Design, implementation and outcomes of the pilot in 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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1. Context of the pilot

Spain is facing a demographic change, with the population ageing and subsequent increase in the number of people who needs a complex and long-term care. According to the Instituto Nacional de Estadistica 20.2% of the Spanish population was over the age of 65 in 2022 and this number is expected to increase to 28.2% by 2050. The number of people with disabilities is also increasing, with 4.38 million people in Spain having some form of disability in 2022.

"Since my mother has become highly dependent, I have seen how badly the public system works. And I am a social services educator. It is very frustrating, believing so much in the value of public services and being confronted with the reality that they are getting worse and worse." – Woman, 46 [excerpt, translated]

This demographic shift presents challenges on the long-term care system in Spain, which is mainly provided by families. In 2022, it is estimated that 30% of dependent older people live in their own homes, and receive care and support from family members, mainly from middle aged female family members. Family caregivers play a crucial role in Spain's LTC services meriting support by the government, market services and community initiatives.

Our baseline country survey (Ilinca et al., 2022)conducted between September 2021 and February 2022 reveals significant care barriers. 1 in 3 respondents reported to face encounter availability challenges in accessing home-based care and 1 in 4 have similar issues in accessing residential care. The cost of care also proves to be a significant barrier, affecting 41% of respondents, with a more pronounced impact on individuals with lower incomes.

"Take care of the carers! Because this is a task that we do with love, but it is very hard and involves many sacrifices." – Woman, 69 [excerpt, translated]

The INCARE pilot project is a mental health intervention program for care givers of people with dementia in Gipuzkoa, Spain. The program provides psychological support groups, individual therapy, and other resources to help carers cope with the challenges of caring for a loved one with dementia. It is open to all caregivers of people with dementia in Gipuzkoa, regardless of whether they are currently receiving support from the SENDIAN program (Decreto Foral 29/2008, De 29 De Abril, Por El Que Se Aprueba El Programa «SENDIAN» De Apoyo A Familias Con Personas Mayores Dependientes A Su Cargo). Established in 2008, the SENDIAN program initially offered comprehensive support, including training, mutual support groups, psychosocial support, short term residential care and day care. However, the program now primarily focuses on support groups and individual therapy. Over the years, participation in the SENDIAN has grown from 136 to 160 individuals across different regions of Gipuzkoa. The caregivers who are currently enrolled in SENDIAN program, were invited to participate in the INCARE pilot project, with 129 accepting the invitation. While the pilot intervention is limited to 10 individual therapy sessions, caregivers can continue attending support groups for as long as they need to.

In this context, the INCARE project aims to:

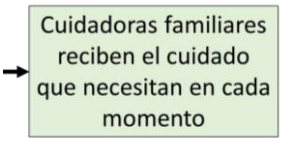
1. *Empower local communities, care users, and their families to contribute to the development of long-term care, ensuring that the social innovations align with their goals and support needs.*
2. *Implement innovative services that are co-designed and developed in partnership with local actors.*
3. *To enable local and national actors to adapt to community-based Long-Term Care services by developing a clear and sustainable vision of a Long-Term Care System through the Theory of Change, promoting coherent policies in multi-level governance.*
4. ***Support inclusive and effective policy processes** and facilitate the development and adoption of national strategies and reforms (including a pathway for scalability and sustainability of social innovation).*
5. ***Strengthen local capacity** to generate and use evidence-based data to inform UNCCD policy and design and facilitate mutual support and transnational learning between communities.*

The Spanish pilot within the INCARE project has been structured upon the pre-existing SENDIAN program, with the overarching aims shared across all three pilots of the INCARE project. This particular pilot was executed in the province of Gipuzkoa, located in Basque County. The pilot articulated through SENDIAN, in turn, has a general impact objective and several specific ones (called results according to the theory of change that can be understood as milestones to be reached sequentially to approach the general impact objective).

2. Theory of Change

To design the pilot plan, two theory of change (ToC) workshops were developed in Spain. One workshop was held at the national level and additional second two session ToC workshop with sixteen stakeholders (representatives of provincial government, care organizations, family caregivers and health services) was carried out to ensure the engagement of local stakeholders and operationalizing the pilot study further. This was carried out in the implementation area, San Sebastian, These ToC workshops were valuable to understand the local context and ensure an implementable and sustainable social innovation (Breuer et al., 2022).

The main impact objective specified in the Spanish ToC map was: “Family caregivers receive the care they need at all times”. An impact objective is one that we consider difficult to achieve, that responds to multiple uncontrollable variables and that affects the level of society, but that we hypothesise that the work carried out in the pilot will have an influence on achieving it, or at least improving its initial situation causing societal impact.



In the map, specific objectives were defined in each step along with interventions and indicators of progress. The map evolved from the first one developed in the national ToC workshops to reflect to the local identified needs and the sequential logic needed for the implementation of the pilot. The inputs extracted from both ToC were analysed, categorised, and grouped to establish a coherent order of the actions.

Table. 1. Objectives

	Objectives
1	Clear criteria for prescribing the SENDIAN programme are established.

2	Consistent and sustainable training on Person Centred Care (PCC) and Case Management is available
3	Professionals are aware of existing resources. Information on support networks is available.
4	Caregivers can receive training
5	Family members are trained and sensitised in Person-Centred Care (PCC)
6	Professionals are trained and sensitised in Person-Centred Care (PCC)
7	Social agents (social workers, psychologists, volunteers) are aware of the needs of all users, by means of PCC instruments
8	Social agents perform case management and prescribe
9	There is coordination between programmes
10	Individuals receive preventive intervention
11	Individuals receive reactive intervention
12	Family caregivers receive the care they need at any given moment.

3. Methodology of evaluation

3.1. Quantitative evaluation

The project employed a non-randomised quasi-experimental design with a control group. In the pilot study, the independent variable under investigation is the provision of case coordination, characterized by two conditions: oriented case coordination with accompaniment in the experimental group, and waiting list without INCARE accompaniment in the control group. The manipulation of this variable is theoretically linked to the expected effects on the impact variables: Quality of Life, Wellbeing, Social Support, Burden, Loneliness and Depression. The experimental group was engaged in coordinating efforts within the SENDIAN program, aimed at instigating changes within the care system and ultimately improving the well-being of caregivers, along with other variables in the caregiving context.

Quasi-experimental design and group assignment

The following strategy has been used for the assignment of groups based on available therapists. Each therapist is in charge of a geographical area that may include different municipalities and a variable number of people. The assignment to each group is made by convenience since the final beneficiaries nor the therapists cannot be assigned randomly to each group, so the possible therapist effect will be considered in the limitations of the study.

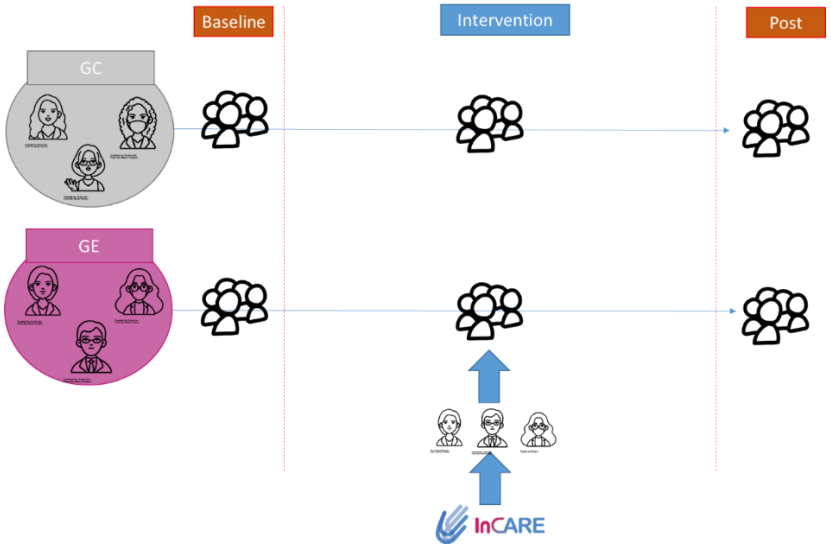


Fig. 1. quasi experimental design diagram

During the project, both groups (CG and EG) were assessed at baseline, during the intervention and after the project ends a follow up evaluation will be carried out. In this report, information on changes according to the mid-term evaluation is presented below.

Description of the sample.

From the original participants sample (n=129), distributed in Experimental (EG) and Control Group (CG), there was some dropout in the mid-term evaluation: CG have a loss of 34.1% and EG 19.7%. Impact study was carried out in people who have received two evaluations (n=88). Both EG and CG groups are SENDIAN participants who receive Individual therapy, support group sessions or both.

There were no significant differences between groups in the descriptive variables (Age, Sex, Marital Status, who she cares for, and number of cohabitants) nor in the key impact variables in the baseline, the groups being statistically equivalent in the studied variables.

The profile of the participants is mostly women (85.2% in CG and 86.9% in EG). The most frequent profile is women over 60 years of age who care for their partner, followed by younger women between 50 and 70 years of age who care for their parents. Regarding men, they are a lower percentage, so there may be one or two men per psychological support group. These men are mainly men over 70 caring for their partner, and to a lesser extent men of varying age range caring for both parents. The profiles remain the same between CG and EG, with the experimental group having a greater variability of care dyads, possibly due to being a sample with a larger number of participants.

Impact measures.

The study variables were selected from relevant variables in studies of caregivers that were hypothesised to be improved by the INCARE intervention: Burden, Loneliness, Depression, Wellbeing, Social Support and Quality of life. These variables were assessed with standardised scales and ad-hoc questions to explore possible changes. The scales were integrated into an assessment protocol and administered at the baseline and repeated in the same format after the intervention (5-6 months depending on the groups). Statistical analyses were performed using non-parametric tests given the non-normal sampling distribution and non-homogeneity of variance.

3.2. Qualitative Study

A qualitative study was conducted to explore the subjective perceptions of the participants and to complement the quantitative study in a mixed approach that makes it possible to understand the changes the intervention was intended to achieve. These objectives were approached from a sociological perspective, focusing on informal caregiving as an activity structured by culturally

prescribed values and obligations. Dominant social discourses that shape a specific 'care culture' within Spanish society articulate the understanding, expectations, and individual motivations of those dedicated to caring for their relatives. These values point to the family, and particularly women within it, as the 'natural' party responsible for meeting the support and care needs of their family members.

In this regard, we've tried to understand how this traditional care culture influences the way SENDIAN program beneficiaries understand care, how this concept translates into their daily experience, and how they value the role of institutions as resources for coping with their needs as informal caregivers. More specifically, the following dimensions of the phenomenon have been explored:

- Delimit the semantics expressing different forms of care in daily life. Explore the vocabulary and the cultural meanings that structure the understanding of care.
- Explore motivational fields and the allocation of responsibilities in caregiving acts.
- Analyze the forms of representation of the private and public spheres as domains where it is considered appropriate to receive support.
- Identify priorities in the needs/demands expressed as caregivers and the areas to which responsibility for providing responses to them is attributed.
- Identify which institutions are considered employable resources in the search for solutions to their needs.
- Analyze the assessment made of the SENDIAN program's actions, as well as its reception of the reference professional figure as a role capable of accompanying and providing solutions for the problems derived from their dedication to informal care.

Following the analysis of these factors, the goal of all this interpretive effort seeks to identify elements of improvement in the implementation of the INCARE program that could help to design an intervention tailored to the needs expressed by its own beneficiaries. To this end, 5 focus groups were conducted with a total of 34 caregiver participants from support groups formed by the SENDIAN program in 4 different locations (San Sebastian, Azkoitia, Zumaia, and Errenteria). During the sessions, attempts were made to address the meaning they attributed to their participation in the program in relation to their dedication to caring for their family members, following the guidelines set by the objectives described. The sessions were recorded in audio format and subsequently transcribed, anonymizing the contributions of everyone by removing any information or names that could allow their identification. With the intention of giving as much weight as possible to the participants' demands, the analysis provided in the report was strictly based on the interpretation of their discourses.

The main results obtained in the qualitative study are discussed in depth elsewhere ((Prieto Sancho, 2023)), As a result of the research, **three main thematic blocks** have been established through the qualitative interpretation of the discourses produced: understanding the participants own situation, the **way caregivers comprehend and interact with institutions and public administration**, **how caregivers understand their participation in the SENDIAN program.**

4. Objectives and Activities conducted as part of the Spanish pilot intervention

The planned results according to the Theory of Change (ToC) framed the activities that should be done to overcome the challenges for the continuity of the long-term care provision. The implementation team developed the intervention through the activities described in the ToC; with a flexible approach to adapt to new challenges posed by an intervention in a complex system. The activities follow two lines of action providing support to the professional caregivers, and to the informal caregivers. To this end, the activities were sequentially developed (but in several occasions, performed simultaneously) following the logic of: understanding the needs of family and professionals, seeking and generating local

resources, training caregivers, exploring ways of coordinating, and fostering services and care provision from the different agents available in the community. Among the activities performed the main ones were:

1. To establish a clear and common criterion for accessing and using the SENDIAN program a document exploring the needs and requirements of the system was unified in close collaboration with the Deputy. This document provides objective criteria and application procedure for the program, to be taken over by the regional and local administration.
2. A desk review provided the main formative resources on Person Centred Care at country level in order to provide administration agents with pragmatic information to train professionals on consistent and sustainable training on person-centred care and case management. Within these activities, psychologists in the experimental group were trained in the case management approach with the aim to support social workers on the procedure and to enhance care coordination actions for the people in their support groups.
3. To raise awareness on the local existing resources and networks, field research was carried out to identify local resources maps for 5 municipalities in which people participating in the psychological support live. The documents provided a list of the formal and informal services categorized into three types (public resources, private resources and community or associative resources). The information was checked with the local social services and have use for the social services and the psychologists.
4. To make possible for the participants to attend the support groups and other local trainings local voluntary organisations were contacted, and ways of support were explored with the administration so that carers could attend the groups and leave their family member in the care of other carers, volunteers or in a health and social care setting.
5. To make possible that Family members were trained and made aware of Person-Centred Care (PCC) a first assessment on training needs were carried out in the experimental group. 91 participants from 12 municipalities provided information on interests and needs that were registered and discussed to create formative oriented trainings. From the several topics that arose, 5 courses were identified, the psychologists trained in the topics and provide training to the participants on: situations that challenge us, emotions, duel and grief, advanced directives and living will and how to cope with loneliness. The satisfaction with the training was assessed with ad hoc satisfaction questionnaires and high satisfaction and perceived usefulness was reported.
6. To train social workers on Person-Centred Care, 14 municipalities were contacted and they were offered to work in PCC through accompaniment and training. Each municipality responded differently to how, however, no professional agreed to receive specific training on PCC. They understood collaboration as a joint work on specific topics rather than receiving training, which requires time and resources from the different administrations.
7. Several coordination actions were carried out to make professionals in the local administrations aware of the needs of the caregivers. 22 meetings were held with the social services of 14 municipalities, The municipalities showed different levels of interest and in some cases several additional coordination meetings were held. More than 30 social workers participated in the meetings and one representative of the Deputy Service for Dependency and Disability Care attended to start a coordination process between the Deputy and the Municipality. As a result, in the 4 most motivated municipalities a coordination procedure was started, and psychologists and social workers held meetings or calls for coordinating services to improve the services coverage for the needs of people attending SENDIAN.
8. To foster the case management and services provision for participants, psychologists in direct coordination with social workers carried out 104 actions oriented to: coordination with the social workers, coordination between services, coordination with the provincial deputy, and information provision. Case management was supported by a document generated describing

key aspects and main procedures to carry out case management from the social services approach.

9. Participants receive the required intervention. Preventive actions in this case were developed from the anticipation of new needs in SENDIAN groups (advanced directives, management of behavioural problems and change of residence or death of the family member). Additionally, two new SENDIAN support groups were created due to the awareness risen in the local environment.
10. The final expected impact was that family carers receive the care they need at any given moment. Theoretically, whatever progress is made in the actions related to the previous objectives will increase the likelihood that people will receive the care they need overall. To assess how the program impacted people attending the groups, the experimental design provided indicators on the variables related to care.
11.

5. Results

5.1. Findings from the quasi-experimental study

Both groups were compared in the identified impact variables between them and within each group. Outliers excluded from the analysis and normality tests were carried out to choose the main tests (Mann-Whitney for independent groups and Wilcoxon ranks test for within groups). No statistically significant differences were found between EG and CG in the baseline and post-evaluation, as the results appear to covary on some of the variables and the changes are in magnitudes of less than 20% with respect to the total scores of the scales used. There are statistically significant changes in some variables in within-group measures between the baseline and the post-intervention measure. The EG improves in all the variables, while the CG improves just on loneliness, depression and social support.

Analyses showed that both groups were equivalent at baseline as comparable groups, although it is noted that consistently the CG showed slightly better scores than the EG at baseline, suggesting that although no statistical differences are found, the CG might be slightly better overall before the start of the assessment.

Significant improvements were recorded within both groups on the variables of loneliness, depression, and social support, covarying the measures in the visual analysis. This may be due to the positive evolution of both groups participating in a support programme or to the fact that there has been a contagion in the intervention as psychologists from both groups participate and share spaces for reflection and work within the SENDIAN programme.

Scores in Burden, Wellbeing and Quality of Life in the EG differ significantly between baseline and post intervention measurements which could mean that the programme has been differentially effective in variables related satisfaction, quality of life and the subjective effects of the load of caregiving. Both groups would be improving in variables related to loneliness, social support (probably related to the support of the group) and depression (probably related to the psychological intervention), and additionally, participants in the pilot also improved in burden, quality of life and wellbeing.

5.2. Findings from the qualitative study

The aim of the qualitative study is to explore the subjective perception of participants by looking at their discourse, not to provide measures of impact as in the quantitative approach. However, there are several areas that emerge in the discourse analysis that can be useful to understand how participants

understand care and how they perceived the intervention providing information to build on a framework for addressing long-term care from the point of view of individuals. Finally, the discourse was analysed in two semantic blocks: the experience of high dependency care and Imaginaries of institutions as resources in the face of care.

The first block explores the transcendental relevance that relatives' dependence has in their lives. Care is understood as an act of love whose responsibility must fall on the family, which is a major symbolic obstacle to seeking help outside the private sphere of affective/familial intimacy. The attribution of a private, affective and deinstitutionalised nature to care work is problematic because it is not recognised as work, having isolation and life project loss as consequences. This is naturally adopted by the system as a whole, including near relatives. Caregivers become involuntary participants in the situation that oppresses and isolates them. The loneliness of the carers does not lie so much in the physical isolation that care implies as in the perception of symbolic isolation due to the incomprehension of others of the ordeal suffered.

The second block analyses how turning to institutions and benefiting from some of their resources implies an exercise in adapting the person to the institutional offer and not the other way round, losing effectiveness and meaning in their conception as universal measures incapable of registering the singularity required for their application. The perception that protocolised procedures make the processes of receiving aid more cumbersome, finding the dehumanisation of an environment whose primary function of social care would be to be closer and more facilitating.

Participants denounce the absolute lack of coordination between the different departments of the administration, especially with regard to the perceived lack of communication between social and health services. This situation, together with the lack of clear and comprehensible information about the resources available, leads to a reduction in their rights because their lack of knowledge.

Regarding the implementation of the INCARE project, both INCARE and SENDIAN resources receive a highly positive evaluation as they provide a space for emotional support for their wellbeing. Consequently, there is a paradoxical effect expressed in the participants' surprise that it is an institutional programme, normally imagined as an area of instrumental support, that provides them with the emotional support they would expect from their closest environment.

Regarding the change of role of the psychologists, a change was identified in the contribution of the coordinators from a strictly psychological work at the beginning to a much broader contribution of information, support and coordination with other departments (doctors, social workers, etc.). For this reason, their work was valued very positively, and they expressed the wish that this role as a reference person acquired by the psychologists in the groups should be strengthened and consolidated in the future.

According to the analysis, it seems necessary to consider the reciprocal empowerment that both programmes have shown to exert on each other recommending broadening its scope (which is currently very limited considering the small number of people benefiting from both programmes) by means of greater institutional support to facilitate the coordination of different departments in order to guarantee comprehensive, personalised and multidisciplinary care.

6. Discussion with key messages

Lessons learned

1. Caring is culturally established, reviled and accepted by the carers themselves as a family act.
2. Looking at the long-term care system for support in the way it is working generates further problems and it perceived as insufficient.
3. Political changes are difficult to foresee and can have effects on the planification, acquisition and generalisation of the social innovation.
4. Social innovation could be more easily accepted when it comes from the administration as internal strategy.
5. There are significant differences between municipalities in the organisation of care provided by the administration.
6. COVID-19 had post-effects on participation and on the restoration of services to their full functionality in the care of older people and disabled people.

The pilot has shown, through extensive documentation of the fieldwork and the experimental design study, indicators of success in achieving the different results set out in the Outcomes in the theory of change. The qualitative study also shows the perception that these programs are helpful for the participants. The achievements have been in terms of processes (creation of new processes: regional-local coordination, application request and provision of services, etc.), enhancement of the capacities of the agents (training of psychologists, training for case management, identification of resources), impact on people (psychological and social variables) and scaling up of the programme (increase in the number of people who perceive it). The objectives to be achieved and the actions identified were generated through the theory of change and worked with flexibility by the implementation team.

The theory of change was worked on in two different groups to incorporate a national and local vision in order to develop the pilot study. The pathway generated consisted in improving different aspects of long-term care in a limited context where we could influence change in the context and for individuals. The final Impact objective is to ensure that carers have the care they need, and to this end, numerous accompanying actions were carried out.

This type of social studies, in which the intervention needs to be broad and flexible in order to influence a complex system with interactions between agents and procedures that have a reciprocal influence on each other, are approached from a design related to but with important differences from a laboratory experimental research where a high degree of control can be exercised over the independent variables. This is why approaches to social innovation increasingly use participatory action research methodologies and flexible mixed methodologies that allow us to approach the object of study in the natural environment.

From the theory of change, a series of desired Outcomes were generated and conceived as necessary by the different actors to achieve a social impact. This approach has great advantages compared to the traditional study:

- it allows the different actors to be linked to the project, thus facilitating future collaborations by generating shared objectives that can only be achieved with the collaboration of the different parties.
- facilitating the identification of needs and challenges (by the people directly affected) and
- generating options for change seen as feasible by the different actors, giving a pragmatic and realistic approach to the project.

However, the theory of change also states that the implementation of the pilots must be subsumed to this, which can generate conflicts and overlaps with previous planning, lack of resources on the part of the implementing team or participants, the need to assume the loss of control from the experimental point of view and to adapt the different actors to the planning generated.

Another aspect to consider is the participation of the agents and their relationship with the theory of change generated, which may vary according to the composition of the group and the social dynamics generated within it. In addition, there are processes of organisation of the information generated and its validation that are not exempt from these biases. The rationale and structured sequential organisation of information is carried out by smaller groups that may bring biases and conflicts of interest that may then govern the planning of the pilot. On the other hand, although there is a validation process, this process is done by the group participants themselves, which again could incorporate the initial biases. The ToC map generated in this way need not be a flawed map, but it should be borne in mind that it describes one of the many possible routes that could be taken to a solution to a problem. This type of planning could benefit from being open to different stakeholder groups, allowing for governance processes and including different contexts to facilitate scaling up and generalising the project in the future.

In this case the generated pathway was described in a relatively complex TOC diagram, with multi-level interactions and information and action loops in which the pilot was framed within a national-level strategy. The itinerary of the pilot provided links to the different levels of both society and administration. The links identified between Outcomes at different levels had two main characteristics: informative and intervention.

- The informative part was related to the dissemination of the pilot's progress to other levels (social and administrative).
- the intervention part was related to the actions that the pilot developed influencing other levels, as well as to the facilitating actions that the different levels of the administration could exercise to enhance the implementation of the pilot.

From these multilevel interactions, mainly informative actions were developed through regular meetings with policy partners. Interaction was however limited in terms of facilitation by both regional and national administrations. This may have been due to different priorities or strategies of the administration, difficulty in making procedures more flexible and the latency of response needed to make changes in procedures. Likewise, the influence of the pilot's actions to make changes at the administrative or social levels was also limited, especially at the national level, with more changes taking place at the local and regional level.

With regard to the different Outcomes, each section of the document describes the challenge to which a solution was sought, how the actions aimed at this solution were developed and the results obtained. As a general reflection, it could be pointed out that the different objectives, despite having been developed in a participatory manner and validated with the same participant group, were not necessarily shared by all participants when put into practice, possibly due to the resource implications that the implementation of the actions entailed. Also, actions involving other entities not participating in the Theory of Change (such as, for example, local councils) could be assumed as relevant or not, depending on their own strategy, resources or field of knowledge, so there is a great variability in local collaboration.

With regard to objectives 6, 7, 8 and 9, the participation of the municipalities, where the social workers of the primary social services are located, was identified as being of high importance. In order to involve them and work with them on training, knowledge of people's needs and flexibility in the provision of services, several meetings were held with Social Services in municipalities where carers from the experimental group of the study reside. These meetings were aimed at presenting the project, proposing coordination between social workers and SENDIAN professionals, and offering support in case management and the creation of resource maps. After implementing different actions in collaboration with Social Services, it is observed that the availability and functioning of Social Services vary according to the size and needs of the municipalities. These centres are staffed by a variety of professionals, including social workers, administrative staff and, in some cases, professionals from additional disciplines such as Social Education or Occupational Therapy. The distribution of people served may be

organised by geographical area or based on the agenda of the professionals. Some specialise in specific areas such as child protection or dependency. The figure of the community worker has also been identified, who collaborates with community organisations and who could be very useful for the management of the case from a social point of view.

As far as coordination by social workers with public services is concerned, this varies depending on whether they are managed locally or by the Provincial Council. Coordination with market services is less common, and is generally limited to providing information about Personal Assistance companies. Some Social Services centres coordinate with community associations, but this is rare, except in centres where a community worker is available. Regarding the SENDIAN programme, coordination and referral criteria vary between professionals and centres due to lack of knowledge and lack of clear procedures, an issue identified as one of the main challenges identified in the project.

When involving Social Services centres, some barriers have been encountered that have hindered the implementation of such actions. In addition to the lack of labour resources to carry out co-ordination work, there has been a lack of confidence on the part of social workers in long-term care at home (possibly due to the fact that it is not an area they can manage directly and that the home care service in Spain is currently insufficient for home care), difficulties in co-ordination with other services, lack of confidence in private and community services, instability of staff in Social Services, varying perspectives on resource guides and barriers related to the conception and acquisition of case management methodology. Despite these difficulties, several actions have been achieved in line with the project objectives: contact and collaboration meetings with Social Services centres, the development and provision of explanatory documents on case management methodology, the creation of resource maps in different municipalities, and the establishment of case coordination and monitoring meetings in 4 municipalities.

The documents, generated within the collaboration to enable social workers to carry out case management, were distributed to all social service centres in the localities participating in the experimental group with varying acceptance. Possibly the implementation of the case management methodology by the social workers through accompaniment during the time of the pilot may have been limited. In our experience in other projects such as Etxean Bizi (García Soler et al., 2022), the change to case management, even if it is a familiar subject from the discipline of social work, requires several preconditions: resources, dedication, trained professionals, confidence from the management in the case management methodology and an internal structure that facilitates it. Likewise, this "change of thinking" requires more time than that dedicated to the pilot, initial involvement in the pilot (participation in the ToC, for example) and feedback circuits on the results in order for the professionals to accept this methodology. In this case, the results may be limited with regard to the case management carried out by social work professionals, but it can be considered the beginning of a collaboration pathway with the municipalities. This flexibilisation-oriented change of concept can be worked on over time with co-creative participation in successive iterations of this social innovation process. Matia has been working in this direction since 2011 with the pioneering development of the implementation of the person-centred care model in the Basque Country, which is now included in the Spanish government's deinstitutionalisation strategy.

Case management, from our point of view, is considered as a driving force of social-health and community coordination, from our point of view, articulated as a role from social work. This barrier of appropriation of the role of case management from social workers has motivated the work of support to case management from clinical psychologists who develop SENDIAN. From the framework that we propose in INCARE, case management, to be efficient, requires the capacity to provide resources, so that it is not only a professional who handles information and advises the person to go through the different services and their requirements, but also knows the different resources and has the power to provide them. The theoretical approach that was broadly given in the Theory of Change map, oriented towards a coordination relationship in which the psychologists would transmit the needs of the people

to the social workers so that the latter could manage the case. However, given the barriers to the appropriation of the role by the social workers, the psychologists of SENDIAN developed actions that could be considered case management by having a greater knowledge of the needs of the people and by promoting coordination with other agents directly: social workers, volunteers, home care service, geriatrics, etc. Thus developing coordination actions, but not directly managing the case.

With regard to the relationship with the administrations, the approach to the pilot project was developed at different times during the preparation of the project in conjunction with the IMSERSO. Initially, a research proposal was considered in the project preparation as an example that served to illustrate the possibilities of a pilot at local level. From the outset, the characteristics of the project proposed the co-creation and participation of different agents in the identification of the objectives, keys and indicator agents to develop a project framed in long-term care, the empowerment of people and the link with the administration, which is why the project was open, participatory and flexible. Changes in the structure of the IMSERSO led to changes in the initial conception of the project, which made it necessary to reformulate the pilot. This change caused an initial delay as the pilot approach had to be rethought with the project already underway and additionally forced to work the partnerships in a different geographical context (Gipuzkoa) and based on a different approach to the intervention with a different group of people. At regional level, there were also changes in the General Directorate for Dependency and Disability Care of the Provincial Council of Gipuzkoa, which in turn led to the absence of participation of the regional administration on the national ToC workshop in the theory of change workshop held in Soria. For this reason, a second theory of change workshop was held to involve the social and political agents of Gipuzkoa in the pilot, without whose participation the pilot could not progress.

This development shows some of the barriers that can occur in social innovation projects at both national and regional level when working with the administration. Barriers come from different approaches within administrations in different sub-directorates, at different levels of the structure or even depending on the category of staff that make up the administration. The administration is made up of political staff, whose function orients the political strategy of the party in charge of the administration, which can change according to electoral processes, and technical civil servants, whose positions tend to be more stable over time regardless of changes of government.

With regard to scalability, the INCARE project understands scalability through the generation of evidence of success in a pilot study, which can be exported to other contexts, groups, or broaden its scope and impact. To this end, the project established links with national partners, generating a dyad of collaboration between implementation partners and policy partners. In the case of the Spanish pilot, this collaboration was considered, on the one hand, as the piloting of social innovation solutions and the transfer of knowledge to the administration and, on the other hand, from the administration as the facilitation of the social innovation actions implemented in the pilot and to enhance their scalability. In our case, no progress has been made from the possible support links identified in the ToC at administrative and community levels such as: flexibilisation of the current training system, improvement of curricular designs in the sector, official ACP formal training, streamlining and flexibilisation of resources and services, institutional and socio-health coordination, flexibilisation of services, accessible and usable shared ICTs with an approach from the PCC, friendly cities and environments, awareness campaigns or fostering the gender equity in care and dignified work conditions. It is understood that these changes are systemic and complex for the administration to undertake in the duration of a pilot project, when changes in integrated care in the most advanced regions have taken 5-10 years to begin to see systemic changes. This disparity between the short-term planning of a pilot project and strategic system change do not facilitate possible synergies between pilot and administration. Thus, the pilot was developed in a direct working relationship in a more local environment in Gipuzkoa than at the national level, generating knowledge about the processes, materials and effects of a social innovation programme. The pilot has allowed the process to be scaled up by increasing the number of programme beneficiaries, creating new groups in municipalities where

this service did not exist, raising awareness on the programme on social workers and municipalities, and creating new procedures. However, the geographical scaling up to other autonomous communities has not taken place, due to the very focus on the local process, but it seems a promising process based on the effectiveness indicators. In order to be able to scale up to other groups and contexts, it would be advisable to study cost-effectiveness and sustainability indicators in a broader economic scenario than the actual expenditure incurred in social services, including health services, cost-opportunity and possible benefits in terms of economic well-being. Generating information in a systematic way will provide administrations with information for decision-making. Networking and trust in participatory processes would be key when there are windows of opportunity in the administration for the systematic development of consolidated processes of social innovation.

With regard to the relationship with the Provincial Council of Gipuzkoa, working on an existing programme is an advantage as it does not start from scratch, it allows access to an existing and accessible sample and, as it is a mature programme, it provides indicators of effectiveness. However, the rigidity of the administration (the programme is established by royal decree and as such established in legal terms) makes it difficult to modify key aspects of the programme, allowing changes within a narrow range. Thus, there is little room for more radical innovations or innovations that incorporate key or very different actors than those already in place. These changes are also perceived as risky in that their incorporation may become a requirement if participants assume it as an established right and not as a pilot that can revert to the previous state. Changes may also be anticipated as an increase in expenditure and there may be reluctance to incorporate them because of the costs that may be incurred, for example in cases of escalation (e.g. if the number of service recipients were to increase based on an information campaign). In addition, there are ethical considerations that could push the administration to incorporate changes based on effectiveness and efficiency results, but in the absence of available resources in the medium term, this would in turn lead to resistance to change. To solve these scalability issues, it would be advisable that the different innovation studies could provide information on effectiveness and sustainability (rather than in terms of efficiency, which can be distorted to provide the cheapest service instead of the most necessary one) from an approach that would look at the whole economic framework, e.g. savings could be perceived in the health system even though expenditure in the social system has increased.

Another limitation identified was the involvement of the health system. The project has focused on changes at the level of coordination in the social and community system, without the support of the health systems of Gipuzkoa, despite their presence in the Theory of Change workshop. This is a sign of the fragmentation of the systems in Spain as described in the situational analysis. From the point of view of supporting case management and promoting coordination, actions have been carried out involving medical services, but from a traditional point of view of identifying the need, advising the carer, facilitating management and providing a service. This dynamic is reactive on the part of the health system, non-participatory and without a preventive approach. In Gipuzkoa, numerous advances are being made in social and health coordination and it is difficult to say whether the project has ultimately benefited from these advances. In any case, it seems appropriate to think of more effective and preventive itineraries if they are carried out in social and health coordination. To this end, in addition to the administration, it would be advisable to include the health services in the social innovation projects themselves from the ideation of the project, thus facilitating ownership of the project and active collaboration in devising these itineraries of change from the outset.

With respect to the study design, the experimental approach provides a structure for comparison and obtaining reliable information on the implementation of a programme. However, as mentioned above, despite the advantages of working on a previous programme, there are certain limitations to be noted: the changes identified in the inter-group comparisons respond to the added value that INCARE has over the SENDIAN programme, given that the control group used also has SENDIAN. In order to identify the differential value between having or not differential support, at least one additional control group without any kind of intervention would be needed, and desirably a group with a placebo intervention

(such as attendance at a non-psychological training course), which would require more resources and a larger sample (difficult to access and ethically not advisable: for example, including carers who would not receive any kind of support during the course of the programme when they mostly need it). Other limitations came from the composition of the groups themselves, which meant that the pilot had to be carried out due to contractual aspects with Matia's psychologists, making it impossible to carry out a random selection among the groups. Likewise, the number of in-house and external psychologists and the number of people they attend to does not facilitate an equitable distribution where the therapist effect is controlled. Due to this, in the results on the impact on individuals, a certain covariation can be observed between the control and experimental groups, possibly due to the fact that both groups benefit from the SENDIAN programme. The additional changes not experienced in the control group in: well-being, burden and quality of life are theoretically due to the INCARE programme.

Another limitation is the time constraint. Although several aspects were worked on simultaneously, the logic of the working model set out in the ToC diagram implies that resources are first identified, professionals are trained on these resources, these professionals extend the methodology to other professionals outside the programme and the trained professionals coordinate with each other to identify people's needs and provide them with the appropriate resources. All these steps would ideally have an impact on the well-being of the caregivers (and theoretically also on the cared-for persons). Given the sequentiality of the steps and the necessary maturation of each of them in the different groups of professionals and of the processes themselves, it is difficult to obtain changes in the last link of the chain in such a short space of time. The qualitative research also shows that even when the participants perceive changes they do not discriminate which program provides them.

Another time limitation would be with respect to the composition of the groups by people who have already been attending the support groups for a long time, so that a large part of their possible improvements would have been achieved, and there may be a ceiling effect on which there may be little range of change from the psychological point of view, although there are possible improvements with the coordination and provision of new services.

Finally, it is worth mentioning that the project was carried out during a pandemic, which led to limitations not only in the context of the intervention, but also in the planning. Some barriers that existed during the project were lifted, but others remain and limit the development of collaboration, participation or availability of services. Although the project has been able to develop with a high degree of progress in many of the identified Outcomes, the changes obtained respond to an unprecedented context in the current Spanish society and could have been different in another context, posing different potentials and barriers if they had been developed outside the pandemic and forcing us to consider the lessons learned as relative to this context and limiting the scalability forecasts in other social, health and economic contexts.

In conclusion, the documentation and data obtained support the hypothesis that a social innovation programme based on co-creation, accompaniment for empowerment and coordination can improve procedures and provide adequate care for caregivers. On the other hand, there is still a long way to go in terms of coordination between levels, collaboration with the administration and with the community, which poses challenges and barriers, but also potential for change and ample room for improvement.

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