider (MIDESO 2017b). Finally, the system offers both, institutional and home-based services (Berner 2015). However, it is not possible to know if it intends to prioritize one type of modality over the other, a decision that, as presented in the previous section, has been explicitly made by other countries.

The SNAC proposes a centralized administration system, in which the system's design is carried out at a national level with local administration and decentralized provision. Its management model is based on the "Local Support and Care Network" program, which represents the SNAC's entry point; the program is responsible for evaluation, referral, and monitoring of beneficiaries. The system was designed using a "polymodal model", in which the central level structure is replicated at the local level, in order to ensure a standard design while allowing adaptation to local needs (MIDESO 2017b): MIDESO transfers resources to municipalities, and they are responsible for delivering the system's services. In addition, the central level structure provides guidelines and technical standards, as well as technical assistance for implementation (World Bank 2017).

Finally, SNAC financing is proposed through the budget of different programs that make up the system's benefit package. In terms of design, this can be classified as direct financing from the government, via general taxes. In this case, the SNAC has no budget as a system; it just acts as a coordinator of several LTC-related government programs. MIDESO's data show that the cost of the system in 2016 was CLP\$2,244 million (US\$3.3 million) for the 12 municipalities

participating in the pilot; the estimated cost in 2023 (steady state) is CLP\$19,170 million (US\$28 million).

These financial needs pose challenges in terms of the financial sustainability in the long run. As MIDESO's estimates show, the SNAC's cost is expected to increase ten times in seven years; this increase can be even higher considering the increase in LTC needs foreseen for the coming years. The system has a cost containment strategy based on its eligibility criteria that, on the one hand allows it to operate with a limited budget but, on the other hand, implies a decrease in coverage –beneficiaries, benefits and/or financial protection– as the demand for these services increases. In terms of order of magnitude, this budget appears as small, considering other figures and estimations regarding the cost of LTC in the country*.

The strategy seems justified in a scheme that pretends to be financed exclusively with central government budget, but it poses a dilemma between coverage (and compliance with its objectives) and financial stability. These types of problems are usually used as arguments in favor of a financing system based on social insurance (Norton and Newhouse 1994; Barr 2010; Drèze et al 2016), and the SNAC should consider different financing schemes if its goal is to respond to the country's rising LTC needs. This can also be an alternative in the case of the Chilean LTC system; a compulsory LTC scheme have several interesting features that should be taken into account when discussing the financing mechanism of a future system. First, in terms of solidarity, LTC social insurance allows financing benefits for a vulnerable group, regardless of their resources and support networks, increasing the coverage of the system (Norton 2000).

* For example, the SNAC's proposed budget for 2023 is similar to SENAMA's budget in 2016 –roughly US\$29 million, according to DIPRES (2016)–, relatively small compared to the cost of LTC needs bear by the health system –around US\$1,000 based on the results presented in section IV.2.1.3.a–, or estimations on the cost of implementing a LTC system in Chile –nearly US\$1,600 million in 2020, according to Matus-López and Cid (2014).

Second, regarding efficiency, it obtains generates funds to meet special and limited needs, increasing greater control and transparency over health resources and preventing that LTC ends up consuming resources initially allocated to other policies. Third, it increases financial sustainability, compared to systems where the burden is exclusively bear by the government or financed through voluntary contributions (Mátus-López and Cid 2014; Favreault et al 2015). Finally, related to quality, the existence of a third party –the insurer–allows controlling quality of service, an important element in a market where patients have difficulty to evaluate and demand quality (Chou 2002).

IV. CONCLUSION

Nothing is as powerful as an idea whose time has come.

Victor Hugo

The project aimed contributing to build the pillars for the future design and implementation of a long-term care system in Chile. It was designed jointly with the Chilean Ministry of Health under the assumption that MINSAL is a key player in the future LTC system.

The project has several components that acted together in order to fulfill its goal. First, it collected, structured and synthesize information on LTC and dependency, mostly within MINSAL, but also considering other government's instances. Second, it assessed the information available, comparing it with other countries' experiences, to propose future directions for working in the field and caveats when designing and implementing a LTC system in the country. Third, it advocated for the need of implementing a LTC system in the country by proposing LTC needs as an umbrella to deal with many currently unrelated problems, and promoting a coordinated and comprehensive response from the government.

In terms of the information regarding LTC needs and the estimation of the dependency in the country, the analysis shows how the country has progressed in highlighting the concept of dependency, including the collection of data, going from measuring disability to start the discussion about functionality and dependency in the last years. There are also some important advances in terms of trying to conceptualize and quantify a term on which there is no consensus about its definition or the best instrument to measure it. Studies carried out in the country over the last 15 years illustrate this evolution, but they also show the lack of consistent and comparable definitions and estimations. In this sense, international experience stresses the need

to advance in a single, official definition of dependency, as well as a specific methodology to measure it. The establishment of a dependency measurement system would allow not only having a concrete estimate of the long-term care needs in the country, but also having an instrument for selecting beneficiaries and defining benefits. As shown in the cases of Germany and the Republic of Korea, making changes to the system can be a long and complex process (Federal Ministry of Health 2009; Jeon and Kwon 2017); it is necessary to make this definition in a serious way and to propose a measurement system that is useful and in accordance with the objectives of the LTC system.

Estimates show that between 4% and 8% of the country's population could be classified as dependent. The range is quite broad (between 625,000 and 1,400,000 persons), which again emphasizes the need to move towards a more accurate measurement. As expected, different definitions, as well as the diversity of instruments, yield different estimations of long-term care needs and their evolution over time, a problem faced by all countries when trying to measure care needs and make international comparisons, including using data of high quality and reliability (Stallard 2008). Second, studies agree that prevalence of dependency increases with age, being particularly relevant among elders (around 15% in this population). Finally, it is necessary to emphasize that although the dependency is more prevalent in the elderly, it is not exclusively restricted to this age group: approximately 40% of the dependents in Chile are younger than 65 years, implying that, although there is a rationale for focusing on elderly, a LTC system has to take into account other age groups that have LTC needs.

Related to the above, it is also important to highlight that, despite the use of “elderly” as a strategy to overcome the complexities in defining and measuring dependency, the concept also lacks of a clear definition. Different studies and institutions use different definitions. In

particular, there are two age thresholds –60 and 65 years old–, which hinders the analysis and measurement of dependency in this subgroup. According to the CASEN 2015 survey, about 45,000 people between 60 and 64 years have some dependency, nearly 7% of the total functional dependents in the country. This definition is relevant if the country wants to adopt age as an eligibility criterion for its LTC systems. Countries like Korea has followed this strategy (people under 65 years can be beneficiaries, but have a different process), using 65 years as threshold (NHIS 2014; 2017), in line with the definitions of older adults used by the OECD (OECD 2017). For its part, the WHO does not have a formal definition for elderly –for example, the Report on Aging and Health (WHO 2015) uses different cut-off ages to present statistics– and highlights the need to apply different criteria according to each country’s situation, recognizing that 65 years is the definition usually accepted in developed countries (Kowal and Dowd 2001). The use of different thresholds to define elderly population in Chile reduces its usefulness as an instrument for decision-making and statistical analysis.

In summary, the analysis shows the existence of important information gaps regarding the measurement of dependency in Chile: since there is no single definition and multiple instruments are used, it is not possible to have an accurate estimate of the current LTC needs in the country.

In terms of what can be done, the analysis shows that designing and implementing a LTC system is not an easy task. As in the case of health systems, LTC systems can be designed in several ways. An important lesson from the international experiences is that, regarding the choices about the different components of the LTC system, these elements need to be aligned to achieve the system’s goals: there is no single design that is superior to the rest and countries adapt systems to their contexts and objectives.

Second, it is also necessary to understand the complexities and challenges posed by the design of a long-term care system from a multisectoral perspective (health versus social, private versus public, national versus local, etc.); many of the alternatives arise from the need to define who is responsible for the different functions and tasks of the system. When analyzing a LTC system, the different actors necessarily overlap, generating confusions and conflicts that may be difficult to solve. Therefore, the identification of relevant stakeholders involved in the implementation of the system is required, as well as a specific definition of their roles. This allows a coordinated work, at least in the short term. In the long term, the area will require a change of paradigm that allows facing the challenges of LTC in a comprehensive and systematic way.

In this regard, it is important to adopt a holistic vision that allows understanding LTC from an intersectoral perspective, but also from an intergenerational angle. As shown in Appendix 5, many of the initiatives currently in operation have prevention and rehabilitation components, usually not considered as LTC programs themselves. The inclusion of these initiatives is important to understand the role of the social security system, and particularly of the health sector, in LTC. As the data from the CASEN 2013 survey shows, many permanent or long-term conditions reported by Chileans –conditions that may eventually cause dependency–have a preventable origin (Table 12).

Table 12. Permanent conditions by cause, Chile 2013

Condition/ cause	Congenital	Illness	Accident	Other
Physical limitation/mobility	11.27	62.11	11.84	14.78
Muteness/speech difficulty	38.58	38.25	6.93	16.24
Psychiatric difficulty	25.27	44.50	5.02	25.21
Mental/ intellectual difficulty	53.33	30.96	4.15	11.56
Deafness/hearing difficulty	13.01	50.80	7.52	28.68
Blindness/difficulty seeing	23.18	51.58	6.86	18.38

Source: Author's elaboration based on CASEN 2013.

It is also important to emphasize the role of the health system not only as a provider of care services, but also in its contribution to the reduction of dependency in the population. In this line, a consensus definition of dependency, as well as an evaluation of programs aimed at its prevention and rehabilitation - such as AUGÉ/GES - can help to better identify the role of the health sector in this issue.

In this line, the Chilean case presents an interesting example for the design analysis of a LTC system, considering the process already in place and the future implementation of the SNAC. The design and first stages of the SNAC represents an enormous step in the construction of a LTC system in the country.

Despite this huge advance, the SNAC still faces important challenges. In the first place, and related to the issue of multisectoral work, it is necessary to advance in the definition of roles within the system. As the international experiences and the SNAC's own example show, this task is not easy to solve. Currently, the SNAC is led by MIDESO, the own institution recognizes the need for coordinated work with other actors in the public and private sectors in order to

successfully implement a National System for Care (MIDESO 2017b). Then, it is necessary to ask about each player's role in the system.

Taking into account the idea of a continuum of services in which social and health services are combined to cover LTC needs, the health sector –and the Ministry of Health– should have a preponderant role in diagnosis, prevention, rehabilitation, and technical support in the provision of long-term care services (Norton 2000; Brodsky et al 2000; Borrayo et al 2002; Colombo et al 2011). This implies that the health sector should assume a leading role in the definition and identification of dependency, as well as in the application of strategies to mitigate the problem, that is to say, actions that seek to diminish the needs of LTC in the population and, consequently, the demand for services of the system. This is aligned, for example, with the concept of integral care and the recommendations to work with the loss of functional capacity, recently raised by the World Health Organization (WHO 2017b). According to these guidelines, the health sector should focus on promoting the following actions:

Table 13. Recommendations for managing declines in intrinsic capacity in older people

Module	Area	Problem/ Recommendation
Declining physical and mental capacities	Improve musculoskeletal function, mobility and vitality	Mobility loss/ Multimodal exercise
		Malnutrition/ Oral supplemental nutrition
	Maintain sensory capacity	Visual impairment/ Routine screening for visual impairment
		Hearing loss/ Screening followed by provision of hearing aids
	Prevent severe cognitive impairment and promote psychological well-being	Cognitive impairment/ Cognitive stimulation
		Depressive symptoms/ Brief, structured psychological interventions
Geriatric syndromes	Manage age-associated conditions	Urinary incontinence/ Prompted voiding and pelvic floor muscle training
	Prevent falls	Risk of falls/ Medication review and withdrawal, multimodal exercise, specialist's assessment, home modifications, multifactorial interventions integrating assessment with individually tailored interventions
Caregiver support	Support caregivers	Caregiver's burden/ Psychological intervention, training, and support

Source: WHO (2017b).

These recommendations are in line with prevention, rehabilitation and technical support activities proposed above as roles to be assumed by the health sector in the implementation of a LTC in the country. LTC is an important area that needs an active participation of the health sector, as showed by the experience of several countries and the recent involvement of the World Health Organization in promoting the establishment of LTC systems in every country (WHO 2016; Pot et al 2017; WHO 2017a).

Finally, regarding the awareness and diffusion component, the experience during the project's implementation showed confirmed, on the one hand, that LTC is not a well understood and widely used concept, particularly within the Ministry of Health. However, it is also true that the idea of LTC and dependency has been developed during the past years; several milestones –as the publication of the National Study of Dependency and the launch of the SNAC– have contributed enormously to generate discussion and create and nascent LTC culture in the country.

Despite this observed trend towards a common understanding of LTC in the country, many challenges are still pending. First, LTC-related issues have to be acknowledged as a multidimensional, and people working on LTC have to recognize the need for multisectoral efforts in coping with them. Second, the topic requires a well-defined space in policymakers' agenda in order to generate changes and move from ideas to action. The project contributed to deal with these challenges in several ways. Many actions and results of the project such as, facilitating the adoption of a definition of dependency for MINSAL, establishing a committee to coordinate LTC-related initiatives within the institution and discussing the need of adopting a LTC system in the country with several stakeholders pointed on this direction. These actions will allow the Ministry of Health to be better prepared to assume its role as a key actor in the LTC debate in Chile: not only it will be able to better coordinate the Ministry's programs, actions and policies in the field, but also contribute improving coordination with other organizations (such the Ministry of Social Development) and promote an active participation of the health sector in a future LTC system. The project also addressed some of these challenges by involving people from different organizations (MINSAL, DSC, MIDESO, international organizations), in different positions roles (professionals, program managers, advisors, authorities). This strategy will help

not only to improve communication by sharing information and promoting agreement, but also will increase the likelihood of including the topic on the agenda, particularly after the new administration takes place; securing support from government authorities was key for generating results within the DELTA's eight-months period, but involving civil servants, program managers, and future authorities will be key to continuing the work.

BIBLIOGRAPHY

AARP (2015). Caregiving in the U. S. 2015 Report. Retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>. Accessed: 22 Aug 2017.

Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS (2014). Caregiver burden. A Clinical Review. *Journal of the American Medical Association*, 311(10): 1052-1060.

Aguilar M (n.d.). Background paper sobre sistemas de cuidados. Inter-American Development Bank.

Albala C, Sánchez H, Bustos C, Fuentes A (2007). Informe Final: Situación de los cuidadores domiciliarios de adultos mayores dependientes con pensión asistencial. Retrieved from <http://www.senama.cl/filesapp/3366.pdf>. Accessed: 19 Jul 2017.

Alvear S, Canteros J, Jara J, Rodríguez P (2013). Costos reales de tratamientos intensivos por paciente y día cama. *Revista Médica de Chile*, 141: 202-208.

Alvear S, Canteros J, Jara J, Rodríguez P, Mujica V, Vorpal U (2012). Determinación y análisis de costos reales de tratamientos intensivos por pacientes y día cama. *Revista Chilena de Medicina Intensiva*, 27(1): 7-14.

Andrews M, Pritchett L, Samji S, Woolcock M (2015). Building capability by delivering results: Putting Problem-Driven Iterative Adaptation (PDIA) principles into practice. In: Whaites A, Gonzalez E, Fyson S, Teskey G (eds.). A Governance Practitioner's Notebook: Alternative Ideas and Approaches. OECD Publishing: Paris.

APA (2017). Zarit burden interview. Construct: caregiver burden. Retrieved from <http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/zarit.aspx>. Accessed: 2 Jan 2018.

Aporto (2014). Diseño de una estrategia para la reducción de brechas entre la demanda de familias en situación de vulnerabilidad por contar con integrantes en condiciones de dependencia (derivadas del envejecimiento, enfermedad y/o discapacidad) y la oferta intersectorial de servicios de cuidado. Retrieved from <http://www.ministeriodesarrollosocial.gob.cl/btca/txtcompleto/protsocial-aporto-inf.final.pdf>. Accessed: 19 Jul 2017.

Arechabala MC, Catoni MI, Palma E, Barrios S (2011). Depresión y autopercepción de la carga del cuidado en pacientes en hemodiálisis y sus cuidadores. *Revista Panamericana de Salud Pública*, 30(1): 74-79.

Arno PS, Levine C, Memmott MM (1999). The economic value of informal caregiving. *Health Affairs*, 18(2): 182-188.

Arntz M, Sacchetto R, Spermann A, Steffes S, Widmaier S (2007). The German social long-term care insurance-structure and reform options. IZA Discussion Paper 2625.

Arriagada I (2011). La crisis de cuidado en Chile. Proyecto de CEM-Chile e INSTRAW Construyendo redes: Mujeres latinoamericanas en las cadenas globales de cuidado. Retrieved from http://www.cem.cl/proyectos/documentos/Arriagada_crisis.pdf. Accessed: 13 Jul 2017.

Arrow KJ (1963). Uncertainty and the welfare economics of medical care. *American Economic Review*, 53 (5): 941–973.

Barr N (2010). Long-Term Care: A Suitable Case for Social Insurance. *Social Policy and Administration*, 44(4): 359–374.

BCN (2017a). Ley 19.828 Crea el Servicio Nacional del Adulto Mayor. Retrieved from <https://www.leychile.cl/Navegar?idNorma=202950>. Accessed: 7 Sep 2017.

BCN (2017b). Ley 20.422 Establece normas sobre igualdad de oportunidades e inclusión social de personas con discapacidad. Retrieved from <https://www.leychile.cl/Navegar?idLey=20422>. Accessed: 10 Oct 2017.

Benavides O, Alburquerque D, Chaná-Cuevas P (2013). Evaluación de la sobrecarga en los cuidadores de los pacientes con enfermedad de Parkinson ambulatorios y sus factores de riesgo. *Revista Médica de Chile*, 141(3): 320-326.

Berner H (2015). El proceso de construcción del Subsistema de Apoyos y Cuidados en Chile. Presentation at seminar “Los desafíos de la institucionalidad social en el desarrollo de una protección social universal bajo el enfoque de derechos”. Santiago, August 12th, 2015. Retrieved from http://dds.cepal.org/proteccionsocial/actividades/seminario-tecnico-cepal-giz-agosto-2015/docs/Mesa%205_H_Berner.pdf. Accessed: 20 Dec 2017.

Bloom DE, Chatterji S, Kowal P, Lloyd-Sherlock P, McKee M, Rechel B, Rosenberg R, Smith JP (2015). Macroeconomic implications of population ageing and selected policy responses. *Lancet*, 385(9968): 649-657.

Bongaarts J (2009). Human population growth and the demographic transition. *Philosophical Transactions of the Royal Society of London. Series B, Biological Sciences*, 364(1532): 2985–2990.

Borrayo EA, Salmon JR, Polivka L, Dunlop BD (2002). Utilization across the Continuum of Long-Term Care Services. *Gerontologist*, 42(5): 603-612.

Bravo D, Puentes E (2012). Female labor force participation and informal care of adults: Evidence for a middle-income country. Serie Documentos de Trabajo 353, Departamento de Economía, Universidad de Chile.

Breinbauer H, Vásquez H, Mayanz S, Guerra C, Millán T (2009). Validación en Chile de la Escala de Sobrecarga del Cuidador de Zarit en sus versiones original y abreviada. *Revista Médica de Chile*, 137(5): 657-665.

Brodsky J, Clarfield AM (2008). Long Term Care in Health Services. In: Heggenhougen HK, Quah S (eds.). International Encyclopedia of Public Health. Academic Press: San Diego.

Brodsky J, Habib J, Mizrahi I (2000). Long-term care laws in five developed countries: a review. Geneva: World Health Organization.

Brown JR, Finkelstein A (2007). Why is the market for long-term care insurance so small? *Journal of Public Economics*, 91(10): 1967-1991.

Brown JR, Finkelstein A (2008). The Interaction of Public and Private Insurance: Medicaid and the Long-Term Care Insurance Market. *American Economic Review*, 98(3): 1083-1102.

Brown JR, Finkelstein A (2009). The Private Market for Long-Term Care Insurance in the U.S.: A Review of the Evidence. *Journal of Risk and Insurance*, 76(1): 5-29.

Brown JR, Shah G, McGarry K (2012). Long-Term Care Insurance Demand Limited By Beliefs About Needs, Concern About Insurers, And Care Available From Families. *Health Affairs*, 31(6): 1294-1302.

Butler SM (2015). Coming Together on Long-term Care. *Journal of the American Medical Association*, 314(7): 659-660.

Butler SM (2016). Consensus Plans Emerge to Tackle Long-term Care Costs. *Journal of the American Medical Association*, 315(14): 1441-1442.

Campbell JC, Ikegami N (2000). Long-term care insurance comes to Japan. *Health Affairs*, 19(3): 26-39.

Campbell JC, Ikegami N, Gibson MJ (2010). Lessons from Public Long-Term Care Insurance in Germany and Japan. *Health Affairs*, 29(1): 87-95.

Campbell JC, Ikegami N, Kwon S (2009). Policy learning and cross-national diffusion in social long-term care insurance: Germany, Japan, and the Republic of Korea. *International Social Security Review*, 62(4): 63-80.

Carcagno GJ, Kemper P (1988). The evaluation of the National Long Term Care Demonstration. 1. An overview of the channeling demonstration and its evaluation. *Health Services Research*, 23(1): 1-22.

Carrera F, Pavolini E, Ranci C, Sabbatini A (2013). Long-term care systems in comparative perspective: Care needs, informal and formal coverage, and social impacts in European countries. In: Ranci C, Pavolini E (eds.). Reforms in long-term care policies in Europe. New York: Springer.

Caruso M, Galiani S, Ibarrán P (2017). Long-Term Care in Latin America and the Caribbean? Theory and Policy Considerations. NBER Working Paper No. 23797.

Castle NG, Ferguson JC (2010). What Is Nursing Home Quality and How Is It Measured? *Gerontologist*, 50(4): 426-442.

CCI (2007). Informe Final: Estudio de Situación de los AM dependientes con pensión asistencial y sus cuidadores domiciliarios SENAMA. Retrieved from http://www.senama.cl/filesapp/Estudio_de_situacion_de_AM_con_pension_y_cuidadores_domiciliarios.pdf. Accessed: 19 Jul 2017.

CDC (2011). Cognitive impairment: A call to action. Retrieved from https://www.cdc.gov/aging/pdf/cognitive_impairment/cogimp_poilicy_final.pdf. Accessed: 8 Sep 2017.

CDC (2016). Long-Term Care Providers and Services Users in the United States: Data From the National Study of Long-Term Care Providers, 2013–2014. Vital and Health Statistics Series 3, Number 38, Centers for Disease Control and Prevention. Retrieved from https://www.cdc.gov/nchs/data/series/sr_03/sr03_038.pdf. Accessed: 23 Aug 2017.

Centro Estudios de Vejez y Envejecimiento UC (2015). Informe Final: Estudio Sistematización y descripción de los perfiles de las cuidadoras de personas dependientes, las demandas de apoyo que las cuidadoras presenten y los programas existentes para aliviar el trabajo de cuidado. Retrieved from http://www.ministeriodesarrollosocial.gob.cl/btca/txtcompleto/Final_Perfil_de_Cuidadoras.pdf. Accessed: 14 Jul 2017.

CEPAL (2017). Estimaciones y proyecciones de población total, urbana y rural, y económicamente activa. América Latina - Revisión 2017. Retrieved from <https://www.cepal.org/es/temas/proyecciones-demograficas/estimaciones-proyecciones-poblacion-total-urbana-rural-economicamente-activa>. Accessed: 06 Oct 2017.

Chacón MJ, Rojas Y (2016). Los cuidadores con vínculo familiar de los adultos mayores con Alzheimer: Impacto en la salud mental, familiar y socio-económica. Tesis para optar al grado de Licenciado en Trabajo Social, Universidad Academia de Humanismo Cristiano.

Chang CF, White-Means SI (1995). Labor supply of informal caregivers. *International Review of Applied Economics*, 9(2): 192-205.

Choi MJ (2015). Long-term care of older persons in the Republic of Korea. SDD-SPPS Project Working Papers Series: Long-Term Care for Older Persons in Asia and the Pacific.

Chou SY (2002). Asymmetric information, ownership and quality of care: an empirical analysis of nursing homes. *Journal of Health Economics*, 21: 293-311.

Cid C, Marín PP, Starck N, Marcó C, Clavero C, López D, Romero A (2014). Informe Final Análisis Prospectivo de un Seguro Obligatorio de Dependencia para Adultos Mayores. Santiago: Subsecretaría de Previsión Social.

Cid C, Prieto L (2012). El gasto de bolsillo en salud: El caso de Chile 1997 y 2007. *Revista Panamericana de Salud Pública*, 31(4): 310-316.

Clínica Alemana (2017). Arancel Clínica Alemana – Arancel 2017. Retrieved from <https://www.alemana.cl/wls/arancel/buscarc.htm?idClasificacion=1&pagina=1&cantidad=100>. Accessed: 12 Oct 2017.

Clínica Bicentenario (2017). Días cama. Retrieved from <https://www.clinicabicentenario.cl/cb/dias-cama/>. Accessed: 12 Oct 2017.

Clínica Las Condes (2017). Aranceles. Retrieved from <https://www.clinicalascondes.cl/INFORMACION-AL-PACIENTE/Aranceles>. Accessed: 12 Oct 2017.

Clínica Santa María (2017). Arancel 2016 – Hospitalización. Retrieved from <https://www.clinicasantamaria.cl/aranceles/pdf/ARANCELES-HOSP-ABRIL-2016.pdf>.

Accesed: 12 Oct 2017.

Clínicas de Chile (2012). Estudio de costos de prestaciones de salud. Retrieved from <http://www.clinicasdechile.cl/wp-content/uploads/2016/11/54.pdf>. Accesed: 12 Oct 2017.

Coe NB, Skira MM, van Houtven CH (2015). Long-term care insurance: Does experience matter? *Journal of Health Economics*, 40: 122-131.

Colombo F, Llena-Nozal A, Mercier J, Tjadens F (2011). Help Wanted. Providing and Paying for Long-Term Care. Paris: OECD Publishing.

Costa-Font J, Courbage C (2012). Financing Long-Term Care in Europe. Institutions, Markets and Models. Basingstoke: Palgrave Macmillan.

Costa-Font J, Courbage C, Zweifel P (2017). Policy Dilemmas in Financing Long-Term Care in Europe. *Global Policy*, 8(2): 38-45.

De Donder P, Leroux ML (2013). Behavioral biases and long-term care insurance: a political economy approach. *B.E. Journal of Economic Analysis and Policy*, 14 (2): 551–575.

de Oliveira Assis L, de Paula JJ, Assis MG, de Moraes EN, Malloy-Diniz LF (2014). Psychometric properties of the Brazilian version of Pfeffer's Functional Activities Questionnaire. *Frontiers in Aging Neuroscience*, 6: 255.

Dias EG, Andrade FB, Duarte YA, Santos JL, Lebrão ML (2015). Advanced activities of daily living and incidence of cognitive decline in the elderly: the SABE Study. *Cuadernos de Saúde Pública*, 31(8): 1623-1635.

DIPRES (2016). Ley de Presupuestos del sector público año 2017. Retrieved from http://www.dipres.gob.cl/572/articles-149470_Ley_de_Presupuestos_2017_V2.pdf. Accessed: 26 Dec 2017.

DIPRES (2017). Informe Final - Programa de Atención Domiciliaria a Personas con Dependencia Severa. Retrieved from http://www.dipres.gob.cl/595/articles-163132_informe_final.pdf. Accessed: 16 Oct 2017.

Dirección Sociocultural de la Presidencia de la República de Chile (2017). Dependencia y Apoyo a los Cuidados, un asunto de Derechos Humanos. Santiago: Palacio de la Moneda.

Donnelly L, MacEntee MI (2016). Care Perceptions among Residents of LTC Facilities Purporting to Offer Person-Centred Care. *Canadian Journal of Aging*, 11: 1-12.

Drèze JH, Pestieau P, Schokkaert E (2016). Arrow's theorem of the deductible and long-term care insurance. *Economic Letters*, 148: 103-105.

Drummond MF, Sculpher MJ, Claxton K, Stoddart GL, Torrance GW (2015). Methods for Economic Evaluation of Health Care Programmes. Fourth Edition. Oxford: Oxford University Press.

Eggink E, Ras M, Woittiez I (2017). Dutch long-term care use in an ageing population. *Journal of the Economics of Ageing*, 9: 63–70.

Ejem DB, Drentea P, Clay OJ (2015). The effects of caregiver emotional stress on the depressive symptomatology of the care recipient. *Aging & Mental Health*, 19(1): 55-62.

España M. (2016). Panorama CASEN: Dependencia funcional en las personas mayores. Retrieved from

http://observatorio.ministeriodesarrollosocial.gob.cl/documentos/Panorama_Casen_Dependencia_funcional_personas_mayores_corr.pdf. Accessed: 10 Jul 2017.

Espinoza K, Jofré V (2012). Sobrecarga, apoyo social y autocuidado en cuidadores informales. *Ciencia y enfermería*, 18(2): 23-30.

EU (2016). Joint Report on Health Care and Long-Term Care Systems and Fiscal Sustainability. Institutional Paper 037. European Commission.

Favreault MM, Gleckman H, Johnson RW (2015). Financing Long-Term Services And Supports: Options Reflect Trade-Offs For Older Americans And Federal Spending. *Health Affairs*, 34(12): 2181-2191.

Federal Ministry of Health (2009). Report by the Advisory Board to Review the Definition of the Need for Long-Term Care. Retrieved from https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3_Downloads/E/Englische_Dateien/Report_by_the_advisory_board_to_review_the_definition_of_the_need_for_long-term_care.pdf. Accessed: 4 Jul 2017.

Federal Ministry of Health (2014). Long-term care. Retrieved from <http://www.bundesgesundheitsministerium.de/en/long-term-care.html>. Accessed: 2 Jan 2018.

Figueroa C (2017). Primer estudio nacional sociosanitario en atención cerrada. Orientaciones de abordaje técnico desde el enfoque de procesos. Santiago: Ministerio de Salud.

Flores E, Rivas E, Seguel F (2012). Nivel de sobrecarga en el desempeño del rol de cuidador familiar de adulto mayor con dependencia severa. *Ciencia y enfermería*, 18(1): 29-41.

Folstein M, Folstein SE, McHugh PR (1975). "Mini-Mental State" a Practical Method for Grading the Cognitive State of Patients for the Clinician. *Journal of Psychiatric Research*, 12(3): 189-198.

FONADIS (2004). Primer Estudio Nacional de la Discapacidad en Chile. Retrieved from http://www.senadis.gob.cl/pag/136/1196/resultados_endisc_i. Accessed: 10 Jul 2017.

FONASA (2017). Aranceles 2015. Retrieved from https://fonasaweb.fonasa.cl/portal_fonasa/site/artic/20150211/pags/20150211155307.html. Accessed: 12 Oct 2017.

Freedman VA, Martin LG, Cornman J, Agree EM, Schoeni RF (2008). Trends in Assistance with Daily Activities: Racial/ Ethnic and Socioeconomic Disparities Persist in the U. S. Older Population. In: Cutler DM, Wise DA (eds.). Health at Older Ages: The Causes and Consequences of Declining Disability among the Elderly. Chicago: University of Chicago Press.

Frenk J (1993). The new public health. *Annual Review of Public Health*, 14(1): 469-490.

Frijters DHM, van der Roest HG, Carpenter IGI, Finne-Soveri H, Henrard JC, Chetrit A, Gindin J, Bernabei R (2013). The calculation of quality indicators for long term care facilities in 8 countries (SHELTER project). *BMC Health Services Research*, 13(1): 1.

Fuentes P, Albala C (2014). An update on aging and dementia in Chile. *Dementia e Neuropsychologia*, 8(4): 317-322.

Gajardo J, Monsalves MJ (2013). Demencia, un tema urgente para Chile. *Revista Chilena de Salud Pública*, 17(1): 22-25.

Gascón S, Redondo N (2014). Calidad de los servicios de largo plazo para personas adultas mayores con dependencia. CEPAL - Serie Políticas Sociales N° 207.

- Gentili E, Masiero G, Mazzona F (2017). The role of culture in long-term care arrangement decisions. *Journal of Economic Behavior & Organization*, 143: 186-200.
- Geraedts M, Heller GV, Harrington CA (2000). Germany's Long-Term-Care Insurance: Putting a Social Insurance Model into Practice. *Milbank Quarterly*, 78(3), 375-401.
- Geriatric Nursing (2000). Katz Index of Independence in Activities of Daily Living. *Geriatric Nursing*, 21(2): 109.
- Gertler PJ, Martinez S, Premand P, Rawlings LB, Vermeersch CMJ (2011). Impact Evaluation in Practice. Washington DC: World Bank.
- Gleckman H (2011). Requiem for the CLASS Act. *Health Affairs*, 30(12): 2231-2234.
- Government of the Netherlands (2016). Health Insurance. Retrieved from <https://www.government.nl/topics/health-insurance>. Accessed: 5 Jan 2018.
- Government of the Netherlands (2017). Nursing homes and residential care. Retrieved from <https://www.government.nl/topics/nursing-homes-and-residential-care>. Accessed: 5 Jan 2018.
- Grabowski DC (2001). Medicaid reimbursement and the quality of nursing home care. *Journal of Health Economics*, 20: 549-569.
- Grabowski DC, Gruber J, Angelelli JJ (2008). Nursing home quality as a common good. *Review of Economics and Statistics*, 90(4): 754-764.
- Graubard SR (1996). Preface to the issue "Social Suffering". *Daedalus*, 125(1): V-X.

Hardy C (2017). El reto de un sistema de cuidados en el contexto de la protección social. En: Dirección Sociocultural de la Presidencia de la República de Chile. Dependencia y Apoyo a los Cuidados, un asunto de Derechos Humanos. Santiago: Palacio de la Moneda.

Harrington C, Cassell C, Estes CL, Woolhandler S, Himmelstein DU (1991). A National Long-term Care Program for the United States. *Journal of the American Medical Association*, 266(21): 3023-3029.

Harvard DrPH Program (2017). DrPH DELTA Doctoral Project Manual Class 2018: Guidelines and Procedures for DrPH Degree Candidates and Committee Members. DrPH Program, Office of Education, Harvard T.H. Chan School of Public Health.

Hojman DA, Duarte F, Ruiz-Tagle J, Budinich M, Delgado C, Slachevsky A (2017). The cost of dementia in an unequal country: The case of Chile. *PLoS ONE*, 12(3): e0172204.

Hospital Clínico UC (2017). Arancel de prestaciones 2017. Pacientes de Isapre o sin previsión. Retrieved from <http://redsalud.uc.cl/ucchristus/arancel-pacientes-isapre.act>. Accessed: 12 Oct 2017.

Hospital Clínico Universidad de Chile (2017). Tarifas de salas de procedimiento y derechos de pabellón. Retrieved from https://www.redclinica.cl/Portals/0/Users/014/14/14/arancel_2017.pdf. Accessed: 12 Oct 2017.

Hospital de Coquimbo (2015). Resolución exenta 001892. Retrieved from <http://www.hospitalcoquimbo.cl/wp-content/uploads/2015/04/Resoluci%C3%B3n-N%C2%B0-001892.pdf>. Accessed: 12 Oct 2017.

Hotez PJ (2013). NTDs V. 2.0:“blue marble health”—neglected tropical disease control and elimination in a shifting health policy landscape. *PLoS Neglected Tropical Diseases*, 7(11): e2570.

Hotez PJ, Molyneux DH, Fenwick A, Kumaresan J, Sachs SE, Sachs JD, Savioli L (2007). Control of neglected tropical diseases. *New England Journal of Medicine*, 357:1018-1027.

INE (2016). ESI. Encuesta Suplementaria de Ingresos – Síntesis de Resultados. Retrieved from http://historico.ine.cl/canales/chile_estadistico/mercado_del_trabajo/nene/esi/archivos/resultados_2015/sintesis_resultados_esi_2015.pdf. Accessed: 21 Jun 2017.

INE (2017). Estadísticas Demográficas y Vitales. Retrieved from <http://www.ine.cl/estadisticas/demograficas-y-vitales>. Accessed: 10 Aug 2017.

Instituto de Sociología PUC (2016). Propuesta de Instrumento de Evaluación de la Dependencia. Retrieved from http://www.ministeriodesarrollosocial.gob.cl/btca/txtcompleto/Informe_Final_Instrumento_Evaluacion_Dependencia.pdf. Accessed: 31 Aug 2017.

Jeon B, Kwon S (2017). Health and Long-Term Care Systems for Older People in the Republic of Korea: Policy Challenges and Lessons. *Health Systems & Reform*, 3(3): 214-223.

Jofré V, Sanhueza O (2010). Evaluación de la sobrecarga de cuidadoras/es informales. *Ciencia y enfermería*, 16(3): 111-120.

Jourmard I, André C, Nicq C (2010). Health care systems: Efficiency and institutions. OECD Economics Department Working Paper 769.

Kang IO, Park CY, Lee Y (2012). Role of healthcare in Korean long-term care insurance. *Journal of Korean Medical Science*, 27(Suppl): S41-S46.

Katz S, Downs TD, Cash HR, Grotz RC (1970). Progress in development of the index of ADL. *Gerontologist*, 10(1): 20-30.

Kim HB, Lim W (2015). Long-term care insurance, informal care, and medical expenditures. *Journal of Public Economics*, 125: 128-142.

Kingdon JW (1995). Agendas, Alternatives, and Public Policies, 2nd Edition. Boston: Pearson.

Kingston A, Wohland P, Wittenberg R, Robinson L, Brayne C, Matthews FE, Jagger C (2017). Is late-life dependency increasing or not? A comparison of the Cognitive Function and Ageing Studies (CFAS). *Lancet*, 390:1676-1684.

Kleinman A, Das V, Lock M (eds.) (1997). Social Suffering. London: University of California Press.

Knapp M, Somani A (2008). Long Term Care, Organization and Financing. In: Heggenhougen HK, Quah S (eds.). International Encyclopedia of Public Health. Academic Press: San Diego.

Kowal P, Dowd JE (2001). Definition of an older person. Proposed working definition of an older person in Africa for the MDS Project. WHO Technical Report. Geneva: World Health Organization.

Kroneman M, Boerma W, van den Berg M, Groenewegen P, de Jong J, van Ginneken E (2016). Netherlands: Health System Review. *Health Systems in Transition*, 18(2), 1-240.

- Kurlowicz L, Wallace M (1999). The Mini Mental State Examination (MMSE). Retrieved from <http://www.zielinskifam.com/papers/MMSE.pdf>. Accessed: 8 Sep 2017.
- Kwon S, Lee J, Kim C (2015). Republic of Korea. Health System Review. *Health Systems in Transition*, 5(4).
- Lee R (2003). The Demographic Transition: Three Centuries of Fundamental Change. *Journal of Economic Perspectives*, 17(4): 167-190.
- Lee R (2011). The Outlook for Population Growth. *Science*, 333(6042): 569-573.
- Letelier R, Yáñez R (2009). Determinación del grado de dependencia funcional de los pacientes del Servicio de Geriátría del hospital Regional Doctor Lautaro Navarro Avaria de la ciudad de Punta Arenas mediante la aplicación de Medida de Independencia Funcional y su relación con el Síndrome de Dismovilidad. Tesis para optar al grado de Licenciado en Kinesiología, Facultad de Humanidades, Ciencias Sociales, Jurídicas y de Salud, Universidad de Magallanes.
- Liese B, Rosenberg M, Schratz A (2010). Programmes, partnerships, and governance for elimination and control of neglected tropical diseases. *Lancet*, 375(9708): 67-76.
- Lilly MB, Laporte A, Coyte PC (2007). Labor market work and home care's unpaid caregivers: a systematic review of labor force participation rates, predictors of labor market withdrawal, and hours of work. *Milbank Quarterly*, 85 (4): 641–690.
- Maarse JAM, Jeurissen PP (2016). The policy and politics of the 2015 long-term care reform in the Netherlands. *Health Policy*, 120(3): 241-245.
- Mahoney FI, Barthel DW (1965). Functional evaluation: The Barthel index. *Maryland State Medical Journal*, 14: 61-65.

Manton KG, Stallard E (1994). Medical Demography: Interaction of Disability Dynamics and Mortality. In: Martin LG, Preston SH (eds.). Demography of Aging. Washington DC: National Academy Press.

Maturo A (2012). Medicalization: Current Concept and Future Directions in a Bionic Society. *Mens Sana Monographs*, 10(1): 122-133.

Matus-López M, Cid Pedraza C (2014). Costo de un sistema de atención de adultos mayores dependientes en Chile, 2012–2020. *Revista Panamericana de Salud Pública*, 36(1): 31-36.

Matus-López M, Cid Pedraza C (2015). Building Long-Term Care Policies in Latin America: New Programs in Chile. *Journal of Post-Acute and Long-term Medicine*, 16(10): 900.e7–900.e10

Mayston R, Guerra M, Huang Y, Sosa AL, Uwakwe R, Acosta I, Ezeah P, Gallardo S, Montes de Oca V, Wang H, Guerchet M, Liu Z, Sanchez M, Lloyd-Sherlock P, Prince MJ (2014). Exploring the economic and social effects of care dependence in later life: protocol for the 10/66 research group INDEP study. *Springerplus*, 3(1), 379.

McCall N (2001). Long Term Care: Definition, Demand, Cost, and Financing. In: McCall N (ed). Who Will Pay for Long Term Care? Insights from the Partnership Program. Chicago: Health Administration Press.

Medina A, Gallegos C, Leyton C, Torres B (2015). Costo día cama servicio pensionado para una enfermedad en un hospital en Chile. *Revista de la Universidad Industrial de Santander. Salud*, 47(3): 301-312.

MHWS (2016). Healthcare in the Netherlands. Ministry of Public Health, Welfare and Sports.

MIDESO (2015a). Casen 2013 – Inclusión social de personas con dificultades y/o condiciones permanentes y de larga duración. Retrieved from http://observatorio.ministeriodesarrollosocial.gob.cl/documentos/Casen2013_inclusion_social.pdf. Accessed: 12 Jul 2017.

MIDESO (2015b). Segundo Estudio Nacional de la Discapacidad en Chile. Retrieved from http://www.senadis.gob.cl/pag/355/1197/ii_estudio_nacional_de_discapacidad. Accessed: 10 Jul 2017.

MIDESO (2016). Camas Socio Sanitarias. Retrieved from http://www.programassociales.cl/pdf/2017/PRG2017_3_59473_2.pdf. Accessed: 16 Oct 2017.

MIDESO (2017a). CASEN 2015 – Adultos Mayores: Síntesis de Resultados. Retrieved from http://observatorio.ministeriodesarrollosocial.gob.cl/casen-multidimensional/casen/docs/CASEN_2015_Resultados_adultos_mayores.pdf. Accessed: 26 Jul 2017.

MIDESO (2017b). Subsistema Nacional de Apoyos y Cuidados – Documento Marco. Comité Técnico Interministerial Desarrollo Social.

MIDESO (2017c). Guía de Beneficios Sociales 2017. Disponible en <http://www.ministeriodesarrollosocial.gob.cl/centro-informacion/guia-beneficios-sociales/>. Acceso: 12 julio 2017.

MIDESO (n.d. a). Minuta Estimación de Población Potencial del Subsistema Nacional de Apoyos y Cuidados. Ministerio de Desarrollo Social.

MIDESO (n.d. b). Instrumento de Evaluación de Necesidades de Apoyos y Cuidados - SNAC. Ministerio de Desarrollo Social.

MIDESO (n.d. c). Estimación de costos por comuna y distribución comunal. Excel file.

MINSAL (2000). Encuesta de Calidad de Vida y Salud. Retrieved from <http://www.crececontigo.gob.cl/wp-content/uploads/2015/11/ENCAVI-2006.pdf>. Accessed: 11 Jul 2017.

MINSAL (2003). Encuesta Nacional de Salud ENS Chile 2003. Retrieved from <http://www.medicinadefamiliares.cl/Protocolos/encnacsalres.pdf>. Accessed: 11 Jul 2017.

MINSAL (2006). II Encuesta de Calidad de Vida y Salud. Retrieved from <http://www.crececontigo.gob.cl/wp-content/uploads/2015/11/ENCAVI-2006.pdf>. Accessed: 11 Jul 2017.

MINSAL (2010). Encuesta Nacional de Salud ENS Chile 2009-2010. Retrieved from <http://web.minsal.cl/portal/url/item/bcb03d7bc28b64dfe040010165012d23.pdf>. Accessed: 11 Jul 2017.

MINSAL (2013). Índice de Barthel. Retrieved from web.minsal.cl/portal/url/item/dabae5e899a823be040010164014f15.pptx. Accessed: 7 Sep 2017.

MINSAL (2014). Programa Nacional de Salud de las personas adultas mayores. Retrieved from http://web.minsal.cl/sites/default/files/files/Borrador%20documento%20Programa%20Nacional%20de%20Personas%20Adultas%20Mayores-%2004-03_14.pdf. Accessed: 10 Jul 2017.

MINSAL (2015). Documento preliminar para la elaboración del Plan Nacional para las demencias. Santiago: Ministerio de Salud. Retrieved from

http://web.minsal.cl/sites/default/files/files/PLAN_DEMENCIA_final.pdf. Accessed: 24 May 2017.

MINSAL (2017). Manual de Uso de Base de Datos “Tercera Encuesta de Calidad de Vida y Salud ENCAVI 2015-2016”. Santiago: Ministerio de Salud.

Morrison D, Pereira B (2004). Estudio descriptiva de la situación funcional del adulto mayor de 80 años y más, de las comunas de Independencia y Recoleta, de la zona norte de la Región Metropolitana de Chile, a través de la medida de independencia funcional. Tesis para optar al grado de Licenciado en Kinesiología, Facultad de Medicina, Universidad de Chile.

Muiser J, Carrin G (2007). Financing long-term care programmes in health systems (with a situation assessment in selected high-, middle- and low-income countries). Discussion Paper N°6, World Health Organization.

Muñoz C, Rojas P, Marzuca N (2015). Valoración del estado funcional de adultos mayores con dependencia moderada y severa pertenecientes a un centro de salud familiar. *Fisioterapia e Pesquisa*, 22(1): 76-83.

Murphy NA, Christian B, Caplin DA, Young PC (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: Care, Health and Development*, 33(2): 180-187.

Nagi SZ (1976). An epidemiology of disability among adults in the United States. *Milbank Memorial Fund Quarterly: Health and Society*, 54(4): 439-467.

NHIS (2014). National Health Insurance System of Korea: Universal Health Coverage for the World. Seoul: National Health Insurance System, Republic of Korea.

- NHIS (2016). National Health Insurance Service. Retrieved from <http://www.nhic.or.kr/static/html/wbd/g/a/wbdga0101.html>. Accessed: 5 Jan 2018.
- NHIS (2017). Long-Term Care Insurance: Introduction. Retrieved from <https://www.nhis.or.kr/static/html/wbd/g/a/wbdga0501.html>. Accessed: 6 Jul 2017.
- NIH (2017). What is prevalence? Retrieved from <https://www.nimh.nih.gov/health/statistics/prevalence/index.shtml>. Accessed: 7 Sep 2017.
- Norton EC (2000). Long-Term Care. In: Culyer AJ, Newhouse JP (eds.). Handbook of Health Economics, Vol. 1. Amsterdam: Elsevier.
- Norton EC (2016). Health and Long-Term Care. In: Piggott J, Woodland A (eds.). Handbook of the Economics of Population Aging, Volume 1B. Amsterdam: North-Holland.
- Norton EC, Newhouse JP (1994). Policy Options for Public Long-term Care Insurance. *Journal of the American Medical Association*, 271(19): 1520-1524.
- Nozaki M, Kashiwase K, Saito I (2017). Health Spending in Japan: Macro-Fiscal Implications and Reform Options. *Journal of the Economics of Ageing*, 9: 156-171.
- OECD (2016). OECD Health Statistics 2016. Retrieved from <http://www.oecd.org/els/health-systems/health-data.htm>. Accessed: 23 May 2017.
- OECD (2017). Elderly population. Retrieved from <https://data.oecd.org/pop/elderly-population.htm>. Accessed: 17 Jul 2017.
- OECD/European Commission (2013). A Good Life in Old Age? Monitoring and Improving Quality in Long-Term Care. Paris: OECD Publishing.

Olivares-Tirado P, Ibáñez C, España M, Miranda V, Gillmore M (2008). Dependencia en adultos mayores en Chile. Documento de Trabajo Superintendencia de Salud. Retrieved from http://www.supersalud.gob.cl/documentacion/666/articles-4471_recurso_1.pdf. Accessed: 7 Jul 2017.

Omran AR (2005). The Epidemiologic Transition: A Theory of the Epidemiology of Population Change. *Milbank Quarterly*, 83(4): 731–757.

OPS (2005). Salud, bienestar y envejecimiento en Santiago, Chile. SABE 2000. Retrieved from <http://iris.paho.org/xmlui/bitstream/handle/123456789/741/9275316090.pdf?sequence=1>. Accessed: 11 Jul 2017.

Orta OR, Barbosa C, Velez JC, Gelaye B, Chen X, Stoner L, Williams MA (2016). Associations of self-reported and objectively measured sleep disturbances with depression among primary caregivers of children with disabilities. *Nature and Science of Sleep*, 8: 181–188.

Pot AM, Briggs AM, Beard JR (2017). *Healthy Ageing* and the need for a long-term care system. Global consultation on integrated care for older people (ICOPE) – the path to universal health coverage. Background Paper 3, World Health Organization.

Pritchett L, Woolcock M, Andrews M (2011). Capability Traps? The Mechanisms of Persistent Implementation Failure. Working Paper 234, Center for Global Development.

Reinhard SC, Feinberg LF, Choula R., Houser A (2015). Valuing the Invaluable: 2015 Update. AARP Public Policy Institute, Washington, DC, 104:1–25.

Rhee JC, Done N, Anderson GF (2015). Considering long-term care insurance for middle-income countries: comparing South Korea with Japan and Germany. *Health Policy*, 119: 1319-1329.

Riquelme K, Silva A, Zepeda P (2007). Perfil del cuidador principal/ familiar de adultos mayores postrados en Chillán-Chile y de adultos mayores inmovilizados en Alicante-España. Tesis para optar al grado de Licenciado en Enfermería. Universidad del Bío-Bío.

Robles C (2011). El sistema de protección social de Chile: Una mirada desde la igualdad. Colección Documentos de Proyectos - CEPAL. Santiago: Comisión Económica para América Latina y el Caribe.

Rodrigues R, Schulmann K, Schmidt A, Kalavrezou N, Matsaganis M (2013). The indirect costs of long-term care. Research note 8/2013, European Commission.

Rogero-García J (2010). Las consecuencias del cuidado familiar sobre el cuidador: Una valoración compleja y necesaria. *Index de Enfermería*, 19(1): 47-50.

Rosson S, Fuentealba C, Hormazábal C, Villena C, Briebe F (2013). Enfermedad de Parkinson y demencia, calidad de vida y sobrecarga del cuidador. Intervención multidisciplinaria en Atención Primaria. *Revista Chilena de Salud Pública*, 17(19): 48-53.

Schäfer W, Kroneman M, Boerma W, van den Berg M, Westert G, Devillé W, van Ginneken E. (2010). The Netherlands: Health system review. *Health Systems in Transition*, 12(1): 1-229.

Scheil-Adlung X (2015). Long-term care protection form older persons: A review of coverage deficits in 46 countries. ESS Working Paper 50, International Labour Office.

Schneider U (1999). Germany's Social Long-Term Care Insurance: Design, Implementation and Evaluation. *International Social Security Review*, 52: 31-74.

Schultz E (2010). The Long-Term Care System for the Elderly in Germany. ENEPRI Research Report No. 78.

Schultz R, Beach SR (1999). Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Journal of the American Medical Association*, 282(23): 2215-2219.

Schultz R, Martire LM (2004). Family Caregiving of Persons with Dementia: Prevalence, Health Effects, and Support Strategies. *American Journal of Geriatric Psychiatry*, 12(3): 240–249.

Schultz R, Tompkins CA (2010). Informal Caregivers in the United States: Prevalence, Caregiver Characteristics, and Ability to Provide Care. In: National Research Council (US). Committee on the Role of Human Factors in Home Health Care. Washington DC: National Academy Press.

Sen A (1985). Commodities and capabilities. Elsevier: Amsterdam.

SENAMA (2010). Estudio Nacional de la Dependencia en Adultos Mayores. Santiago: Servicio Nacional del Adulto Mayor. Retrieved from <http://www.senama.cl/filesapp/Estudio%20Nacional%20de%20Dependencia%20en%20las%20Personas%20Mayores.pdf> . Accessed: 24 May 2017.

Slachevsky A, Budinich M, Miranda-Castillo C, Nunez-Huasaf J, Silva JR, Muñoz-Neira C, Gloger S, Jiménez O, Martorell B, Delgado C (2013). The CUIDEME Study: determinants of burden in Chilean primary caregivers of patients with dementia. *Journal of Alzheimer's Disease*, 35(2): 297-306.

Spillman BC, Lubitz J (2000). The Effect of Longevity on Spending for Acute and Long-Term Care. *New England Journal of Medicine*, 342: 1409-1415.

SPS (2017). Seguridad social como un derecho humano. Retrieved from <https://www.previsionsocial.gob.cl/sps/seguridad-social/>. Accessed: 13 Nov 2017.

Stallard E (2008). Long Term Care for Aging Populations. In: Heggenhougen HK, Quah S (eds.). *International Encyclopedia of Public Health*. Academic Press: San Diego.

Swartz K (2013). Searching for a Balance of Responsibilities: OECD Countries' Changing Elderly Assistance Policies. *Annual Review of Public Health*, 34: 397-412.

Swartz K, Miake N, Farag N (2012). Long-Term Care: Common Issues and Unknowns. *Journal of Public Analysis and Management*, 31(1): 139-152.

Tamiya N, Noguchi H, Nishi A, Reich MR, Ikegami N, Hashimoto H, Shibuya K, Kawachi I, Campbell JC (2011). Population ageing and wellbeing: lessons from Japan's long-term care insurance policy. *Lancet*, 378(9797): 1183-1192.

Thumala D, Kennedy BK, Calvo E, Gonzalez-Billault C, Zitko P, Lillo P, Villagra R, Ibáñez A, Assar R, Andrade M, Slachevsky A (2017). Aging and health policies in Chile: new agendas for research. *Health Systems & Reform*, 3(4): 253-260.

Umegaki H, Yanagawa M, Nonogaki Z, Nakashima H, Kuzuya M, Endo H (2014). Burden reduction of caregivers for users of care services provided by the public long-term care insurance system in Japan. *Archives of Gerontology and Geriatrics*, 58(1): 130-133.

Van Houtven CH, Norton EC (2004). Informal care and health care use of older adults. *Journal of Health Economics*, 23(6): 1159–1180.

Vaquiero S, Stiepovich J (2010). Cuidado informal, un reto asumido por la mujer. *Ciencia y enfermería*, XVI(2): 9-16.

Vigo D, Thornicroft G, Atun R (2016). Estimating the true global burden of mental illness. *Lancet Psychiatry*, 3(2):171-8.

Villalobos P (2017). Envejecimiento y cuidados a largo plazo en Chile: desafíos en el contexto de la OCDE. *Revista Panamericana de Salud Pública*, 41: e86.

Weiner JM (2011). Long-Term Care Financing, Service Delivery, and Quality Assurance: The International Experience. In: Binstock RH, George LK (eds.). Handbook of Aging and the Social Sciences, Seventh Edition. Amsterdam: Elsevier.

WHO (2000). A Lifecourse Approach to Health: The Implications for Training of Embracing. Geneva: World Health Organization.

WHO (2001). ICF International Classification of Functioning, Disability and Health. Geneva: World Health Organization.

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

WHO (2010a). Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. Geneva: World Health Organization.

WHO (2010b). The World Health Report: Health systems financing: The path to universal coverage. Geneva: World Health Organization.

WHO (2015). World Report on Ageing and Health. Geneva: World Health Organization.

WHO (2016). Global strategy and action plan on ageing and health (2016-2020): A framework for coordinated global action by the World Health Organization, Member States, and Partners across the Sustainable Development Goals. Geneva: World Health Organization.

WHO (2017a). Towards long-term care systems in sub-Saharan Africa. Geneva: World Health Organization.

WHO (2017b). Integrated Care for Older People: Guidelines on Community-level Interventions to Manage Declines in Intrinsic Capacity. Geneva: World Health Organization.

Wolff JL, Kasper JD (2006). Caregivers of frail elders: Updating a national profile. *Gerontologist*, 46(3): 344-356.

Won CW (2013). Elderly long-term care in Korea. *Journal of Clinical Gerontology and Geriatrics*, 4(1), 4-6.

World Bank (2015). Clasificación preliminar de la oferta pública nacional para adultos mayores y personas con discapacidad. Report commissioned by Ministerio de Desarrollo Social, Chile.

World Bank (2017). Primera fase del Sistema Nacional de Apoyos y Cuidados – Evaluación del proceso de implementación. Report commissioned by Ministerio de Desarrollo Social, Chile.

Zagreb Consultores Ltda (2016). Costos y estándares de calidad de servicios sociales relacionados con apoyos y cuidados a personas dependientes. Informe final. Retrieved from http://www.ministeriodesarrollosocial.gob.cl/btca/txtcompleto/Final_Costos_y_Estandares_Cuidados.pdf. Accessed: 16 Oct 2017.

Zarit SH, Reever KE, Back-Peterson J (1980). Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*, 20(6): 649-655

Zarit SH, Todd PA, Zarit JM (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist*, 26(3): 260-266.

Glossary

Activities of daily living: basic activities necessary for daily life, such as bathing or showering, dressing, eating, getting in or out of bed or chairs, using the toilet, and getting around inside the home (WHO 2015).

Advanced activities of daily living: activities based on intentional conducts involving the physical, mental, and social functioning that allow the individual to develop multiple social roles and maintain good mental health and quality of life (Dias et al 2015).

Ageing (ageing): at a biological level, ageing results from the impact of the accumulation of a wide variety of molecular and cellular damage that occurs over time (WHO 2015).

Barthel index: standard measure developed by Mahoney and Barthel (1965) used to assess the independence degree in patients, according to their ability to perform activities of daily living (ADL) (MINSAL 2013).

Caregiver: person who provides care and support to someone else; such support may include:

- helping with self-care, household tasks, mobility, social participation and meaningful activities;
- offering information, advice and emotional support, as well as engaging in advocacy, providing support for decision making and peer support, and helping with advance care planning;
- offering respite services; and
- engaging in activities to foster intrinsic capacity

Caregivers may include family members, friends, neighbors, volunteers, care workers and health professionals (WHO 2015).

Any person providing permanent assistance to people with disability in performing activities of daily living, within a household, paid or unpaid, regardless the existence of family ties (BCN 2017b).

Caregiver burden: extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning (Zarit et al 1986).

Set of physical, mental and socioeconomic problems suffered by caregivers of sick people, affecting their leisure activities, social relationships, friendships, intimacy, freedom and emotional balance (Espinoza and Jofré 2012).

Cognitive impairment: when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. With mild impairment, people may begin to notice changes in cognitive functions, but still be able to do their everyday activities. Severe levels of impairment can lead to losing the ability to understand the meaning or importance of something and the ability to talk or write, resulting in the inability to live independently. (CDC 2011).

Demographic transition: recent period of very rapid demographic change in most countries around the world in which declines in birth rates are followed by declines in death rates and rapid population growth. This transition usually accompanies the development process that transforms an agricultural society into an industrial one (Bongaarts 2009).

Dependency: state in which functional ability has decreased to a point where the person is no longer able to perform the basic tasks necessary for day-to-day life without the assistance of others (WHO 2015).

Permanent condition experienced by people who, due to one or more cause –physical, mental, sensorial, or linked to lack or loss of autonomy– require services or help from one or more persons in performing essential activities of daily living (BCN 2017b).

Particular kind of disability that involves two components: 1) limitation to perform certain activities and; 2) need of personal or technical help to interact with environmental factors (SENAMA 2010).

Disability: umbrella term for impairments, activity limitations and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (WHO 2015).

Elderly: any person, male or female, older than 60 years (BCN 2017a).

Epidemiologic transition: complex change in patterns of health and disease and on the interactions between these patterns and their demographic, economic and sociologic determinants and consequences (Omran 2005).

Frailty: extreme vulnerability to endogenous and exogenous stressors that exposes an individual to a higher risk of negative health-related outcomes (WHO 2015).

Functional ability: health-related attributes that enable people to be and to do what they have reason to value; it is made up of the intrinsic capacity of the individual, relevant environmental characteristics and the interactions between the individual and these characteristics (WHO 2015).

Functioning: umbrella term for body functions, body structures, activities and participation; it denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (WHO 2015).

Instrumental activities of daily living: activities that facilitate independent living, such as using the telephone, taking medications, managing money, shopping for groceries, preparing meals and using a map (WHO 2015).

Intrinsic capacity: composite of all the physical and mental capacities that an individual can draw on (WHO 2015).

International Classification of Functioning, Disability and Health: classification of health and health-related domains that describe body functions and structures, activities and participation; the domains are classified from different perspectives: body, individual and societal; because an individual's functioning and disability occur within a context, this classification includes a list of environmental factors (WHO 2015).

Katz index: also known as the index of independence in activities of daily living. The instrument was developed by Katz et al (1970) to measure functionality through the evaluation of elderly's ability to perform activities of daily living independently. Elderly are assessed in six functions: bathing, dressing, toileting, transferring, continence, and feeding (Geriatric Nursing 2000).

Lifecourse approach: approach that emphasizes a temporal and social perspective, looking back across an individual's or a cohort's life experiences or across generations for clues to current patterns of health and disease, while recognizing that both past and present experiences are shaped by the wider social, economic and cultural context (WHO 2000).

Long-term care: activities undertaken by others to ensure that people with a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity (WHO 2015).

Range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL) (OECD/European Commission 2013).

Continuum of medical and social services designed to support the needs of people living with chronic health problems that affect their ability to perform everyday activities (McCall 2001).

Long-term care system: national system that ensures integrated long-term care that is appropriate, affordable, accessible and upholds the rights of older people and caregivers alike. Depending on the national context, funding and care may be provided by some combination of families, civil society, the private sector and/ or the public sector. Governments do not need to do everything but should take overall responsibility for ensuring the system's functioning (WHO 2017a).

Medicalization: process by which some aspects of human life come to be considered as medical problems, whereas before they were not considered pathological. It can be defined as conceptual (when medical lexicon is used to define non-medical entities), institutional (when physicians have the power to steer non-medical personnel), or interactional (when the physician, in interaction with the patient, redefines a social problem into a medical one) (Maturro 2012).

Mini-Mental State Examination (MMSE): instrument used for conducting a systematic and complete assessment of the mental health status. Developed by Folstein et al (1975), the questionnaire has 11 questions evaluating five areas of the cognitive function: orientation,

registration, attention and calculation, recall, and language. The maximum score is 30; a score of 23 or lower is indicative of cognitive impairment (Kurlowicz and Wallace 1999).

Nagi's model: conceptual framework organized around the concepts of pathology, impairments, body's levels of performance, and disability, measured by different indexes taking into account the performance dimension (physical and emotional) and disability (work and independent life) (Nagi 1976).

Older person: a person whose age has passed the median life expectancy at birth (WHO 2015).

Pfeffer test: also known as Pfeffer Functional Activities Questionnaire (PFAQ). Developed by Pfeffer et al (1982, 1984) is one of the most used tests to study cognitive pathologies in elderly. The instrument evaluates degree of independence and performance in several activities of daily living such as: managing one's own finances; shopping; heating water and shutting off the stove; making meals; keeping track of current events, watching news reports and discussing them; maintaining oneself orientated when walking outside the neighborhood; remembering commitments; managing one's own medications; and being at home alone (de Oliveira et al 2014).

Prevalence: proportion of a population who have (or had) a specific characteristic in a given time period (NIH 2017).

Rehabilitation: set of measures aimed at individuals who have experienced or are likely to experience disability to assist them in achieving and maintaining optimal functioning when interacting with their environments (WHO 2015).

Social security: includes all measures providing benefits, whether in cash or in kind, to secure social protection (WHO 2015).

Instrument of social justice. In Chile, it is called *Sistema Previsional*, and includes a set of laws and policies available for people confront a contingency that prevents them to generate income in different stages of life (older age, unemployment, sickness, disability, work accident) (SPS 2017).

Zarit scale: caregiver self-report measure developed by Zarit et al (1980). Originally designed as a 29-item questionnaire, the revised version contains 22 questions scored on a Lickert scale (5-point scale), ranging from 0 (never) to 4 (nearly always). Scores are added to obtain a total score (22-110 points) that classifies caregivers as: "absence of overload" (<46), "light overload" (47-55) or "intense overload" (> 56) (Breinbauer et al 2009; APA 2017).

APPENDICES

Appendix 1: List of meetings and interviews – Government and international organizations

Organization	Topic	Date
DSC	Presentation of the project and discussion about its scope. DSC role and action plan	Jul 10 th
MINSAL-DEIS	Presentation of the project and discussion about its scope. Access to MINSAL statistics	Jul 19 th
Superintendence of Health	Presentation of the project and discussion about its scope. Access to Superintendence statistics and collaboration	Jul 27 th
PAHO	Presentation of the project and discussion about its scope. Discussion on activities to be executed in 2017 (LTC and aging)	Jul 28 th
MINSAL-DIPLAS	Presentation of the project and discussion about its scope	Jul 28 th
MDS	Presentation of the project and discussion about its scope. Role of MDS in the topic; information on the National System of Care (SNAC)	Aug 1 st
MINSAL-DEIS	Presentation of the project and discussion about its scope. Access to MINSAL statistics	Aug 2 nd
DSC	LTC in Chile. Preparation for the PAHO meeting on aging	Aug 7 th
MINSAL-GES	Presentation of the project and discussion about its scope. Link AUGE/GES and LTC/dependency	Aug 11 th
MINSAL-APS	Interview on definition of dependency used by the home care program for severe dependents, MINSAL. Other initiatives on dependency in MINSAL and other institutions	Aug 16 th
DSC	LTC in Chile. Preparation for the PAHO meeting on aging	Aug 24 th
MINSAL-	Interview on definition of dependency used by the rehabilitation unit,	Aug 25 th

Rehabilitation	MINSAL. Other initiatives on dependency in MINSAL and other institutions	
World Bank	Presentation of the project. Discussion on the state of LTC and Chile	Aug 28 th
MINSAL-DEIS	Presentation of the project and discussion about its scope. Access to MINSAL information on hospital discharges	Sep 7 th
DSC	Conclusions and tasks from the PAHO meeting on aging	Sep 8 th
DSC	Conclusions and tasks from the PAHO meeting on aging. Forming group at MINSAL to work on indicators	Sep 10 th
MINSAL-PAHO	Discussion on aging initiatives at MINSAL	Sep 12 th
PAHO indicators group	First meeting. Assessment of indicators and next steps	Sep 13 th
MINSAL-GRD	Access to MINSAL information on hospital discharges	Sep 15 th
Christus UC	Presentation of the project and discussion about similar initiatives in the private sector	Sep 21 st
MINSAL-GRD	Access to MINSAL information on hospital discharges. DRG statistics	Sep 22 nd
PAHO indicators group	Structure and conceptual framework to understand indicators	Sep 25 th
PAHO indicators group	Prioritization of indicators	Oct 12 th
MINSAL-Minister	Presentation of the project. Discussion on potential actions from MINSAL. Need to establish a ministerial definition of dependency	Oct 17 th
PAHO-MINSAL-DSC	Guidelines and goals for the indicators on aging	Oct 18 th
World Bank	Information collected by consulting activities for SNAC (MIDESO)	Oct 20 th
Christus UC	Christus UC project on home-based care	Oct 23 th
DSC	Second part of the project. Terms of reference for the IADB contract	Nov 7 th
DSC-MINTRAB	Presentation of the project and request of information to MINTRAB	Nov 9 th

MINSAL dependency group	Origins of the group. Discussion of the state of the art in the Ministry	Nov 13 th
MINSAL-DESAL	Indicators of financial protection and out-of-pocket expenditure in Chile (PAHO aging indicators)	Nov 15 th
PAHO indicators group	Indicators on dependency	Nov 16 th
MINSAL- Minister-DSC	Future actions on the topics of LTC and aging. Need of a ministerial definition and change in MINSAL organization chart to prioritize aging	Nov 17 th
MINSAL dependency group	Ministerial dependency definition	Nov 21 st
MDS	CASEN statistics, data on dependency	Nov 27 th
MINSAL dependency group	Instrument to measure dependency	Nov 28 th
PAHO workshop on aging and LTC	Presentations on LTC in Chile and discussion on indicators to measure the impact of aging on health systems	Nov 29 th – Dec 1 st
MINSAL dependency group	Conclusions and next steps	Dec 6 th
IADB	Presentation of the project and discussion about its scope	Dec 12 th
MINSAL dependency group	Presentation of results to the Minister	Dec 20 th
MINSAL-MDS- DSC	Joint seminar on the National System for Care	Jan 23 rd
MINSAL	Reporting LTC statistics to OECD	Jan 29 th
IADB	Report on aging indicators and LTC system design	Jan 30 th
MINSAL	Closing the project	Feb 12 th

Appendix 2: Interview guide and consent form

Original documents were written in Spanish

Oral Consent Form

Project title: Towards a long-term care system in Chile

Consultant: Pablo Villalobos

My name is Pablo Villalobos and I am currently working with the Ministry of Health in a project on long-term care. As part of this project, I would like to ask you some questions related to your work in the Ministry and the way in which it relates to the issue of long-term care.

You have been selected for your knowledge and involvement in the topic. Other interviewees will also be selected from other units of the Ministry, in order to have a global vision of the subject within the institution.

Important to consider:

- If you want to collaborate, this is a one-time interview that takes between 25 and 45 minutes
- Participation is voluntary
- You can choose not to answer any question
- There are no costs to participate in this project and no compensation will be given
- The interview will be recorded
- Depending on the needs of the project, some parts of the interview could be reproduced, always ensuring confidentiality

Participation involves no risk. The project also does not expect to generate individual benefits for participants. However, by participating you will be helping the Ministry's authorities to collect information and plan actions related to the issue of long-term care in the future.

Your privacy is very important and several methods will be used to protect it. However, despite all the security measures, we cannot assure you that your identity will remain secret. The interview records will be kept and only the project's principal investigator will have access to them.

The results of the project may be published or presented in the future, but your name or any other personal characteristic will be kept secret. Your answers will be put together with those of the rest of the interviewees.

IT'S YOUR DECISION! You are free to choose between participating or not. You can decide to participate and then change your mind. You can refuse to participate, answer some questions, or end the interview at any time without any consequences.

If you have any questions or comments, please direct them to:

Pablo Villalobos: pablo.villalobos@minsal.cl

Consent:

At the beginning of this interview you confirm that:

- You understand the information provided in this form and by the personnel associated with the project
- All questions regarding the project were answered satisfactorily

- You agree to participate in the interview
- A copy of this form has been made available to you

In order to protect your privacy, your signature is not necessary unless you choose to sign. If you still have questions about the protection of your privacy, you may choose not to continue.

This section is optional if you wish to participate anonymously. Your signature indicates your desire to participate voluntarily in this project.

Interviewee's name: _____

Interviewee's signature: _____ Date: _____

Name of the person getting the consent: _____

Signature of the person getting the consent: _____ Date: _____

MINSAL's interview guide

Good morning/ afternoon. My name is Pablo Villalobos and I am currently working with the Ministry of Health in a project on long-term care. As part of this project, I would like to ask you some questions related to your work in the Ministry and the way in which it relates to the issue of long-term care.

(Remember / read the consent for the interview)

Questions? Doubts?

1. First, I would like to know something about his role in the ministry. What are you currently doing? Since when?

2. Moving on to the main theme of this project, what do you think “long-term care” means? How does it relate (or not) to your daily work in the Ministry?

WHO defines long-term care as “activities undertaken by others to ensure that people with a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.”

3. Given this definition, do you consider your program/ work at the Ministry is related to the subject? What programs/ initiatives would be related?

4. A fundamental concept in LTC is dependency. Is this concept present in the operation of your program? How do you define it? How do you measure it? (e.g.: how they define potential population, target population, beneficiaries)
5. Do you know other studies or sources of information that can be useful to estimate the number of dependents in the country?
6. Do you know of any other initiative (within the Ministry or in other institution) related to the issue of LTC? (*show list*)
7. Other information (DEIS data, definitions used in the program, what is the MINSAL's dependency program?)

Appendix 3: Studies measuring dependency in Chile

Reference	Source	Population	Variable used	Instrument	Results ^c
MINSAL (2003)	National representative ness survey (N= 3,619)	General population (>17 years)	Cognitive impairment in elderly (>60 years) and disability	Abbreviated Mini Mental (MMSE) Pfeffer test	MMSE<13 Total: 14.9% Men: 14.5% Women: 15.2% MMSE<13 + disability Total: 8.5% Men: 8.3% Women: 8.6%
FONADIS (2004)	National representative ness survey (N= 13,769)	General population (>15 years)	Disability (based on ICF ^a)	Disability prevalence index	Total: 12.9% 0- 5 years: 0.1% 6- 14 years: 0.6% 15- 29 years: 1.1% 20- 59 years: 5.3% > 60 years: 5.8% Mild: 7.2% Moderate: 3.2% Severe: 2.5% <i>Elderly</i> Disability: 39.0% Mild: 17.3% Moderate: 11.1% Severe: 10.7%
OPS (2005)	Survey in Santiago (N= 1,301)	Elderly (>60 years)	Functional ability (limitations	Katz and Barthel tests	<i>Limitations ADL</i> Total: 19.2% Men: 17.3%

			ADL and IADL)		<p>Women: 25.1%</p> <p><i>Limitations IADL</i></p> <p>Total: 28.1%</p> <p>Men: 17.2%</p> <p>Women: 22.1%</p> <p>Total: 23.8%</p> <p>Men: 14.4%</p> <p>Women: 30.1%</p>
			Mobility and flexibility	Nagi test	
			Cognitive impairment	Modified MME and Pfeffer Activities Questionnaire (PFAQ)	<p><i>MMS<13</i></p> <p>Total: 10.7%</p> <p>>75: 22.2%</p> <p><i>MMS<13 + Pfeffer >5</i></p> <p>Total: 8.1%</p> <p>>75: 18.2%</p>
MINSAL (2006)	National representative ness survey (N= 11,207)	General population	Functional ability	SF-12 test	<p><i>Using public transportation (IADL)</i></p> <p>Total: 9.9%</p> <p>> 65 years: 25.3%</p> <p><i>Using objects (IADL)</i></p> <p>Total: 4.3%</p> <p>> 65 years: 14.4%</p> <p><i>Sphincter control (ADL)</i></p> <p>Total: 4.7%</p> <p>> 65 years: 13.7%</p>
Olivares-Tirado et al (2008)	Social Protection Survey (EPS) 2004	Workers (> 60 years)	Dependency (help in performing tasks)	Question f16	<p>Total: 21.4%</p> <p>Men: 16.5%</p> <p>Women: 26.9%</p> <p>Mild: 25,9%</p>

					Moderate: 34,5% Severe: 36,6%
MINSAL (2010)	National representative ness survey (N= 5,434)	General population (>15 years)	Cognitive impairment in elderly (>60 years) + limitations ADL Disability (based on ICF ^a)	Abbreviated Minimental (MMSE) + Pfeffer test Health State Module: WHS2003	MMSE<13 Total: 10.4% Men: 10.1% Women: 10.6% <i>MMSE<13 + Pfeffer>6</i> Total: 4.5% Men: 6.4% Women: 2.9% Total: 6.9% Men: 5.4% Women: 8.3%
SENAMA (2010)	National representative ness survey (N= 4,766)	Elderly (>60 years)	Dependency	Three levels based on 6 conditions	Total: 24,1% Mild: 6.7% (28%) Moderate: 5.1% (21%) Severe: 12.4% (51%)
MINSAL (2014)	MINSAL (2010) SENAMA (2010) Preventive Exam for	Elderly (>60 years) Elderly (>60 years) Elderly in primary care	Cognitive impairment Dependency Functional ability	Abbreviated Minimental (MMSE) + Pfeffer test Three levels based on 6 conditions Elderly evaluation	Total: 10.4% Men: 10.1% Women: 10.6% 60-69: 7.2% 70-79: 12.8% 80+: 20.9% Total: 24,1% Independent: 69.8% With risk: 41.2%

	Elderly (EMPAM), DEIS (2012)			(EFAM) + Barthel index	No risk: 28.7% Dependency risk: 17.2% Dependent: 13% Mild: 50,8% Moderate: 22,9% Severe: 12,8%
Cid et al (2014)	SENAMA (2010) MINSAL (2010) Subsecretaria de Previsión Social (2009)	Elderly (>65 years)	Dependency	Different instruments for different sources	Severe dependency: 12.2% Postrate: 1.14%
MIDESO (2015a)	CASEN survey 2013	General population (>15 years)	Difficulties due to health condition Functional dependency	Difficulty to perform ADL, cognitive problems Questions s36 and s38	Total: 15.6% Total: 8.5% (100%) Mild: 3.4% (40%) Moderate: 2.4% (28%) Severe: 2.7% (32%)
MIDESO (2015b)	National representative ness survey (N= 17,780)	General population	Disability (based on ICF ^a)	Capability index and performance	Total: 16.7% <i>Adults</i> Total: 20.0% Mild/moderate: 11.7% Severe: 8.3% Men: 14.8%

					<p>Women: 24.9%</p> <p><i>Children + Adolescents</i></p> <p>Total: 5.8%</p> <p><i>Dependents</i></p> <p>% population: 8.1%</p> <p>% disabled population: 40.4%</p>
España (2016)	CASEN survey 2013	Elderly (>60 years)	Functional dependency	Questions s36 and s38	<p>Total: 19.0% (100%)</p> <p>Mild: 7% (37%)</p> <p>Moderate: 6% (31.5%)</p> <p>Severe: 6% (31.5%)</p>
MINSAL (2017)	National representative ness survey (N= 7,041)	General population (>15 years)	Caregivers (includes only people working)	¿Are you caregiver for children, elderly, sick or disabled people or people with chronic diseases?	<p>% sample</p> <p>Yes (exclusive caregivers): 4.6%</p> <p>Yes (shared caregiver): 10.3%</p>
MIDESO (2017a)	CASEN survey 2015	Elderly (>60 years)	Functional dependency	Functional dependency index	<p>Total: 14.4%</p> <p>Mild: 4.5% (31%)</p> <p>Moderate: 6.2% (43%)</p> <p>Severe: 3.7% (26%)</p>
MIDESO (n.d. a)	Households Social Registry (RSH),	Vulnerable population (60% higher)	Dependency or disability	Self-report	Total: 1.72% ^b

	National Disability Registry				
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Source: Author's elaboration.

Notes:

^a ICF: International Classification of Functioning, Disability and Health (WHO 2001).

^b Percentage calculated using as numerator the figures by MIDESO (n.d. a) (314,166 persons) divided by the country's total population in 2016, according to INE (2017).

^c Number in parenthesis show the distribution of the total number of dependents according the different dependency levels.

Appendix 4: Methodology and sources uses in the study of social patients

The study uses hospital discharge data from DEIS-MINSAL database; all hospitals in the country are obliged to inform discharges to the Ministry of Health (Decree No. 1671/2010).

Contrary to the strategy adopted by Figueroa (2017), the analysis includes information on total hospital discharges for the period 2005-2015, instead of samples from different patients in certain periods of time.

The identification of sociosanitary patients is based on the presence of statistical outliers, i.e. patients whose stay exceed a “normal” lenght of stay in a Chilean hospital. To move from statistical outlier to social patients, several assumptions are required:

1. Outliers are patients who stay in the hospital beyond the time needed
2. These longer stays are due to extra medical reasons, i.e. they are social patients in the sense that after receving the needed healthcare services, they continue using hospital services (MIDESO 2016).

The above assumptions are key because they allow, identifying sociosanitary patients and the "extra" use of hospital beds from statistical outliers. As explained above, the strategy requires setting what is meant by a "normal" stay, in order to identify outliers (outlier = 1 if stay > normal stay). In this case, three thresholds were used; both definitions consider "normality" regarding duration in each health condition (about 7,000 diagnoses grouped according to the International Classification of Diseases, ICD-10):

1. Threshold 1: 75th percentile of the distribution (using the primary diagnosis)
2. Threshold 2: one standard deviation above the average (using primary diagnosis)

3. Threshold 3: Threshold 1 + dependency-related diagnosis (codes ICD-10 V and XXI)

In order to calculate the cost of these patients in the health system, several estimations were used:

Estimations cost per bed day in a public hospital (CLP\$ 2015)

Source	Description	CLP\$ 2015
FONASA (2017)	FONASA fee (public hospital): Day bed/ shared room	34.010
Figuerola (2017)	Day bed/ integral	35.301
Medina et al (2015)	Day bed/ shared room	39.856
FONASA (2017)	FONASA fee (public hospital): Day bed/ intensive therapy unit	68.290
Clínicas de Chile (2012)	Day bed/ integral	110.852
FONASA (2017)	FONASA fee (public hospital): Day bed/ shared room/ intensive care unit	141.410
Alvear et al (2012)	Day bed/ intensive therapy unit	351.133 - 503.390
Alvear et al (2013)	Day bed/ intensive therapy unit	426.000 - 550.024

Source: Author's elaboration.

Estimations cost per bed day in a private hospital (CLP\$ 2015)

Source	Description	FONASA code	CLP\$ 2015
Figuerola (2017)	Day bed/ integral	02 02 101	51.344
Hospital de Coquimbo (2015)	FONASA fee (private hospital): Day bed/ shared room (type C: 3 beds per room + bathroom)	02 02 101	94.000
Hospital Clínico Universidad de Chile (2017)	Day bed/ shared room	02 02 101	95.444
Hospital de Coquimbo (2015)	FONASA fee (private hospital): Day bed/ shared room (type B: 2 beds per room + bathroom)	02 02 102	125.000
Clínicas de Chile (2012)	Day bed	02 02 101	133.028
Hospital Clínico UC (2017)	Day bed/ shared room	02 02 101	160.481

Clínica Bicentenario (2017)	Day bed/ 2 beds per room	02 02 102	165.242
Hospital Clínico Universidad de Chile (2017)	Day bed/ 2 beds per room	02 02 102	181.273
Hospital de Coquimbo (2015)	FONASA fee (private hospital): Day bed/ shared room (type A: 1 bed per room + bathroom)	02 02 104	188.000
Hospital Clínico UC (2017)	Day bed/ 2 beds per room	02 02 102	228.181
Clínica Bicentenario (2017)	Day bed/ 1 bed per room	02 02 104	246.993
Hospital Clínico Universidad de Chile (2017)	Day bed/ 1 bed per room	02 02 104	252.437
Hospital Clínico UC (2017)	Day bed/ shared room	02 02 104	361.593
Clínica Alemana (2017)	Day bed/ 1 bed per room	02 02 104	541.950
Clínica Las Condes (2017)	Day bed/ 1 bed per room	02 02 104	555.011
Clínica Santa María (2017)	Day bed/ 1 bed per room	02 02 104	707.476

Source: Author's elaboration.

Estimations daily cost of a home-based care LTC system (CLP\$ 2015)

Source	Description	CLP\$ 2015
Matus-López & Cid (2014)	Benefit package for 12 programs of care (average)	5.346
Matus-López & Cid (2014)	Benefit package for 12 programs of care (upper bound)	9.387
Zagreb Consultores Ltda (2016)	Home visits	3.714
DIPRES (2017)	MINSAL's program of home-based care: cost per patient	992

Source: Author's elaboration.

Appendix 5: List of public LTC-related initiatives

Program	Ministry	Institution	Criteria/population	LTC component	Starting date
Ayudas Técnicas	MIDESO	SENADIS	Condition: Disability (moderate or severe) SES: 70% poorer (RSH) Other: National Disability Registry	Rehabilitation/ prevention	1994
Fondo Nacional de Proyectos (FNP)	MIDESO	SENADIS	Condition: Disability	Rehabilitation/ prevention Other (depending on the project)	1995
Corporación de Ayuda al Niño Limitado (COANIL)	MIDESO	SENADIS	Condition: Cognitive impairment (National Disability Registry) SES: 70% poorer (RSH)	Rehabilitation/ prevention Care services	2004
Apoyo a la Implementación de Centros Comunitarios de Rehabilitación (CCR)	MIDESO	SENADIS	Age: adults Condition: Disability Geography: distance to centers	Rehabilitation/ prevention	2007
Tránsito a la Vida Independiente - SNAC	MIDESO	SENADIS	Condition: Disability or dependency SES: medium-low	Rehabilitation/ prevention	2016
Apoyo a Instituciones Educativas para la Inclusión de Estudiantes en Situación de Discapacidad	MIDESO	SENADIS	Condition: Disability	Rehabilitation/ prevention	2017
Apoyo a la Intermediación Laboral	MIDESO	SENADIS	Condition: Disability	Rehabilitation/ prevention	2017
Fondo Nacional de Proyectos Inclusivos (FONAPI)	MIDESO	SENADIS	Condition: Disability	Rehabilitation/ prevention	2017
Oficinas Comunales de Discapacidad (OCD)	MIDESO	SENADIS	Condition: Disability	Rehabilitation/ prevention	2017

Recursos de Apoyo para Estudiantes de Educación Superior en Situación de Discapacidad	MIDESO	SENADIS	Age: older than 18 Condition: Disability Other: student (tertiary education)	Rehabilitation/ prevention	2017
Fondo Nacional del Adulto Mayor	MIDESO	SENAMA	Age: elderly Condition: dependency SES: vulnerability	Rehabilitation/ prevention Others (depending on the project)	2003
Consejo Nacional de Protección a la Ancianidad (Conapran)	MIDESO	SENAMA	Age: elderly Condition: dependency SES: 60% poorer, no family support	Care services	2003
Establecimientos de Larga Estadía para Adultos Mayores	MIDESO	SENAMA	Age: older than 60 Condition: dependency SES: 60% poorer, no family support Other: elders victims of violence Exclusion: requires healthcare services in hospital	Care services	2007
Escuela de Formación para Dirigentes Mayores	MIDESO	SENAMA	Age: elderly	Rehabilitation/ prevention	2007
Turismo Social para el Adulto Mayor	MIDESO	SENAMA	Age: older than 60 Condition: independent or mild dependency SES: 60% poorer (RSH)	Rehabilitation/ prevention Caregivers (respite)	2009
Condominio de Viviendas Tuteladas para Adultos Mayores	MIDESO	SENAMA	Age: older than 60 Condition: independent SES: 60% poorer (RSH) Gender: priority to women (ceteris paribus)	Rehabilitation/ prevention	2010
Buen Trato al Adulto Mayor	MIDESO	SENAMA	Age: older than 60 Other: victims of violence	Caregivers (training)	2012
Fondo Subsidio ELEM	MIDESO	SENAMA	Age: older than 60 Condition: dependency SES: 60% poorer (RSH) Household situation: housing condition Others: elderly, victims of violence, no family support	Care services	2013

			Exclusion: requires healthcare services in hospital		
Envejecimiento Activo	MIDESO	SENAMA	Age: older than 60 Condition: independent	Rehabilitation/ prevention	2013
Centros Diurnos del Adulto Mayor	MIDESO	SENAMA	Age: elderly Condition: dependency (mild or moderate) SES: social vulnerability	Rehabilitation/ prevention caregivers (respite)	2013 REF: 2017
Cuidados Domiciliarios	MIDESO	SENAMA	Age: older than 60 Condition: dependency (moderate or severe) SES: social vulnerability Geography: municipalities where SNAC is present Other: no caregiver	Rehabilitation/ prevention Care services Caregivers	2013 REF: 2016
Fondo de Iniciativas para la Superación de la Pobreza - Chile de Todas y Todos	MIDESO	SSE	Organizations	Others (depending on the project)	2012
Apoyo Integral al Adulto Mayor Vínculos – SS y OO	MIDESO	SSS	Age: older than 65 Condition: independent SES: 40% poorer Household situation: one or two persons Geography: elderly concentration	Rehabilitation/ prevention	2007
Apoyo a la Atención en Salud Mental	MIDESO	SSS	Age: older than 10 Condition: mental health problem SES: homeless (from programs "Calle" and "Abriendo Caminos") Geography: Metropolitan Region	Diagnosis	2011
Programa de Apoyo a la Salud Mental Infantil - CHCC	MIDESO	SSS	Age: between 5 and 9 Condition: mental health problem Other: FONASA beneficiary, registered in the local health center	Rehabilitation/ prevention Caregivers (training)	2016
Red Local de Apoyos y Cuidados - SNAC	MIDESO	SSS	Condition: dependency (RSH)	Diagnosis Care services Caregivers (training)	2017
Respira	MIDESO	SSS	Age: older than 18 Condition: dependency (severe) (RSH) SES: 60% poorer Other: unpaid caregiver, registered at the <i>Red Local de Apoyos y Cuidados</i>	Caregivers (training and respite)	2017

			- SNAC		
Adaptación Funcional de Viviendas - Adapta/ SNAC	MIDESO	SSS	Condition: dependency (moderate or severe)	Rehabilitation/ prevention	2017
Educación Especial Diferencial	MINEDUC	SE-DEG	Age: between 6 and 18 (students) Condition: special educational needs, disability	Rehabilitation/ prevention	1998
Protección - Residencias de Protección para Niños, Niñas en Situación de Discapacidad	MINJUS	SENAME	Age: between 0 and 18 Condition: disability, dependency Other: children's right violations	Care services Caregivers (training)	2005
Programa Residencias y Hogares Protegidos	MINSAL	SRA	Age: older than 18 Condition: cognitive disability SES: no family support Other: FONASA beneficiary	Diagnosis Rehabilitation/ prevention Care services	1998
Atención Domiciliaria Personas con Dependencia Severa	MINSAL	SRA	Condition: dependency (severe, Barthel) Other: FONASA beneficiary, registered in local primary care center SES (caregivers' subsidy): FPS<8500, Chile Solidario, PASIS	Diagnosis Care services Caregivers (training and allowance)	2006
Más Adultos Mayores Autovalentes	MINSAL	SRA	Age: older than 60 Condition: independent (including those in risk of dependency) Other: FONASA beneficiary, registered in local health center (population > 200,000)	Rehabilitation/ prevention	2015
Camas Socio Sanitarias	MINSAL	SRA	Age: adults Condition: need of care Other: FONASA beneficiary, discharged from a public hospital	Care services	2015
Centros de Apoyo Comunitario para Personas con Demencia (Ex Centros Diurnos para Personas con Demencia)	MINSAL	SRA	Age: older than 60 Condition: dementia (mild or moderate) Other: FONASA beneficiary, registered in local mental health center	Diagnosis Rehabilitation/ prevention Care services Caregivers (training)	2015
Plan Nacional de Demencia	MINSAL	SRA	Condition: dementia	Diagnosis Rehabilitation/ prevention Caregivers	2017

				(training)	
Programa Nacional de Inmunizaciones (PNI)	MINSAL	SSP	Age: older than 65	Rehabilitation/ prevention	1978 REF: 2016
Programa de Alimentación Complementaria del Adulto Mayor (PACAM)	MINSAL	SSP	Age: older than 60 Other: FONASA/PRAIS beneficiary	Rehabilitation/ prevention	1999
Certificación de Discapacidad	MINSAL	SSP	Condition: disability	Diagnosis	2014
Aporte Previsional Solidario (APS)	MINTRAB	IPS	SES: Non-contributory pension (<i>Pensión Básica Solidaria</i> , PBS)	Caregivers (allowance)	1968 REF: 2008
Pensión Básica Solidaria de Invalidez	MINTRAB	IPS	Age: between 18 and 65 Condition: disability SES: 60% poorer Other: at least 5 years living in the country	Caregivers (allowance)	1968 REF: 2008
Subsidio Familiar (SUF)	MINTRAB	IPS	Age: < 6 in health programs / between 6 and 18 going to school Condition: disability, cognitive impairment (certified by COMPIN) SES: 60% poorer Other: pregnancy	Caregivers (allowance)	1981
Subsidio Discapacidad Mental	MINTRAB	IPS	Age: less than 18 Condition: cognitive impairment SES: per capita income lower than CLP\$48,195 Other: at least 3 years living in the country	Caregivers (allowance)	2008
Chile Cuida	NA	Dirección Sociocultural de la Presidencia	Age: older than 60 Condition: dependency (moderate or severe, Barthel), caregiver burden (Zarit) SES: 60% poorer (RSH), caregiver without social support Geography: living in municipalities with the program	Care services Caregivers (respite and allowance)	2015

Source: Author's elaboration.

Note: MIDESO: Ministry of Social Development; MINEDUC: Ministry of Education; MINJUS: Ministry of Justice; MINSAL: Ministry of Health; MINTRAB: Ministry of Labor and Social Security, SENADIS: National Office for Disability, SENAMA: National Office for the Elderly; SSE: Undersecretary of Social Evaluation; SSS:

Undersecretary of Social Services; SE-DEG: Undersecretary of Education - General Education Division; SENAME: National Office for Children; SRA: Undersecretary of Health Providers' Networks; SSP: Undersecretary of Public Health; IPS: Social Security Institute; RSH: Social Household Registry; COMPIN: Preventive Medicine and Disability Committee; PRAIS: Comprehensive Reparation and Healthcare Program; REF: reformulation year.

Appendix 6: Decree that creates MINSAL's Advisory Committee for Aging and Long-Term Care



DISPONE CREACIÓN DE COMISIÓN ASESORA MINISTERIAL PARA ENVEJECIMIENTO Y CUIDADOS DE LARGO PLAZO

SANTIAGO, 09 MAR. 2018

Nº 22

CONTRALORIA GENERAL TOMA DE RAZON RECEPCION	
Depart. Jurídico	
Dep. T.R. y Regist.	
Depart. Contabil.	
Sub.Dep. C. Central	
Sub.Dep. E. Cuentas	
Sub.Dep. C.P. y B.N.	
Depart. Auditoría	
Depart. VOPU y T	
Sub. Dep. Munip.	
REFRENDACION	
Ref. por \$.....	
Imputación.....	
Anot. por.....	
Imputación.....	
Deduc.Dcto.....	

VISTO, lo establecido en los artículos 4º Y 7º del Decreto con Fuerza de Ley Nº 1 de 2005, que fija el texto refundido, coordinado y sistematizado del Decreto ley Nº 2.763 de 1979 y de las leyes Nº 18.933 y 18.469; en los artículos 6º, 7º Y 9º del Decreto Supremo Nº 136 de 2004, Reglamento Orgánico del Ministerio de Salud; en el Decreto Supremo Nº 19 de 2001, del Ministerio Secretaría General de la Presidencia; en la Resolución Nº 1.600, de 2008, de la Contraloría General de la República y sus modificaciones y;

CONSIDERANDO

- Que, al Ministerio de Salud le compete ejercer la función que corresponde al Estado de garantizar el libre e igualitario acceso a las acciones de promoción, protección y recuperación de la salud y de rehabilitación de la persona enferma, así como coordinar, controlar y cuando corresponda ejecutar tales acciones.
- Que, dado que el país experimenta un proceso de envejecimiento acelerado de su población, concentrando una población de adultos mayores cada vez más numerosa, surgen nuevos desafíos país que incluyen atender a una mayor demanda de prestaciones de seguridad social, entre ellas, las prestaciones de salud que benefician a los adultos mayores.

3. Que, se requiere recabar antecedentes y elaborar estudios que contribuyan a la adecuada toma de decisiones de parte de las autoridades, a efectos de dimensionar los alcances del envejecimiento poblacional y aportar criterios que permitan definir y medir la dependencia a la que se ven expuestos los adultos mayores en el orden social y comunitario, así como también, contribuir al diseño de políticas basadas en las nuevas evidencias y que contemplen análisis estadísticos y de monitoreo.

4. Que, para asesorar a las autoridades en el desarrollo de una política nacional para el envejecimiento y los cuidados de largo plazo, es necesario crear una comisión de carácter consultivo que contribuya en el diagnóstico, conocimiento e identificación de estos factores en el sistema público de salud.

5. Que, teniendo presente lo anterior y en uso de las facultades que me confiere la ley, dicto el siguiente:

DECRETO

1. **CRÉASE** una comisión asesora ministerial denominada “Comisión Asesora Ministerial para el Envejecimiento y los Cuidados de Largo Plazo”, en adelante “La Comisión”, de carácter permanente, cuyo objetivo general es asesorar al Ministerio de Salud en la articulación de una política nacional que responda a los desafíos que surgen del envejecimiento poblacional y el incremento en las necesidades de cuidados de largo plazo.

2. La Comisión tendrá las siguientes funciones:

- a) Realizar propuestas y asesorar en lo relativo al trabajo legislativo en el área.
- b) Recabar información estratégica para que las autoridades adopten decisiones de política en la materia.
- c) Asesorar en la evaluación del impacto del envejecimiento y de los cuidados a largo plazo en el sistema de salud chileno y proponer una estrategia para adaptar el sistema a estas nuevas necesidades.
- d) Asesorar en la identificación de las necesidades de capital humano requeridas y proponer un plan de formación de recursos humanos en salud a estos efectos.
- e) Asesorar en la gestión del conocimiento en el tema de envejecimiento, adulto mayor y cuidados al interior del Ministerio de Salud e identificar las necesidades de investigación en el área.
- f) Asesorar en la elaboración de alianzas estratégicas y en la promoción de la participación ciudadana, incluyendo la labor de asesoramiento en la coordinación con otras instituciones públicas, privadas y de la sociedad civil.

3. **ESTABLÉCESE** que la Comisión estará integrada por las siguientes personas:

- Jefe División Jurídica, Gabinete de la Ministra de Salud.
- Jefe del Departamento de Comunicaciones y RR. PP., Gabinete de la Ministra de Salud.
- Jefe Oficina de Cooperación y Asuntos Internacionales, Gabinete de la Ministra de Salud.
- Jefe Unidad de Género, Gabinete de la Ministra de Salud.

- Encargado de Participación Ciudadana, Ministerio de Salud.
 - Jefe División de Gestión de la Red Asistencial, Subsecretaría de Redes Asistenciales.
 - Jefe División de Atención Primaria, Subsecretaría de Redes Asistenciales.
 - Jefe División de Gestión y Desarrollo de las Personas, Subsecretaría de Redes Asistenciales.
 - Encargado Departamento GES y Redes Integradas, División de Gestión de la Red Asistencial, Subsecretaría de Redes Asistenciales.
 - Jefe Unidad de Rehabilitación, Departamento de Gestión de Procesos Asistenciales Integrados, División de Gestión de la Red Asistencial, Subsecretaría de Redes Asistenciales.
 - Jefe División de Prevención y Control de Enfermedades, Subsecretaría de Salud Pública.
 - Jefe División de Planificación Sanitaria, Subsecretaría de Salud Pública.
 - Jefe División de Políticas Públicas Saludables y Promoción, Subsecretaría de Salud Pública.
 - Jefe Departamento de Discapacidad y Rehabilitación, División de Prevención y Control de Enfermedades, Subsecretaría de Salud Pública.
 - Jefe Departamento de Enfermedades no Transmisibles, División de Prevención y Control de Enfermedades, Subsecretaría de Salud Pública.
 - Jefe Departamento de Ciclo Vital, División de Prevención y Control de Enfermedades, Subsecretaría de Salud Pública, quien además ejercerá la Secretaría Ejecutiva de la Comisión.
 - Jefe Departamento de Salud Mental, División de Prevención y Control de Enfermedades, Subsecretaría de Salud Pública.
 - Jefe Departamento de Estadísticas e Información de Salud, División de Planificación Sanitaria, Subsecretaría de Salud Pública.
4. La Comisión podrá invitar a sus sesiones y solicitar la colaboración de cualquier persona experta y/o profesional del Ministerio de Salud, o representantes de otras instituciones públicas o privadas que estime conveniente en las materias de su cometido. La persona invitada participará ad honorem y en carácter no deliberativo.
 5. La Comisión sesionará en las dependencias del Ministerio de Salud, el cual proporcionará el apoyo técnico y administrativo necesario.
 6. La Comisión resolverá por mayoría absoluta de votos de todos sus miembros, todas las cuestiones que se requieran para su funcionamiento, tales como: la calendarización de reuniones, recopilación de antecedentes y elaboración de documentos de trabajo.
 7. La Comisión tendrá un tiempo de duración indefinido y podrá variar su composición y su vigencia cuando la Autoridad Ministerial lo estime pertinente, mediante acto administrativo sujeto a la tramitación correspondiente.

ANÓTESE, TÓMESE RAZÓN Y PUBLÍQUESE

POR ORDEN DE LA PRESIDENTA DE LA REPÚBLICA



DRA. CARMEN CASTILLO TAUCHER
MINISTRA DE SALUD

Appendix 7: Presentations and publications

1. Presentations

- “Towards a LTC system in Chile”. Presented at MINSAL. Santiago, July 6th, 2017.
- “Aging, dependency and LTC in Chile”. Presented at Superintendencia de Salud. Seminar “Challenges of the Chilean health system”. Santiago, November 9th, 2017.
- “LTC in Chile: Challenges from a social security perspective”. Presented at the 3rd Congress: Health Commissions of the Parliaments of the Americas. “Health challenges in the 21th century”. Santiago, November 28th, 2017.
- “Long-term care system in Chile”. Presented at International workshop “Assessing the impact of aging in health systems”, organized by PAHO. Santiago, November 30th, 2017.
- “Social and economic implications of a long-term care system in Chile”. Presented at International workshop “Assessing the impact of aging in health systems”, organized by PAHO. Santiago, November 30th, 2017.
- “A definition of dependency for MINSAL”. Presented at MINSAL. Santiago, December 20th, 2017.
- “Long-term care in Chile”. Presented at course “Health reform and community medicine in Chile” (GHP297), HSPH. Santiago, January 18th, 2018.

2. Publications

- Villalobos Dintrans P. Envejecimiento y cuidados a largo plazo en Chile: Desafíos en el contexto de la OCDE. *Rev Panam Salud Publica*. 2017; 41:e86.
- Villalobos Dintrans P. Long-term care in Chile and the US: Not important enough?. Published at the DrPH on-line blog. Available at:

<https://harvarddrph.wordpress.com/2017/09/22/long-term-care-in-chile-and-the-us-not-important-enough/>

Appendix 8: LTC-related proposals in the presidential campaign

Candidate	Initial proposals (May-Jun)	Final proposals (Oct-Nov)
Carolina Goic	<ul style="list-style-type: none"> • AUGE for elderly. Includes geriatric services, daily (short-term) facilities and long-term facilities [p 15] • Mental health as pillar of the healthcare system [p 15]. Mental Health Law (equal coverage with other health problems) [p 27] • Support families with dependency: strengthening National System of Care to support people with disability (physical and cognitive) and caregivers [p 15, 28] • Promote gender equity in caregiving [p 26] <p>Geriatric Plan for Chile: to deal with aging and aging-related issues such as health, education and labor [p 27]</p>	<ul style="list-style-type: none"> • Identification of frail persons [p 246] • Start preventive exam at 60 instead of 65, in order to detect dependency and other conditions. Home care program for people with severe dependency. Rehabilitation and orthosis program. Dementia program [p 255] • Mental health law and increase in resources, including short-term facilities [p 259, 260] • Training and formalization of caregivers [p 326] • AUGE for elderly [p 327] • Offices for disabled people at municipality level [p 331] • Opportunities in the labor market [p 332] • Increase programs for dependents [p 333] <p>Promote shared responsibility in caregiving (gender bias) [p 343, 344]</p>
José Antonio Kast	<ul style="list-style-type: none"> • Promote a new policy on mental health [p 19] • Disability: work on a new model to promote autonomy, improve data and information; National System of Care [p 25-26, 29] (props 86, 88, 89, 90, 94, 108) • Integral policy for elderly: pensions, health, housing [p 28] (prop 99) • Strengthening SENAMA. Programs to prevent and treat dependency. Includes: programs in primary care, and short and long-term care facilities (AUGE ELEAM) [p 28-29] (props 101, 103, 107) 	No new proposals

Candidate	Initial proposals (May-Jun)	Final proposals (Oct-Nov)
Sebastián Piñera	<ul style="list-style-type: none"> National Policy for Healthy Aging. Provision through: families, short/ long-term facilities, and home care [p 8, 17] Elderly-related GES (oral health, chronic diseases, kinesiology) 	<ul style="list-style-type: none"> National Policy for Healthy Aging [p 16, 31, 93] AUGE for elderly, including Alzheimer [p 103, 115] Creation of a care system, including programs to deal with dependency [p 104] Healthy aging plan (<i>Plan Adultos Mejores</i>): AUGE for elderly, more geriatricians, and oral health program. Implementation of a dependency insurance; strengthen long and short-term facilities [p 105, 106, 119, 120] Strengthen institutions: SENAMA, presidential office for elderly [p 107] Labor market: inclusion for people with disability and caregivers [p 120]
Alejandro Guillier	<ul style="list-style-type: none"> Mental health law [p 25] Gender equality: equal labor opportunities and the unequal burden of caregiving [p 47] 	<ul style="list-style-type: none"> Strengthen national system of care [p 27] Create a national policy of care for people with dependency. Extend national system of care, including home care as well as long and short-term facilities [p 125, 129, 155, 159] Promote autonomy and prevention of dependency [p 126, 159] Dependency law [p 128] Caregivers' registry and labor policies [p 159] Mental health law [p 160]
Beatriz Sánchez	Aging: pensions; Gender: maternity	<ul style="list-style-type: none"> Increase density of geriatricians [p 166] Guarantee free diagnosis and treatment for age-related diseases. Eliminate compulsory health contribution for retired elders [p 166] Creation of National System of Care [p 166, 213-217] Increase resources to mental health, creation of a mental health law, strengthen national plan for dementia [pp 209, 303] Create a long-term care system along with the National System of Care [p 211] Create Ministry of disability [p 302]
Marco Enríquez-Ominami	Aging: pensions	No new proposals
Eduardo Artés	No proposals on the topic	No new proposals
Alejandro Navarro	<ul style="list-style-type: none"> Training 200 geriatricians and creation of Ministry for Elderly [p 18] Mental health law [p 19] 	No new proposals

Source: Author's elaboration based on www.servei.cl and candidates' websites.