



Policy Roadmap Spain

InCARE Short Report

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**Supporting INclusive development of community-based
long-term CARE services through multi-stakeholder
participatory approaches**



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InCARE (Supporting Inclusive development of community-based long-term CARE services through multi-stakeholder participatory approaches) aims contribute to the design of a coordinated approach to the development of national long-term care policy and care services at local and regional level, by establishing socially innovative and participatory decision-making processes. We work with care users, care providers and policymakers in Spain, Austria and North Macedonia to design, implement and scale-up innovative care services.

More information on the project's website: <https://incare.euro.centre.org/>.



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Introduction

This policy roadmap presents findings from the Supporting Inclusive development of community-based long-term CARE services through multi-stakeholder participatory approaches project (InCARE).

The project has two aims: to implement socially innovative pilot community-based projects in Austria, North Macedonia and Spain and to contribute to the development of the long-term care systems in all three countries.

The InCARE project has had policy partners involved in all three countries from the project application stage and throughout. The project started with a formative research phase that involved a situational analysis of the Long-Term Care (LTC) system and its context in each country, the identification of pilot projects that would be relevant in each country, and engagement with a variety of stakeholders to co-develop a roadmap of the necessary steps to bring about positive change in the LTC sector in Spain over the next decade and to support the development of a local social innovation pilot.

The pilot projects themselves have provided key inputs in the process of developing the long-term care systems further. Beyond the pilot projects, InCARE also contributes to the evidence base for developing national long-term care systems further. This included four different elements: data collection through an online survey on attitudes, experiences and expectations of long-term care, analysis of the status quo through situational and SWOT analyses, a Theory of Change workshop and projections of future costs of long-term care based on the expected service use.

Summary of findings from the InCARE survey for Spain

The InCARE project's Attitudes, Experiences and Expectations on Long-Term Care survey found that in Spain¹ a large proportion of respondents reported high barriers of access to formal care due to lack of services availability, high out-of-pocket payments and low quality. In particular, the respondents highlighted the following problems with the existing LTC system:

- Higher barriers in accessing home care than residential care.
- Higher barriers of access to LTC for those with lower incomes and living in rural areas.
- A high share of respondents expect to be cared for in a residential home, despite preferring home-based care.
- Declining preferences for family care.
- Wide agreement that social rights and financial support for informal carers need to be strengthened.
- High preference for the state to have a prominent role in financing, organising and delivering care.
- Low trust in the responsiveness of the system to individual wishes and circumstances.

¹ This is based on 375 responses to the InCARE survey Spain, a convenience online sample in which older people, women and those with higher education degrees are over represented. For more information: https://incare.euro.centre.org/wp-content/uploads/2022/04/InCARE-factsheet-2_-Attitudes-experiences-and-expectations-on-long-term-care-in-Spain.pdf

Situational analysis of the challenges faced by the Spanish long-term care system

Spain has a universal right to public support for long-term care, this is one of the pillars of the Welfare State, alongside the right to Public Health coverage, however it faces some important challenges². In particular, the degree of effective coverage is limited due to delays in access to public support, high administrative barriers to access, relatively high co-payments, and a lack of community and home care-based infrastructure.

As a result, there is an over-reliance on institutional care, high burdens on family carers, high reliance on the informal economy (mostly women and migrants), a lack of person-centred care and high regional inequalities in access, quality and copayments.

The Situational analysis also identified important opportunities to improve the system as the Government has been working to change the model of long-term care to a person-centered de-institutionalised model, and to improve health and social care coordination.

Using Theory of Change to co-develop a roadmap towards a better LTC system and to support the implementation and potential scale-up of social innovations in the long-term care system

The InCARE project used Theory of Change³ to bring together a wide range of stakeholders in the LTC system, including people who use care and support, to co-develop a roadmap towards a LTC system that would make it possible 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”.

The participants identified key intermediate outcomes that were needed to achieve this vision that included:

- People can live in the community as long as possible
- People have more say in the type of support and services
- There is improved quality of care and quality of employment
- Family members are supported and have meaningful choice on whether to provide care and with which intensity.

For these outcomes to be achieved, the participants identified key interventions that would need to be implemented including:

- Scaling-up of community-based services.
- Flexibilisation of care packages.
- Increased regulatory oversight to ensure improved quality of care.
- Care management support, respite and training for family carers (upscaled InCARE pilot).
- Improvements in staff working conditions, training, providers are accredited.

² For more details, please read the Situational Analysis summary https://incare.euro.centre.org/wp-content/uploads/2023/06/InCARE_Short-Report_Spain_20062023_Final.pdf

³ The Theory of Change for the Spanish LTC system is described here (in Spanish): https://incare.euro.centre.org/wp-content/uploads/2023/10/InCARE-Policy-Brief-4_Potential-for-Social-Innovation_Spain.pdf

- Incorporation of domestic helpers who carry out personal care into the formal care system: training, working conditions

Additionally, workshop participants also developed a “nested” Theory of Change to look specifically at how to develop, implement and scale-up a pilot designed with this specific objective: "all carers receive the care they need when they need it", the workshop (including a specific follow-up local workshop) outlined the steps to be taken to achieve this in terms of objectives, interventions, and indicators with which to evaluate the achievements of the pilot.

Short summary of the Spanish pilot project

The InCARE project set up community-based care pilots in all three countries, chosen to fit with the national context of the participating partners. The pilots structured their objectives within the framework of the general objectives of the InCARE project:

- Empower local communities;
- Implement innovative services that are co-designed,
- Enable local and national actors to develop local community-based Long-Term Care services in the context of a clear and sustainable vision of a Long-Term Care System through the Theory of Change;
- Support inclusive and effective policy processes and strengthen local capacity to generate and use evidence-based data.

The pilot was developed in Gipuzkoa, building on a mature service of psychological support for carers of people with dementia. This existing service, originally developed with funding from the Provincial Council of Gipuzkoa, provides carers of people (with a degree of dependency) with individual or group psychological support. It is especially aimed at those who care for a person with dementia and who are facing the gradual loss of their relative's faculties that accompany the progressive impairment caused by the dementia. The InCARE pilot was designed to facilitate the coordination of services for the carers through the psychologists who work with them, so that the people could receive the care they need and be able to develop their life's project⁴. From the Theory of Change, a series of ordered intermediate objectives were established which can be summarised as follows:

1. Establish clear criteria for the prescription of services.
2. Have consistent and sustainable training on Person Centred Care (PCC) and case management.
3. Professionals are aware of available resources and support networks.
4. Caregivers are able to receive training
5. Family members and professionals are trained in PCC
6. Social workers (social workers, psychologists, volunteers) are aware of the needs of the people.
7. Social workers are able to perform case management
8. There is coordination between programmes
9. People receive intervention and preventive intervention
10. Carers receive the care they need at all times.

To achieve these objectives, work was done to: train psychologists to change their role towards offering case management support, identify the needs of carers, provide training and psychological support adapted to these needs, establish collaboration with primary care social services, network with voluntary services and associations, create resources for collaboration with social services (community resources maps, case management, person centred-care), establish a collaboration psychologist-social services based on cases for facilitating the coordination of services, and work with the Provincial Council to adapt formal procedures and service objectives. The key to this intervention was the empowerment and training of a group of psychologists to act as a driving force for change, taking advantage of the

⁴ You can read more about the Spanish InCARE pilot here: <https://incare.euro.centre.org/new-incare-short-report-design-implementation-and-outcomes-of-the-pilot-in-spain/>

relationship of trust with the carers and their knowledge of their individual needs to promote coordinated service provision and specific support for their needs.

This intervention was structured by means of a quasi-experimental study with two groups, which enabled the study of the differences between the existing intervention and the InCARE intervention. The findings show that the carers in the intervention group obtained significantly better outcomes in terms of psychological variables: improved well-being, decreased burden and increased quality of life. This evidence supports the case for making this intervention more widely available.

Estimating resources needed to deliver improved Long-Term Care and support in Spain by 2036

The main objectives of this work were to estimate the current costs of Long-Term Care in Spain, from a societal perspective in 2021, to project the future costs of care in 2036 based on projected demographic change and to estimate the resources that would be needed to deliver improved care and support based on policy scenarios developed through engagement with stakeholders as part of the project. By societal perspective we mean that we aim to include all costs of care including those linked to unpaid care by family and others, publicly funded care and private spending on care services.

The construction of the simulation model consisted of, broadly, of 7 steps:

- 1) Conducting a rapid review of existing literature on LTC projections and estimates of costs of care in Spain, as well as the data available to construct the model.
- 2) Analysis of all the data sources to establish which can be used for which part of the model and to establish which variables are needed to estimate the probabilities of, first, having a care need and, second, using different types of care.
- 3) Estimating the distribution of care needs for adults aged 20 and older in Spain according to the characteristics relevant to use of LTC for the base year.
- 4) Estimating the probability of long-term care use (informal and formal care services) for the same group of adults according to the same characteristics.
- 5) Projecting the anticipated number of adults aged 20 and over with care needs and subsequent use of LTC in 15 years based on official demographic projections.
- 6) Projecting alternative scenarios for LTC policy in the year 2036 chosen through engagement with stakeholders.
- 7) Estimating the resources needed to both meet the projected demographic change and to improve the LTC system.

A more detailed description of the model is included in the Technical Annex.

The model's structure and initial data was used to prompt a discussion with key stakeholders in September 2023, including the project's policy partners in IMSERSO, to develop key scenarios that reflect an improved LTC system, also building on the findings from the survey, situational analysis, Theory of Change and the pilot project. The following scenarios were agreed in the policy event.

We then explored policy scenarios, developed through the formative research parts of the project including the survey, Theory of Change workshop and a stakeholder policy event. The following key scenarios were identified:

1. Scaling up of community-based care scenarios:
 - Identifying people at risk of unnecessary use of care homes (e.g. people with high levels of care needs, and whose family carers are providing a high number of hours of care, or who live alone). Increasing access to and intensity of home care and other community-based services such as day care to enable people to live at home for longer.

- Addressing potential inequalities such as lower access to formal community-based LTC formal services in rural areas (considering that the cost of providing services in rural areas is higher per unit of service provided due lower population density and associated travel costs).
- Improving targetting of care home use to people with higher levels of care needs, this scenario will require an adjustment of the costs of care homes, given that having higher shares of people with high care needs would require higher staff to resident ratios and more inputs from health care professionals such as nurses and nursing assistants.

2. Personalisation scenarios

- Increasing the use of personal assistants, considering, for example findings from the Ruralcare project.
- Increased role for care managers
- More combinations of care services due to flexible “packages”.

3. Supporting unpaid family carers scenarios

- Increase use of formal care, particularly for family carers providing very intense care
- Increase access to SAD, day centres
- Higher hours of formal care
- Support through care management, training, etc., by modelling the upscaling at national level of the InCARE pilot.

4. Professionalisation scenarios

- Changes in qualification levels of the workforce
- Changes in pay in conditions
- Professionalising domestic helpers who provide personal care
- Replacement of unpaid care?

Due to key data used in the model having become available to the team at the end of the project and to the fact that these data have not yet been published, it is not possible to share the model's estimates in time for this brief, but the model will be published and submitted to peer-review as soon as it is possible to do so.


Recommendations

Taking into consideration the findings from the different parts of the InCARE project in Spain and in line with the objectives of the European Care Strategy, we suggest the following recommendations:

- The LTC system needs to be oriented towards responding to people's wishes to live at home as long as possible, which requires improving access to community-based services and support, while ensuring that co-payments do not act as deterrents to using formal care services. This is consistent with the National Government's ongoing commitment to de-institutionalisation of the LTC system.⁵
- To deliver a more person-centered approach it is necessary to reform the administrative systems through which people access public LTC more efficient and flexible, and better coordinated with the health care system.
- There is a need to create a regulatory infrastructure that ensures quality of care and supports care providers in improving the quality of care.
- Continue with the implementation of the Agreement of the Territorial Council of Social Services and the System for Autonomy and Care for Dependency⁶ on common criteria for the accreditation and quality of the centres and services of the System for Autonomy and Care for Dependency. This agreement establishes minimum requirements and is a fundamental milestone for progress in the change from the current model of care to the person-centred care

⁵ <https://estrategiadesinstitucionalizacion.gob.es/>

⁶ <https://www.mdsocialesa2030.gob.es/derechos-sociales/servicios-sociales/docs/AcuerdoSAAD.pdf>



model. This Agreement guarantee service provision adapted to the needs and preferences of dependent persons, to their context, to the intensities of support required, to safety and universal accessibility, sets requirements and standards for staffing and quality in employment and ensures the dignity of treatment and the exercise of rights of users.

- The pilot has shown the feasibility of a co-produced approach to developing and implementing social innovations through Theory of Change, and the findings from the evaluation of the pilot suggest that care management can have an important role in supporting unpaid carers and improving their wellbeing and quality of life.
- There is room for improvement in enhancing engagement and coordination among public and private organizations. Administrative processes, care and services providers, professionals, and the coordination among all the partners must be well aligned towards the common purpose of providing personalised high-quality care.
- It is fundamental pillar improve the quality of employment in the care sector, so that care staff have they have good working conditions and the sector can attract more workers, especially men. In this respect, the above-mentioned Agreement is a major step forward.
- There is a need to improve community environment programmes so that people can age in their own homes and make their own decisions, this requires, among others, actions to support non-professional carers, cohousing and other neighbourhood networks in rural areas, projects to strengthen the competences of people moving from an institution to the community.
- Addressing the financing of LTC is key to ensure these changes can be delivered, no just in terms of ensuring the system is able to provide enough resources as the population continues to age, but also to ensure that the care financing system incentives investment in community-based, high-quality care.

Technical Annex

The InCARE Long-Term Care Spanish simulation model:

The key data sources used for the model are:

- **Population estimates and projections:** from the National Statistics Institute⁷ (Instituto Nacional de Estadística, INE), using the latest 2021 census and population projections for 2036.
- **Characteristics of the population living in private households,** including variables relevant to estimate **care needs** and probabilities of **using different services at home and in the community:** Survey EDAD⁸. EDAD is a large nationally representative survey focusing on Disability, Autonomy and Dependency that was carried out in August 2020 to October 2021, covering 67,500 households.
- **National level data on the use of publicly funded Long-Term Care services:** Data on people covered by the public system, by age and sex, including people living in residential care homes: IMSERSO (National Institute of Older people and Social services)⁹.
- **Data on the level of dependency of people living in care homes:** IMSERSO's National Census of residential care homes (made available by project partners pre-publication).
- **Costs of care:** estimates from studies of unpaid care^{10,11} and, for formal care, from the IMSERSO¹²

The model has been built using EXCEL, following regression analysis of data from the EDAD survey (using STATA) to establish which variables predict, first, care dependency, followed by analysis of which variables predict use of unpaid care, and, taking into account the use of unpaid care, which variables predict use of each of the home and community-based services included in the EDAD questionnaire.

The structure of the model is summarised in figure 1.

⁷ <https://www.ine.es/index.htm>

⁸ https://www.ine.es/dyngs/INEbase/es/operacion.htm?c=Estadistica_C&cid=1254736176782&menu=r esultados&idp=1254735573175#!tabs-1254736195764

⁹ <https://imserso.es/el-imserso/documentacion/estadisticas/sistema-autonomia-atencion-dependencia-saad>

¹⁰ <https://www.emerald.com/insight/content/doi/10.1108/AEA-02-2023-0044/full/html>

¹¹ <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0217016>

¹² https://imserso.es/documents/20123/2794117/inf_sspmmesp2021.pdf/8f175b2f-016d-17e2-bbb1-ea46141ea095

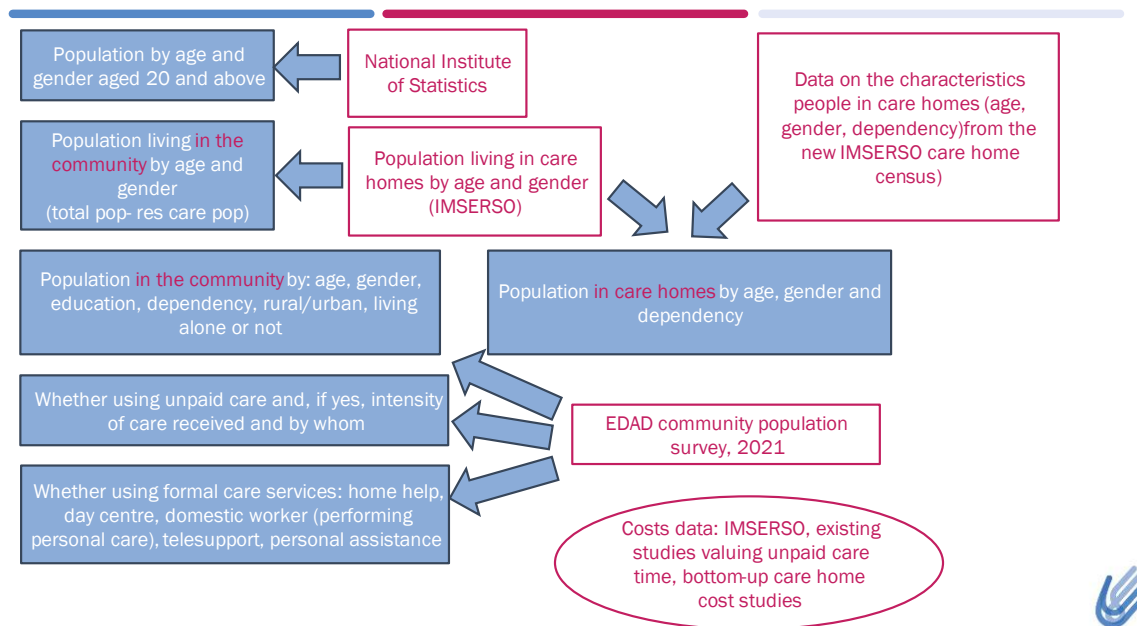


TABLE 1 OVERVIEW OF THE INCARE MODEL FOR SPAIN

Our analysis of the EDAD survey showed that age, sex and education were key predictors of care needs. Care needs were measured using Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) questions available in the EDAD survey, as well as a question on the ability to take decisions, which are also part of the Spanish Dependency and Autonomy System’s (SAAD) needs assessment instrument. We reproduced¹³ the weights given to each question, and based on this, we allocated people in the EDAD survey to the classification of dependency used by SAAD. However, the SAAD’s dependency groups exclude people with lower levels of dependency who are using care (mostly unpaid care), therefore we added two additional levels of dependency: one for people who require some level of supervision to perform ADLs or IADLs, and one for people who require supervision and or support in performing activities.

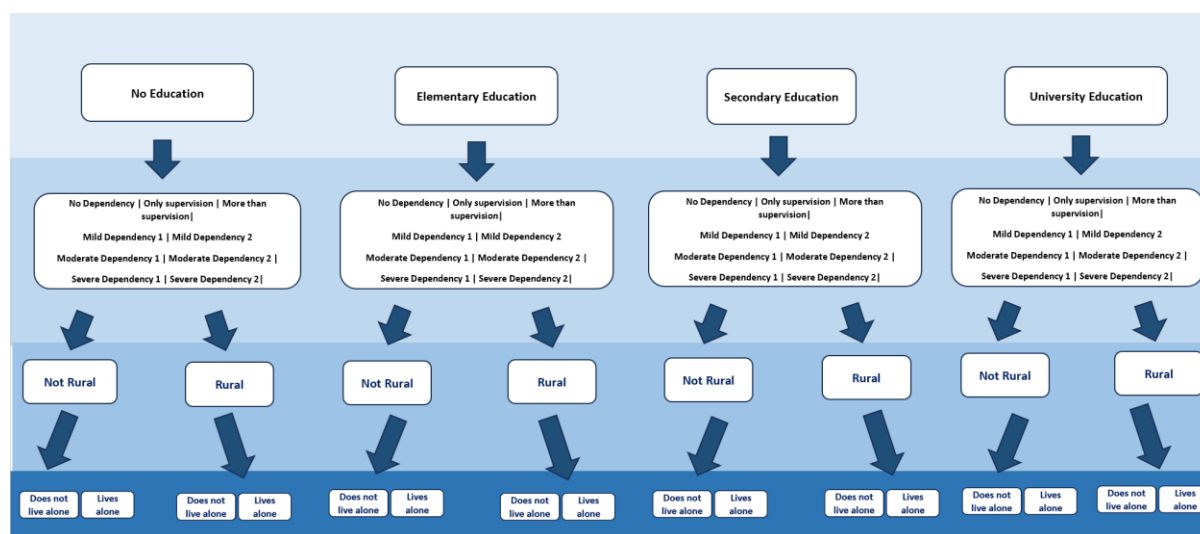



TABLE 2 OVERVIEW OF STEPS TO DISAGGREGATE THE 2021 HOUSEHOLD POPULATION USING DATA FROM THE EDAD SURVEY IN ORDER TO DISTRIBUTE THE POPULATION INTO GROUPS WITH SIMILAR PROBABILITIES OF USING CARE.

¹³ With thanks to Cristina Vilaplana Prieto, from the Universidad de Murcia.



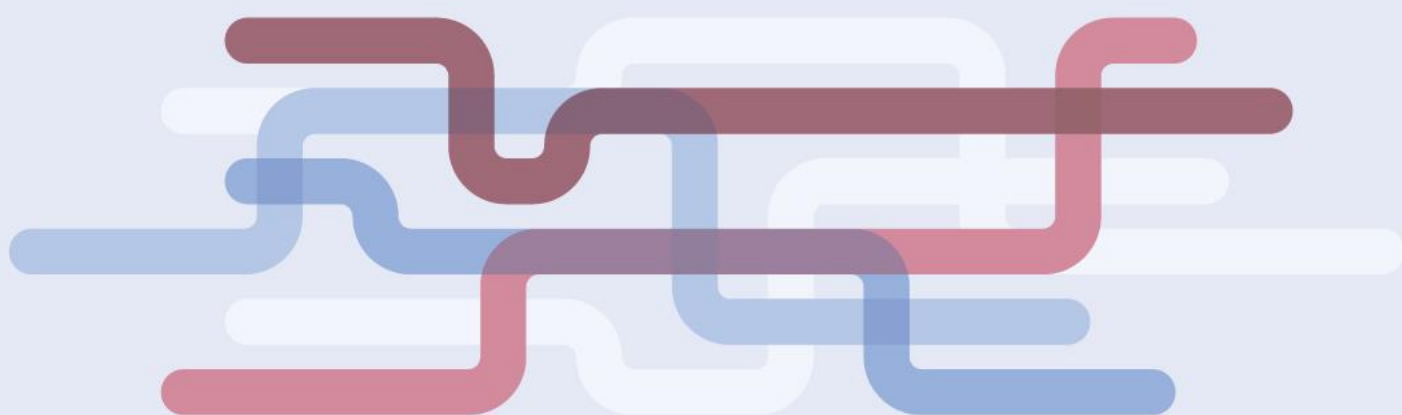
The model's estimates of the number of people who use different types of care, and of the total number of hours of care used, are then compared, for the services for which national data is available from the IMSERSO, to ensure that the baseline estimates are nationally accurate. It is not possible to do this for unpaid care and services such as care provided by privately contracted domestic workers.

In order to estimate the baseline costs of care we multiply the estimated volumes of the different care services by the corresponding unit costs, using data from existing studies for unpaid care and domestic help, and from IMSERSO for formal care services.

In the simulation, to estimate the impact of demographic change, we substitute the population in the base year, 2021, by the projected population in 2036. This allows us to estimate the numbers of people who, if the system continues as it is and there were no other changes in the probability of having a care dependency or of using services, would be using care in 2036, the volume of services that would be required to meet changes in demand due to demographic change, and the resources needed to meet that demand.

In order to investigate how sensitive the model is to changes that may not be linked to LTC policy we investigate the following alternative „policy neutral“ scenarios:

- Alternative population assumptions based on National Institute of Statistics variants
- Consider changes in future age/gender-specific dependency rates (particularly given strong relationship between education level and dependency).
- Changes in rural/urban population distribution
- Changes in the probability of living alone
- Changes in availability/propensity/ability to provide unpaid care
- Changes linked to economic context (i.e. growth in wages in the wider economy)



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