Transforming Long-Term Care: A Participatory Theory of Change Approach Towards Community-Centred Solutions

ULLA-DÍEZ, Sara M.[(1)]; OLIVA MANZANO, Silvia[(2)]; COMAS-HERRERA, Adelina[(3)]; BREUER, Erica[(4)], GARCÍA-SOLER, Álvaro[(5)], RAMÓN JIMÉNEZ, María[(2)]

(1) Institute for the Older People and Social Services (Imserso). Ministry of Social Rights, Consumer Affairs and Agenda 2030, Madrid, Spain.

(2) National Reference Centre for Social and Health Care for People in a Dependency Situation. Institute for the Older People and Social Services (Imserso). Ministry of Social Rights, Consumer Affairs and Agenda 2030. Soria. Spain

(3) Care Policy and Evaluation Centre, Department of Health Policy, London School of Economics and Political Science, London, UK

(4) Heidelberg Institute of Global Health, Medical Faculty and University Hospital, University of Heidelberg; Honorary Lecturer, College of Health, Medicine and Wellbeing, University of Newcastle, Australia.

(5) Matia Gerontological Institute, Madrid, Spain

Corresponding Author: Sara M. Ulla Díez. saraulla@imserso.es; sulladiez@gmail.com.

Institute for the Older People and Social Services

Avenida de la Ilustración s/n

28029 Madrid-Spain

Acknowledgements:

The authors want to acknowledge the valuable help of the InCARE team in Spain: Sara Marsillas, Miren Iturburu, Nerea Galdona, and Manuel Montero; and the European Centre for Social Welfare Policy and Research: Stefania Ilinca and Selma Kadi.

Authors headings

SU: ULLA-DÍEZ, Sara M.

SO: OLIVA MANZANO, Silvia

AC: COMAS-HERRERA, Adelina

EB: BREUER, Erica

AG: GARCÍA-SOLER, Álvaro,

MR: RAMÓN JIMÉNEZ, María

Declaration of conflicting interest:

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding statement:

The InCARE project has received financial support from the European Union Programme for Employment and Social Innovation (EaSI) 2014-2020 (VS/2020/0258).

Ethics approval and consent to participate:

All participants were informed about the project and invited to participate in the workshops. Prior to the workshop, participants were provided with detailed information

about the project and the activities to be conducted. They were invited to participate, and those who chose to attend did so voluntarily at the designated facilities.

Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Author's Contributions:

Conceptualization, SU, SO, AC, EB, AG, MR; methodology, SU, SO, AC, EB, AG, MR; validation, SU, AC, EB, SO, AG, MR; formal analysis, SU, AC, SO, MR, AG; investigation, SU, AC, SO, MR, AG; resources, SO, MR; data curation, SO, MR; writing—original draft preparation, SU, SO; writing—review and editing, SU, SO, EB, AC, MR, AG; visualization, SU, SO, EB, AC; supervision, SU, AC, EB; project administration, SO, MR; funding acquisition, AC, EB, SO, AG.

Abstract

Long-term care is a priority for public policy in Spain, especially after COVID-19. The InCARE Project (Supporting INclusive development of community-based long-term CARE services through multi-stakeholder participatory approaches) promoted participatory policy and service development, using a Theory of Change approach. The Theory of Change describes a causal pathway for making strategic changes in the long-term care system over the next decade, aiming to achieve the desired impacts. A two-day workshop was held with 32 stakeholders, including policymakers, professionals, family carers, and people who use care services. A national ToC and a specific pilot project ToC outlined the steps required to improve the long-term care system to fulfil the needs and preferences of people in situations of dependency. The Theory of Change approach can be highly valuable for policy design, and it provides an integrated action map to guide the changes and inform political and management actions in the coming years.

Contribution to the literature

- The use of a Theory of Change provides a clear roadmap for implementing long-term care reforms in the coming decade, integrating the needs and preferences of professionals and dependent individuals, encouraging stakeholder engagement and ensuring that interventions are aligned with the local context.
- By highlighting the active involvement of various stakeholders—policymakers, professionals, family carers, and care service users—the paper contributes to the literature on participatory policymaking. It provides empirical evidence on the benefits of including diverse perspectives in policy development.
- The article emphasizes the importance of a system-wide approach to long-term care policy, offering a holistic vision that ensures more effective and coordinated service

delivery. This approach contributes to the growing body of work advocating for integrated, whole-system solutions in complex policy areas like LTC, addressing the need for long-term strategic planning rather than short-term fixes.

Applications of study findings to gerontological practice, policy and/or research

- The article introduces the ToC as a participatory methodology in the field of long-term care policy. While ToC is often used in health, social, and educational interventions, its use in LTC policy development is less common. This contribution demonstrates how ToC provides a structured framework for policy reform, which could inspire its application in other policy domains and further research.
- Focusing on community-based long-term care services, the article supports the decentralization of care and highlights the need for locally tailored solutions. It shifts away from institutionalized care models, encouraging further exploration of localized service delivery approaches.

Keywords:

Long-term services and support, person-centered care, qualitative methods, policymaking, participatory approach, care for dependency

1. Background

Long-term care (hereinafter LTC) comprises a diversity of activities to ensure that people with or at risk of a significant loss of capacity maintain a level of functional ability consistent with their basic rights, fundamental freedoms, and human dignity (WHO, 2015). Long-term care aims to provide health, social, or personal assistance, and support for an extended period. Care is provided by both non-professional and professional caregivers, primarily in settings such as homes, community care centres, long-term care facilities, or other housing solutions (Arias-Casais et al., 2022; European Commission, 2022).

In recent years, LTC systems have received increasing attention from policymakers and are the object of numerous studies. Population aging throughout the world, particularly in Europe and some Asian countries, together with low fertility rates, poses important challenges for public policies and the sustainability of public systems. The United Nations estimates that the number of people aged 60 and over worldwide will increase from 962 million in 2017 to 1.4 billion in 2030 and 2.1 billion in 2050 (United Nations, 2018).

Despite the growing adoption of approaches focused on preventing frailty and promoting healthy aging, the aging population and increasing longevity will inevitably escalate the need for long-term care (UNDESA, 2023). This demand will be particularly pronounced among women, who tend to constitute a larger proportion of care recipients within their homes and in residential care. In the European Union, for instance, 33% of women aged 65 or older require long-term care, in contrast to 19% of men. This gender disparity is substantially influenced by the greater longevity of women, resulting in a larger number of them being widowed and lacking potential support from a spouse, thus necessitating professional care (European Commission, 2021). This rise in demand will be compounded by the pressing challenge of a shortage of adequately skilled professionals

and the concerning trend of caregivers exiting the profession (Llena-Nozal et al., 2022; Pfortner et al., 2021). The challenge of population aging and the associated care needs have been addressed by governments and administrations, and also by multilateral organizations (European Commission, 2022; UNDESA, 2023; UNECE, 2022; WHO, 2020; WHO Regional Office for Europe, 2022). Currently, and even more pronounced after the pandemic, there is a wide perception that LTC needs significant expansion and improvement to meet adequate care requirements.

In addition to the increasing need for care, its quality and the individuals' preferences related to the care they need must also be considered. A significant number of older individuals express a desire to continue residing in their homes and communities until the end of their lives (Díaz-Veiga & Del Barrio, 2020). The preferred care arrangement is receiving assistance from professional caregivers within their homes if required (Ilinca et al, 2022).

The InCARE Project

The project '*Supporting INclusive development of community-based long-term CARE services through multi-stakeholder participatory approaches (InCARE)*' aimed to promote participatory, innovative, and integrated approaches to long-term care (LTC) policy and service development. It was funded by the European Commission under the EaSI (Employment and Social Innovation) framework. InCARE responds to the complexity of LTC systems and the challenges in providing adequate, affordable, and sustainable support to the aging populations of European countries.

Managing the complexity of LTC systems requires a comprehensive understanding and a flexible but coordinated approach to addressing the unique needs and circumstances of each local environment at the governance level (European Commission, 2017; European

Commission, Directorate-General for Employment, Social Affairs and Inclusion, 2018; Gori et al., 2023).

The project establishes innovative and participatory social decision-making processes. To achieve this objective, InCARE incorporates both a global analysis of the national system and the design of a pilot project for community intervention. This pilot project aims to provide a stepping-stone towards the implementation of a community intervention that could be scaled up to the national level. The objective was to promote reciprocity in non-professional care relationships, focusing on the well-being of family caregivers of older people with dementia and fostering a more equitable distribution of care within households, providing individual and group psychological support.

A key part of the project was a Theory of Change (ToC) workshop to develop a comprehensive understanding of the necessary steps and interventions required to bring about positive change in the long-term care sector in Spain over the next decade and to support the development of a local social innovation pilot. This paper describes the process and outcomes of the Theory of Change workshop.

2. Methods

2.1.Theory of Change

Theory of Change is an approach that makes explicit the underlying theory of whether and how a program, innovation, or policy might work in a specific context, and it is increasingly used in global health and social programs (Breuer et al., 2016; Breuer et al, 2022; Coryn et al., 2011; Desch et al., 2022; Gutiérrez-Barreto et al., 2023; Vogel, 2012). The premise is that every program has an implicit theory or mental model which should be articulated to understand whether and how a program works (Coryn et al., 2011).

The ToC approach is grounded in the principles and methods of program evaluation, leveraging the causal logic inherent in scientific methodology and social research. Traditional evaluation models, as well as the extensive literature on theory-based evaluation and planning also emphasize the importance of having a theory that describes the relationships between the objectives, activities, results, impacts, and interactions within the system (Fernandez et al., 2019; Kirkpatrick & Kirkpatrick, 1994; Scriven, 1998; Smith, 1994; Stufflebeam, 2002; Weiss, 2010).

One key aspect of the Theory of Change is that it can be used as a co-production tool for participatory planning, bringing together stakeholders' views and building consensus, through a structured and reflective process. The process of developing a ToC begins with identifying the desired long-term impact and working backward, with stakeholders proposing outcomes in the medium or short term, as well as the strategies required to achieve them. The ToC makes explicit why and how the change (policy or intervention) should work, which enables the discussion of the theoretical foundations upon which the intervention is based (Cassetti & Paredes-Carbonell, 2020).

In this project, we used participatory Theory of Change workshops in the planning phase of the InCARE project (Breuer et al., 2022). We used the ToC workshops to 1) develop a plausible causal pathway for making systemic changes in the long-term care system in Spain over the next decade, and 2) develop a social innovation pilot project for implementation and evaluation. We followed the guidelines for ToC development from the Strengthening Responses to Dementia in seven middle-income countries (STRiDE) Project (Breuer et al., 2019).

2.2.Steps to Design the Theory of Change in the InCARE Project

Step 1. Situational analysis

In preparation for the workshop, the team conducted a situational analysis and a Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis of the long-term care system in Spain. This involved a thorough review of key data and literature relevant to the different aspects of the long-term care system: demographics, utilization of services and benefits, profiles of people who use care, and organization of the LTC system.

Step 2. Selection of stakeholders for the Theory of Change workshop

Informed by the situational analysis, participants were intentionally selected according to different criteria. a) policymakers, managerial, technical, and research profiles; b) national, regional, and local levels of administration; c) health, and social services professionals; d) professional, and non-professional carers, personal assistance professionals for people in a dependency situation, and people receiving care.

All stakeholders were invited by email, with subsequent email and telephone follow-ups, resulting in 32 participants, including facilitators, who actively joined and participated in the workshop.

Step 3. Preparation of the workshop

The facilitation team conducted several meetings to select the participants, determine the workshop structure, create the agenda, and prepare the materials to be sent to the participants in advance. These materials included the invitation, flyer, agenda, a summary outlining the objectives of Project InCARE, and information on the workshop and the ToC methodology.

Step 4. Theory of Change workshop

The workshop was held in person at the National Reference Centre for Social and Health Care for People in a Dependency Situation of the Institute for the Older People and Social Services (Imserso) in Soria. The workshop facilitators were three women and one man and were supported by the rest of the technical Spanish team. The facilitators held PhD

or MSc in Social Sciences and Research Methods and all occupied positions related to social research. All facilitators had extensive experience in group facilitation and qualitative research.

Over two days, the participants were asked to agree on the impact that the Theory of Change was trying to achieve, identify the key challenges faced by the LTC system in Spain, and, working backward from the final impact, suggest logical steps (short and mid-term outcomes) that would be needed to achieve the final impact. They were then asked to identify key assumptions that need to be in place for each of the intermediate outcomes to occur.

- ***First day meeting***

The workshop commenced with a brief introduction of the facilitators and to the InCARE project and provided an overview of objectives and the ToC approach and methodology. The facilitators' backgrounds and interests in the research topic were also shared with the participants. To stimulate the discussion, the technical team presented a draft long-term impact statement to the stakeholders, derived from the situational analysis conducted earlier. The changes in the LTC model in Spain should result in "People who require LTC can pursue their life projects within the community and enhance their quality of life". Participants were encouraged to provide feedback and engage in an open debate about the statement.

After agreeing upon the impact statement, the participants were divided into two groups and separate rooms, each one focusing on developing a specific ToC: the long-term care system in Spain and the pilot project.

Participants were provided with different-coloured Post-it notes representing various elements of the ToC map. Participants were instructed to write their proposals on the notes and place them on different sections of the walls of the room, fostering interaction

and visual representation of their ideas. The in-person sessions were audio-recorded, after asking for authorization from all the participants. The online consolidation meeting was also video recorded. No other individuals were present during any of the sessions.

- ***Technical session after first-day workshop***

At the end of the first day, the technical team carefully organized and grouped the notes, representing the proximal and intermediate outcomes identified by the participants, to facilitate the following day's session and facilitate activities, and discussions.

- ***Second-day meeting***

On the second day of the workshop, the participants were divided into the same groups to identify assumptions and indicators related to the results and outcomes identified the day before. During the final plenary session, a comprehensive summary of both maps was presented to the entire group. Participants had the opportunity to express their opinions, ask questions, and provide feedback. It was agreed that the consolidated map would be shared in the online session, and a feedback form would be distributed for completion.

Step 5. Analysis and drafting of the first ToC map

Following the workshop, all the information gathered was processed, analysed, and interpreted by the project team. This review led to the development of a first draft of the ToC. The draft encompassed the national Theory of Change for the Spanish LTC system, which incorporated and nested the pilot project ToC.

Step 6. Consolidation meeting

The workshop participants were invited to take part in a consolidation meeting to review the ToC maps generated for the Spanish LTC system and the pilot project three weeks after the in-person workshop. The complete structure and causal logic of the ToC were presented and explained in detail.

During the consolidation meeting, which had a total attendance of twenty-two participants, the structure, causal pathway, and various elements of the ToC were evaluated and discussed to ensure that the final ToC map accurately reflected the necessary components. Stakeholders actively provided comments and suggestions during the meeting and communicated additional feedback via email.

Step 7. Second draft of the ToC map

All the suggestions and comments received from the stakeholders were analysed and incorporated into the final version of the ToC map. The second version incorporating these revisions was shared with the participants. Through an email validation process, participants were allowed to review and confirm the accuracy and appropriateness of the ToC map. Subsequently, the technical team refined the ToC map to ensure it contained all relevant information and to make it graphically comprehensible for dissemination.

To ensure the local relevance of the ToC map for the pilot, the team conducted an additional in-person ToC workshop in Gipuzkoa, where the pilot would take place, to engage local political actors, stakeholders, local care providers, and beneficiaries from the local context. This one was also followed by an online consolidation meeting.

2.3.Participants

A total of 30 people were initially invited to participate in the workshop. However, 10 could not attend due to scheduling conflicts (8) or health issues (2). These participants suggested colleagues from their teams as replacements.

A total of 32 people participated in the two-day in-person workshop and 22 of them in the online consolidation session. An additional 20 people took part in the local pilot ToC workshop and 17 of them in its consolidation meeting. Most participants were women (75%), the distribution by profiles is presented in Table 1.

PLEASE INSERT TABLE 1

3. Results

The Situational Analysis served as the foundation for the ToC. According to this analysis, Spain guarantees a universal right to public long-term care support, which is a fundamental component of the Welfare State, alongside the right to public health coverage. Nevertheless, the system faces some challenges. Specifically, the effectiveness of coverage is hindered by delays in accessing public support, high administrative hurdles, and insufficient community- and home-based care infrastructure. As a result, there is an excessive reliance on institutional care, significant burdens on family caregivers, a high dependence on the informal economy (particularly women and migrants), a lack of person-centered care, and substantial regional disparities in access, and quality. The situational analysis also highlighted important opportunities for improvement, as the government has been working to transform the long-term care model into a more person-centered, de-institutionalized approach while improving the coordination between health and social care services (García-Soler et al., 2022; Oliva et al., 2022) (Table 2).

PLEASE INSERT TABLE 2

The ToC workshop with the stakeholders generated a substantial number of elements for both the national LTC system ToC and the pilot project ToC (see Table 3). All these inputs were summarized and reviewed to avoid duplication and to identify clear action pathways that could be mapped within the ToC framework.

PLEASE INSERT TABLE 3

The final national ToC map is shown in Figure 1. We provide a description below.

PLEASE INSERT FIGURE 1

3.1.Impact

The desired ultimate impact that should be achieved was that "all people who require long-term care can pursue their life projects within the community, experience improved quality of life, through access to quality care that is provided with quality jobs. Family and professional caregivers should also have the opportunity to continue their life projects".

3.2.Long term outcomes

• *Sufficient and equitable financing*: the system has adequate financing that adheres to the principles of co-responsibility, equity, and justice, ensuring that resources are allocated fairly and in a way that meets the diverse needs of individuals requiring long-term care.

• *Coherent regulation*: the regulatory framework is consistent with the new model and aligned with the objectives of the LTC system. It aimed to promote person-centered attention, ensuring that regulations and policies supported individual needs and preferences.

• *Health and social services coordination*: the health system adapts and coordinates with the social services system to provide comprehensive support throughout the lifespan and aims to accompany individuals in realizing their life projects and ensuring their well-being.

• *Sufficient and quality resources*: resources and services are sufficient in quantity and maintain high-quality standards. These resources are aimed to support individuals in

remaining at home or in the community for as long as possible, promoting independence and well-being.

• *Dignified and personalized care*: dignified and high-quality care is provided based on personal decisions, allowing individuals to maintain autonomy and control over their care until the end of life. Personal preferences and choices are respected, promoting a person-centred approach to care.

•*Empowered users*: users of the LTC system are actively involved in creating their life projects and can make informed decisions about their support. Their voices and choices are respected, empowering them to shape their care experience.

• *Positive perception of an aging society*: society perceives old age as another stage in the life cycle, with value and dignity. Stereotypes and ageism are challenged, promoting a more inclusive and respectful view of older adults.

3.3. Proximal outcomes

The proximal outcomes mentioned by the participants varied in nature and targeted different mechanisms of change. To better organize them within the ToC framework, they were classified into three types for the global ToC: a) family and society; b) processes and policies; and c) organization; and a fourth type pertaining to the ToC for the pilot project.

Family and society. The catalyst for the change in the LTC system is social pressure and the demand to improve care, complemented by other interventions for raising awareness about the significance of LTC. Consequently, the demand and social pressure progressively escalate, leading to a cultural change in attitudes towards long-term care.

From the perspective of the care recipients, the intervention seeks to empower them to demand appropriate support and quality care to pursue their life plans.

The map also includes the transformation of environments, communities, and cities, which must be friendly, inclusive, and accessible to all individuals with varying abilities and care needs.

Processes and policy. A political decision would trigger a comprehensive agreement between all the political forces and administration levels towards a profound change in the LTC system in Spain.

Two additional sectors of the administration should be involved. First, is the healthcare sector, where coordination between the health and social systems is deemed crucial. Secondly, the education sector, as there is a need to align educational programs and competencies with the requirements of the care sector due to the increasing demand for care professionals.

Political decisions would trigger a process for restructuring the system, involving legal aspects, infrastructure adaptation, financial, material, and human resources, changes in procurement regulations, and the information and data management system.

Organizational. From those political and system-wide decisions, many other organizational changes are expected to occur to accomplish the outcomes.

The administrative processes need to be simplified to offer better and more flexible care and support to people throughout the life course.

Specific interventions are also necessary regarding providers to ensure that they are accredited, thereby guaranteeing the required quality standards and ensuring decent working conditions for long-term care professionals.

In addition, it would be necessary for all professionals, as well as citizens, to have a thorough understanding of the services and supports available in the public LTC system, to ensure that all eligible individuals can apply for services and supports and receive them.

Both professionals and family members involved in care, as well as volunteers and the

whole society, should be aware of and sensitized to the shift in the LTC model, the need for personalized care, and the focus on meeting the needs and preferences of individuals throughout their lives.

Another set of required changes would pertain to information and data management. To ensure the effectiveness and quality of interventions, a coherent information system is imperative. Highly related is the implementation of a quality control system that offers insights into the system's evolution and its impact on the quality of life of care recipients. Informed decision-making for improved services would also depend on evidence generated from evaluations and monitoring data derived from the quality system.

Pilot project. This nested ToC is specific to the pilot project and emphasizes the importance of training and raising awareness among professionals and family members regarding person-centered care and case management. Personalizing care requires social agents, social workers, psychologists, and volunteers to be familiar with the needs of people receiving care and ensure coordination between programs.

This pilot map comprises distinct outcomes, challenges, proximal outcomes, and indicators, but at the same time is integrated into the national map, aligns with the impact, and maintains a connection through flow lines. The outcomes within the pilot map are interwoven with those of the whole LTC system map through various mechanisms, including generalization from the pilot to society, systemic routes that can bolster the pilot or the dissemination of information generated in the pilot to society or policymakers. The pilot has been implemented and evaluated, and details and results of the pilot will be reported elsewhere.

3.4.Interventions

To achieve the outcomes, participants proposed interventions of different complexity and character that can be structured into seven categories (Table 4). They highlight the need for an integrative approach that encompasses training, social awareness, service coordination, and regulatory adaptation, all aimed at improving long-term care with a focus on person-centered and community-based approaches.

PLEASE INSERT TABLE 4

3.5.Assumptions

Assumptions and preconditions were identified as essential for enabling the change depicted in the ToC map (Table 5). These assumptions identify the underlying hypothesis on which the intervention is founded and represent risks to the causal link between the proximal and intermediate outcomes (Mayne, 2017).

PLEASE INSERT TABLE 5

4. Discussion

The Theory of Change map developed during this process provides a comprehensive and internally coherent overview of the necessary changes for improving the care system. It also aligned with the findings of the situational analysis. Following the (hypothetical) political decision for the wholesale transformation of the LTC system, it is crucial to provide sufficient funding that prioritizes equity and is supported by an adequate regulatory framework. This framework should not only enable effective management and timely provision of care but also be flexible enough to accommodate the unique needs of everyone at different stages of life.

Furthermore, there is a need to achieve integration among the care provided by different services or administrations. A challenge lies in integrating healthcare and long-term care, often governed by different ministries and under different logic. In many cases, such as in Spain, a medical prescription is sufficient to access any service within the National Healthcare System. However, this is not the case in the Social Services System, which requires a technical evaluation and an administrative assessment to determine the eligibility and intensity of care from a non-technical or person-centred perspective.

Care must be sufficient, of high quality, dignified, and tailored to individuals and their needs, which are not solely determined by their level of dependency but also by their context and personal, familial, or social resources. Because of making adapted care available based on individuals' needs, the burden currently placed on families would decrease, particularly on women caregivers who often have to reduce their work hours to provide care for their family members. Caregivers also need support, training, and opportunities for respite.

Another clear focus of action is related to care professionals, who must also have quality, dignified, and socially recognized work that enables them to pursue their own life goals. They should receive training that covers both technical skills and attitudes to ensure quality care, respecting the person’s dignity, intimacy, and preferences in all interactions. All of this must be accompanied by a social and environmental change that is non-discriminatory, supportive, and friendly, not only towards older people but also towards any person in need of care.

The workshops highlighted the significance of stakeholder involvement, not only for ensuring positive participant engagement but also to capture the knowledge and experience of people with professional and lived experience of the various stages and mechanisms of change of the ToC map.

The changes outlined in this ToC, which are fully derived from the participants' inputs are consistent with the recommendations from the external evaluation of the Spanish LTC system. It also emphasized, among others, the need to implement changes regarding the caregiving profession, family caregivers, and the necessity to streamline processes to make them simpler, more flexible and centred in the person needs (Rodríguez Cabrero et al., 2022).

Communities should be considered as a key setting for long-term care provision (Arias-Casais et al., 2022). However, to ensure that community-based care is appropriate and that needs are met, significant development of resources and services is required. There is evidence that older adults who receive paid care in the community experience a higher number of unmet needs in comparison with those receiving only unpaid care or residential care (Jenkins Morales & Robert, 2023). Therefore, care arrangements in the community should be designed and resourced to meet the needs of the older people who stay in their communities.

Despite all the positive outcomes of the workshop, it is also necessary to bear in mind its limitations. Firstly, since we invited participants involved in caregiving who were familiar with the sector, we may have induced a selection bias. A second limitation regarding participants is the low number of LTC users and families. Hence, the Theory of Change map formulated within the project using participatory methodologies is inherently tailored to the specific timeframe and context of its development. Nevertheless, this approach proves to be valid and resource-efficient, as it inclusively incorporates insights from diverse viewpoints and disciplines, encompassing the outlooks of both professionals and care receivers in a participatory manner. Additionally, the InCare project included the voices of users, relatives, and society in general in another stage of

the research, complementing the final approach to the LTC system in each country (Ilinca & Simmons, 2022)

Another limitation is related to the complexity of the ToC methodology within the available time frame for the workshop. With such a highly complex system as LTC, the number of elements provided by participants is extensive and not always aligned with specific components of the ToC model. We have chosen to maximize the utilization of the information provided, even if it deviates from the orthodoxy of the model and perfect alignment with each layer of the map.

Lastly, we want to highlight a challenge more related to the utilization of the results rather than the objective of this study, which also depends on factors related to policy development and cultural, health, and social backgrounds (Szczepura et al., 2023). The necessary change involves a significant number of political decisions that affect different sectors and levels of the administration, particularly in a country as decentralized as Spain. The assumptions indicate the need for global involvement, agreement, and ownership at the highest political level to achieve comprehensive change.

5. Conclusions

A Theory of Change approach can support long-term care policy and system change by offering a framework that promotes the engagement of stakeholders and interventions alignment to the local context (Breuer et al., 2016; De Silva et al., 2014).

All the elements of the map, from assumptions to impact, define a model of long-term care that understands caregiving as a support for individuals to continue living their lives and should be organized around and respect their needs, preferences, and desires at each moment. Therefore, if their wish is to remain in their home or community and continue with their activities, there should be sufficient and appropriate resources available to make this a reality until the end of life. To achieve this goal, the whole system must be

addressed. The public and private organizations, processes, care and services providers, professionals, and the coordination among all the partners must be well coordinated and aligned towards the same purpose.

In this case, the Theory of Change development process has proven to be highly valuable for policy design, as it has provided an integrated, coherent, and comprehensive action map that can guide the necessary changes in the care system and inform political and management actions in the coming years.

References:

Arias-Casais, N., Thiyagarajan, J. A., Rodrigues Perracini, M., Park, E., Van den Block, L., Sumi, Y., Sadana, R., & Han, Z. A. (2022). What long-term care interventions have been published between 2010 and 2020? Results of a WHO scoping review identifying long-term care interventions for older people around the world. *Bmj Open*, *12*(1), Article e054492. https://doi.org/10.1136/bmjopen-2021-054492

Breuer, E., Comas-Herrera, A., Docrat, S., Freeman, E., Schneider, M., & Stride-Team. (2019). STRIDE Theory of Change Workshops: Guidance and Resources. STRIDE Research Tool (version2). In: Care Policy and Evaluation Center, LSE.

Breuer, E., Lee, L., De Silva, M., & Lund, C. (2016). Using theory of change to design and evaluate public health interventions: a systematic review [Review]. *Implementation Science*, *11*, 17, Article 63. https://doi.org/10.1186/s13012-016-0422-6

Breuer, E., Kadi, S., Champeix, C., Garcia, A., Grbevska, T., Comas-Herrera, A.,…Ilinca, S. (2022). *Co-developing and contextualising long-term care innovations in Europe using Theory of Change: lessons from InCARE* (Policy Brief, Issue. https://incare.euro.centre.org/wp-content/uploads/2022/07/InCARE-ToC-Policy-Brief_3_TOC_final_.pdf

Cassetti, V., & Paredes-Carbonell, J. J. (2020). Theory of change: a tool for participatory planning and evaluation in community health [http://purl.org/dc/dcmitype/Text]. *Gaceta sanitaria*, *34*(3). https://doi.org/https://dialnet.unirioja.es/servlet/dcart?info=link&codigo=7402585&orden=0

Coryn, C. L. S., Noakes, L. A., Westine, C. D., & Schroter, D. C. (2011). A Systematic Review of Theory-Driven Evaluation Practice From 1990 to 2009 [Review]. *American Journal of Evaluation*, *32*(2), 199-226. https://doi.org/10.1177/1098214010389321

De Silva, M. J., Breuer, E., Lee, L., Asher, L., Chowdhary, N., Lund, C., & Patel, V. (2014). Theory of Change: a theory-driven approach to enhance the Medical Research Council's framework for complex interventions. *Trials*, *15*, Article 267. https://doi.org/10.1186/1745-6215-15-267

Desch, A., Förstner, B., Artmann, J., Häusler, A., Hauptmann, M., Altin, S., Rap, M. & Holmberg, C. (2022). A theory of change of an innovation for therapeutic care and meaningful living in a German nursing home [OriginalPaper]. *BMC Geriatrics*, *22*(1), 1-14. https://doi.org/doi:10.1186/s12877-022-03462-0

Díaz-Veiga, P., & Del Barrio, E. (2020). Estudio sobre las condiciones de vida de las personas de 55 y más años en Euskadi. Servicio Central de Publicaciones del Gobierno Vasco. https://www.euskadi.eus/contenidos/informacion/publicaciones_ss/es_publica/adjuntos/1.Resumen_CONDICIONESVIDA_ES.pdf

European Commission. (2017). *BLOCKS: tools and methodologies to assess integrated care in Europe*. https://health.ec.europa.eu/publications/blocks-tools-and-methodologies-assess-integrated-care-europe_en

European Commission. (2021). *Long-term care report: trends, challenges and opportunities in an ageing society. Volume I.* [Website]. http://op.europa.eu/en/publication-detail/-/publication/484b0ceb-cd83-11eb-ac72-01aa75ed71a1/language-en

European Commission. (2022). *European Care Strategy for caregivers and care receivers*. https://ec.europa.eu/social/main.jsp?langId=en&catId=89&furtherNews=yes&newsId=10382#navItem-1

European Commission, Directorate-General for Employment, Social Affairs and Inclusion. Coster, S., Vanhercke, B., Peña-Casas, R. (2018). *Challenges in long-term care in Europe – A study of national policies*. Publications Office. https://data.europa.eu/doi/10.2767/84573

Fernandez, M. E., Ruiter, R. A. C., Markham, C. M., & Kok, G. (2019). Intervention Mapping: Theory- and Evidence-Based Health Promotion Program Planning: Perspective and Examples. *Frontiers in Public Health*, *7*, Article 209. https://doi.org/10.3389/fpubh.2019.00209

García-Soler, A., Ulla-Diez, S. M., Oliva, S., Montero, M., Ramón, M., Iturburu, M., & Galdona, N. (2022). Situational Analysis [Spain]. Internal Report from INCARE Project. Supporting INclusive development of community-based long-term CARE services through multi-stakeholder participatory approaches. Unpublished document.

Gori, C., Fernández, J. L., & Wittenberg, R. (2023). *Long-Term Care Reforms in OECD Countries*. Policy Press. https://doi.org/10.1332/policypress/9781447305057.001.0001

Gutiérrez-Barreto, S. E., Sosa-Tinoco, E., Rojas-Calixto, O., Deniss-Navarro, Z., Avila-Avila, A., & Gutierrez, J. P. (2023). Evaluating the design of the Integrated Care for Older People: a theory of change approach. *Frontiers in Medicine*, *10*, Article 1166196. https://doi.org/10.3389/fmed.2023.1166196

Jenkins Morales, M. & Robert, S. A., (2023). Examining Consequences Related to Unmet Care Needs Across the Long-Term Care Continuum. *The Journals of Gerontology: Series B*, *77*. https://doi.org/10.1093/geronb/gbab210

Kirkpatrick, D. L., & Kirkpatrick, J. D. (1994). *Evaluating training programs: The four levels*. Nerret-Koehler. saraulla@imserso.es; s.ulla@cop.es

Ilinca, S. & Simmons, C. (2022). The time to care about care. Responding to changing attitudes, expectations and preferences on long-term care in Europe. https://incare.euro.centre.org/wp-content/uploads/2023/10/InCARE-Policy-Brief-2_The-time-to-care-about-care_261023_WP1.pdf

Ilinca, S., Simmons, C., Lucius, A., Oliva, S., Montero, M., & Ulla Díez, S. (2022). Attitudes, experiences and expectations on long-term care in Spain. In. https://www.euro.centre.org/publications/detail/4338

Llena-Nozal, A., Rocard, E., & Sillitti, P. (2022). Providing long-term care: Options for a better workforce. *International Social Security Review*, *75*(3-4), 121-144. https://doi.org/10.1111/issr.12310

Mayne, J. (2017). Theory of Change Analysis: Building Robust Theories of Change. *Canadian Journal of Program Evaluation*. https://doi.org/10.3138/cjpe.31122

Oliva, S., García-Soler, A., Ramón, M., Iturburu, M., Montero, M., Galdona, N.,…Ulla-Díez, S. M. (2022). Short Report: Long-Term Care landscape in Spain. Internal Report from INCARE Project.Supporting INclusive development of community-based long-term CARE servicesthrough multi-stakeholder participatory approaches (InCARE). Unpublished document.

Pfortner, T. K., Pfaff, H., & Hower, K. I. (2021). Will the demands by the covid-19 pandemic increase the intent to quit the profession of long-term care managers. A

repeated cross-sectional study in Germany. *Journal of Public Health*, *43*(3), E431-E434. https://doi.org/10.1093/pubmed/fdab081

Rodríguez Cabrero, G., Marván, V., Aguilar, M., Huete, A., Jiménez, A., Martínez, R., & Zalakain, J. (2022). *Informe de evaluación del sistema de promoción de la autonomía personal y atención a las personas en situación de dependencia (SAAD).* https://www.mdsocialesa2030.gob.es/derechos-sociales/inclusion/docs/estudio_evaluacion_saad_ completo.pdf

Scriven, M. (1998). Minimalist theory: The least theory that practice requires. *American Journal of Evaluation*, *19*(1), 57-70. https://doi.org/10.1177/109821409801900105

Smith, N. (1994). Clarifying and expanding the application of program theory-driven evaluations. *Evaluation Practice*, *15*(1), 83-87. https://doi.org/10.1016/0886-1633(94)90064-7

Stufflebeam, D. (2002). Evaluation models. *New Directions for Evaluation*, *2001*(89). https://doi.org/doi:https://doi.org/10.1002/ev.3

Szczepura, A., Masaki, H., Wild, D., Nomura, T., Collinson M. & Kneafsey, R. (2023). Integrated Long-Term Care 'Neighbourhoods' to Support Older Populations: Evolving Strategies in Japan and England. *International journal of environmental research and public health*, *20*(14). https://doi.org/10.3390/ijerph20146352

UNDESA. (2023). *World Social Report 2023: Leaving no one behind in an ageing world*. https://www.un.org/development/desa/pd/content/launch-world-social-report-2023

UNECE. (2022). *2022 Rome Ministerial Declaration. A Sustainable World for All Ages: Joining Forces for Solidarity and Equal Opportunities Throughout Life*. https://unece.org/sites/default/files/2022-06/Rome__Ministeri al_Declaration.pdf

United Nations. (2018). *World Population Ageing 2017*. https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2017_Report.pdf

Vogel, I. (2012). *ESPA guide to working with Theory of Change for research projects* (Isabel Vogel in association with LTS/ITAD for the ESPA Programme ed.). https://www.espa.ac.uk/files/espa/ESPA-Theory-of-Change-Manual-FINAL.pdf

Weiss, C. H. (2010). Theory-Based Evaluation: Past, Present, and Future. *New Directions for Evaluation*. https://doi.org/https://doi.org/10.1002/ev.1086

WHO. (2015). *World report on ageing and health*. https://www.who.int/publications/i/item/9789241565042

WHO. (2020). UN Decade of Healthy Ageing: Plan of Action 2021-2030. , https://www.who.int/publications/m/item/decade-of-healthy-ageing-plan-of-action

WHO. Regional Ofice for Europe (2022). *Rebuilding for sustainability and resilience: strengthening the integrated delivery of long-term care in the European Region*. World Health Organization. Regional Office for Europe

Transforming Long-Term Care: A Participatory Theory of Change Approach Towards Community-Centred Solutions

TABLES

Characteristics	Workshop 1 (n=32) In person, Soria	Workshop 2 (n=22) Consolidating session online	Workshop 3 (n=20) In person, Gipuzkoa	Workshop 4 (n= 16) Consolidating session online
	National and pilot project		Pilot only	
Gender				
Male	8	3	3	3
Female	24	19	17	13
Relation with LTC[(a)]				
Policymakers	10	7	6	9
LTC users	2	1	-	-
Informal carers	2	-	3	-
Health care professionals	2	2	4	3
LTC service providers	10	6	4	2
Expert researchers	6	6	3	2

a. Multiple options are possible.

Table **1**: Distribution of participants

1

STRENGTHS	WEAKNESSES
General country context	**General country context**
• Spain is a democratic developed country that upholds all national and international human rights. • A long-term care system that supports individuals with fewer resources.	• Service availability varies across different regions.
Support-capacity and care needs in the community	**Support-capacity and care needs in the community**
• Increased migratory flow into Spain. • Strong pension coverage system. • High life expectancy.	• Increasing percentage of population at risk of poverty or social exclusion. • Limited coordination between social and healthcare services.
Service delivery	**Service delivery**
• The Public System of Social Services and the Public System of Health are two of the pillars of the Welfare State.	• Institutionalization is currently being over-promoted. • Excessive bureaucracy in accessing dependency benefits. • Care model relies heavily on informal caregivers, primarily women and immigrants.
Performance	**Performance**
• Most people have easy access to affordable health and social services	• Regional inequalities, with different methods to assess service quality.
System enablers	**System enablers**
• Formalized structures have been established to promote coordination, in some cases with representation and involvement of various stakeholders in the care process.	• Increased funding is needed. • The role of caregivers is not fully professionalized.
OPPORTUNITIES	**THREATS**
General country context	**General country context**
• The pandemic has highlighted the need for a systemic change in the system.	• Spain has 17 autonomous communities, making it complex to reach agreements.
Support-capacity and care needs in the community	**Support-capacity and care needs in the community**
• With more women in the labor market, the traditional model must evolve.	• Jobs are often precarious and many lack formal or stable contracts. • Many people live alone but would prefer to live with someone else.
Service delivery	**Service delivery**
• People prefer LTC services that enable them to remain at home and live within their communities.	• Family caregivers are overburdened

• Advancing new technologies and incorporating innovation in the service delivery.	
Performance	**Performance**
• LTC users are satisfied with the care they receive; improving the system would further increase their satisfaction.	• Although legislation protects users' choice, decision-making is often not shared.
System enablers	**System enablers**
• Successful initiatives in one region should be replicated in others. • The Dependency Law needs to be reformed to better promote personal autonomy.	• Limited collaboration between administrations, with little information exchange.

Table 2. SWOT Matrix derived from the Situational Analysis.

1

	National ToC	Pilot Project ToC	Total
Challenges	33	26	**59**
Proximal Outcomes	125	39	**164**
Intermediate Outcomes	33	20	**53**
Indicators	52	32	**84**
Assumptions	21		**21**

Table 3: Elements generated by the participants during the workshops.

1. Educational and Awareness Interventions

- Education on the use of care services, awareness programs, and empowerment of care recipients.
- Training for professionals, curriculum adaptations, and campaigns to normalize volunteer accompaniment.
- Reflection workshops on the perspective toward people in need of care, using positive examples.
- Campaigns against ageism and ableism.

2. Coordination and Management of Socio-Health Services

- Creation of a common service portfolio, unification of health and social sectors, and local governance
- Integrated home care services with immediate response and creation of common information platforms.
- Continuity of care adapted to territorial transitions and equal access to services.

3. Policy and Regulation

- Modifications to contract law and regulations to better integrate care services within the system.
- Political consensus and commitment to drive legislative changes and restructure the care system.
- Innovative funding programs, such as shared budgets between health and social sectors.

4. Evaluation and Continuous Improvement

- Evaluation of service providers, audits, and creation of control and transparency systems in care.
- Participation of service users in quality assessment and the creation of care quality standards.
- Institutionalization of evaluation in care services and the creation of ethical reflection spaces.

5. Caregiver Training and Professionalization

- Ongoing training in person-centered care and empowerment.
- Enhancing employability for vulnerable groups and formalizing the employment of informal caregivers.
- Review of collective agreements, regulation of professional profiles, and promotion of fair working conditions.

6. Technology and Autonomy

- Development of technologies to promote autonomy for older adults.
- Promoting the involvement of older adults in the design of technologies from early stages, not just in validation.
- Accessibility and technology training for older adults and caregivers.

7. Community Focus and Friendly Environments

- Involving the community through awareness campaigns and development of neighborhood networks.
- Planning friendly environments in urban design, considering mobility, safe spaces, and barrier-free access.
- Expanding the availability of services in rural areas and developing inclusive activities based on interests.

Table 4. Interventions proposed by the participants

Processes and policies

- Priority and resources are given to the LTC system.
- Value added to Gross National Product for LTC.
- Policy decisions are articulated around LTC.

Organisational level

- Transversal teams in the LTC program.
- Balanced male/female workforces.
- Domestic workers included in the system of care for dependency.
- Health and social databases are shared, with unique identification codes.
- Technologies are applied to benefit people's Life Projects.

Quality

- There is a protocol for good treatment and person-centered Care.
- Availability of metrics that measure experience and care quality.

Society

- Environments are friendly to all people and all abilities.

InCare Pilot

- The dependency assessment system is faster and more flexible to changes.

Table 5: Assumptions proposed by the participants during the workshops.