Investing in the mental wellbeing and resilience of informal carers and long-term care workers

through the identification, evaluation and promotion of good practices across Europe

Well Care

Final report on 10 in-depth case studies in 5 European countries

June 2026

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In December 2025, the Coordinator (LNU) requested and obtained approval from the Project Officer of the WELL CARE project to extend the deadline for submitting D2.2 to 31 March 2026, in order to allow the WELL CARE project's external Ethics Advisor to carry out the necessary ethical review as outlined below and ensure full ethical compliance and quality of the deliverable.

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Executive summary

- This report, namely "D2.2 "Final report on 10 in-depth case studies in 5 European countries", is a public deliverable of the WELL CARE project, developed within "WP2: Review, selection and analysis of good practices", and produced at month 27 (March 2026). The overall aim is to report findings of case studies in the five project partner countries (Germany, Italy, the Netherlands, Slovenia and Sweden) on a total of 10 selected good practices supporting informal carers and long-term care (LTC) workers[1] from the list of the top ranked good practices identified in the previous phase of WP2 and included in D2.1 ("Final report on 40 good practices in 5 European countries") submitted to the European Commission (EC) at month 20 (August 2025). The specific aim of this report (D2.2) is to contribute relevant contextual insights and evidence from the 10 case studies which will help inform the next stages of the project (e.g. developing solution prototypes in WP3).
- Europe is undergoing profound demographic, social, and organisational changes that are reshaping the LTC landscape. Population ageing, declining healthy life expectancy, and a rapidly rising share of older persons in need of care are intensifying demand for both formal LTC services and informal care provided by family and community members. The EC anticipates that the European Union (EU) population potentially needing LTC will increase from 31.2 million in 2022 to nearly 38 million by 2050. During the same period, the old-age dependency ratio will reach 50.4%, signaling a significant shift in the balance between working-age people and older people. Healthy life years are not keeping pace with increased longevity, widening the gap between life expectancy and healthy lifespan and suggesting that more years of life will be spent living with physical or cognitive limitations and ensuring LTC needs.
- This widening gap, combined with labour shortages and rising care needs, threatens the sustainability and quality of LTC systems across Europe. Approximately 6.3 million people currently work in the LTC sector. However, at least 1.6 million additional workers will be needed by 2050 in order to maintain existing coverage rates. Yet, projected workforce growth in LTC remains limited, while population ageing accelerates. This mismatch creates labour scarcity, intensifying workloads and weakening service capacity. The sector suffers from low wages, as LTC workers earn only 80% of the average hourly wage across the economy, and personal care workers just 69%. Almost 40% of workers doubt they will be able to remain in their jobs until the age of 60 due to physical demands, psychological strain, and poor working conditions. Mental health risks, exhaustion, and burnout are increasingly prevalent among formal LTC workers.
- More than 52 million people (14.4% of the adult population aged 18-74 in the EU) provide informal care on a weekly basis, with women providing two thirds of all informal care. Thus, informal carers can be seen to play a vital role in sustaining LTC systems. Many people of working age balance paid employment and care duties, leading to reduced labour market participation and lower life satisfaction. Surveys indicate that 48% of informal carers feel extreme loneliness, and many, especially high intensity carers, frequently experience stress, anxiety, and depression. These challenges highlight the urgency of strengthening both institutional and community responses to adequately address informal carers' wellbeing, resilience, and social inclusion.
- In response to these challenges, the EU has placed LTC and carer support high on the policy agenda. The 2022 European Care Strategy emphasises improving working and living conditions for both formal and informal carers, promoting quality and accessibility of LTC services and strengthening support systems for informal carers. The Horizon Europe funded WELL CARE project directly aligns with this policy priority. The project aims to identify, assess, and promote practices that enhance the mental health and resilience of both LTC workers and informal carers and strengthen cooperation between them. The central concept guiding the project is the strengthening of "care partnerships", defined in the context of the WELL CARE project as the coordination, integration (i.e. working together), and mutual recognition of care and caring activities performed by LTC workers and informal carers, in a vision of integrated LTC, strengthening the mental wellbeing and resilience of both groups.
- This report presents findings from 10 in-depth country case studies of selected good practices that aim to support informal carers' and LTC workers' mental wellbeing and resilience. WP2 followed a structured research process. First, systematic and grey literature reviews mapped existing practices across Europe. Next, selection criteria for defining good practices were agreed. Then, based on expert inputs, Blended Learning Network stakeholder consultations, and rigorous assessment procedures, 170 good practices were initially identified, of which the top 40 highest-ranked were included in deliverable D2.1 "Final report on 40 good practices in 5 European countries".
- Following the above research and innovation activities, case studies were carried out (September- December 2025). In each of the five project partner countries, stakeholders discussed the top-ranked practices identified earlier and selected - according to agreed selection criteria - two promising ones for in-depth case studies at country level. Selection criteria focused on: relevance to WELL CARE's aims; potential to support mental wellbeing and resilience

of formal and informal carers; capacity to foster care partnerships; transferability potential; national applicability; ranking position among the top ranked 40-60 practices identified in D2.1; and whether the initiative was still active.

- The resulting overall 10 selected good practices to investigate through case studies (for gathering more specific knowledge on e.g. their characteristics, mechanisms and outcomes) reflect diverse LTC contexts, intervention types, and organisational settings. Some practices are broad and systemic, whilst others are targeted to specific care contexts such as, care transitions, community support for mental health, intellectual disabilities, quality management in residential LTC, and culturally sensitive care support. Seven practices were explicitly identified as strengthening care partnerships, and several demonstrated a strong potential for regional or national transferability. The majority of good practices investigated through case studies mainly target informal carers and to a much lesser extent LTC workers. Nevertheless, most case studies highlight elements of care partnerships between informal carers and LTC workers.
- A structured topic guide was developed by the WP2 leader (INRCA) and agreed on by project partners to ensure comparability across settings, whilst flexible interviewing captured context-specific features. Information was derived from multiple sources, including in-depth individual interviews or focus group interviews with key informants of the selected good practices, further desk research, in addition to information collected in earlier phases of the project, organisational documentation, and online sources. In total, 27 key informants participated across nine newly conducted case studies; an additional case study (i.e. the Dutch "Colourful Relief" practice) drew upon pre-existing original individual interviews (conducted in the context of another project by the national Dutch research partner) on the initiative, selected for its relevance for targeting culturally diverse carers often underrepresented in research.
- The participant key informant sample reflected the predominantly female composition of the LTC workforce and included representatives from human resources management, voluntary organisations, health and LTC service providers, policy and advocacy bodies, and front-line practitioners. Most participants reported extensive experience in their roles, ensuring that insights reflected in-depth institutional and professional knowledge.
- Findings from the 10 in-depth case studies provide evidence that diverse practices across Europe are mitigating mental strain, improving carer support, and reinforcing integrated care, supporting care recipients including older adults, individuals with chronic illnesses, mental health conditions, cognitive impairments, and disabilities. Reported benefits include reduced stress and burnout for informal carers; increased LTC workers' confidence, competence, and job satisfaction; strengthened community networks, collaboration with formal services and coordination between care actors; and improved quality, continuity, and person-centredness of care for care recipients. Care partnership aspects were seen to be central among the majority (eight out of ten) of the practices, helping to foster trust, communication, shared decision-making, and multi-stakeholder collaboration and which enabled more balanced and equitable care responsibilities between professional and informal carers. Sustainability emerged as a key factor for successful practices. Sustainable initiatives tended to have stable funding, legal or institutional anchoring, multi-level governance collaboration, or community ownership. Transferability potential of the investigated initiatives also arose and, according to the key informants and available relevant desk research, it was seen to mainly depend on clear protocols, adaptable methodologies, and alignment with local policies and cultures.
- Approaches of practices range from Germany's anonymous online psychological counselling and structured hospital-to-home transitional support, to Italy's standardised individualised care plans and community-based service hubs. Dutch practices focus on social engagement and culturally sensitive family support, whilst Slovenian interventions provide participatory training for carers and structured quality management. Finally, Swedish models emphasise integrated mental health care and structured dialogue with carers by municipal carer advocates.
- Overall, the evidence generated confirms that interventions supporting both informal carers'and LTC workers' mental wellbeing benefit the wider care ecosystem. Improving carers' wellbeing not only strengthens resilience and labour force retention but also enhances care quality and outcomes for care recipients. Holistic, evidence-informed, and participatory approaches (combined with strong partnerships, community engagement, and stable funding) offer scalable models for sustainable LTC systems. The WP2 case study findings help to provide the empirical foundations for subsequent WELL CARE project phases, including developing solution prototypes (WP3), informing policy recommendations (WP4), and dissemination and exploitation activities (WP6).
- To sumarise, WELL CARE's case study findings illustrate how strategic support for carers, grounded in evidence-informed, participatory, and partnership-based approaches, offer a compelling pathway towards sustainable, high-quality and integrated LTC systems across Europe.
- Policy and system-level implications and practical suggestions drawn from the results include formal recognition of carers, holistic support programs, structured evidence-based methodologies, investment in care partnerships and community engagement, and planning for sustainability and transferability. By adopting these lessons, policymakers and practitioners can create inclusive, resilient, and high-quality care networks that empower carers while meeting the complex needs of care recipients across Europe.

1. Introduction

Contextual backdrop

Due to population ageing trends, Europe faces unprecedented demographic challenges that are fundamentally reshaping the landscape of long-term care (LTC). The European Union (EU) population potentially in need of LTC is projected to rise from 31.2 million in 2022 to 37.8 million by 2050 (European Commission, 2024). The old-age dependency ratio is expected to reach 50.4% by 2050, while between 2007 and 2022 the gap among life expectancy and healthy life years widened by 0.6 years, indicating that a growing proportion of later life is spent with health limitations requiring long-term care (Eurofound, 2025).

The EU's LTC sector also faces severe sustainability challenges: despite approximately 6.3 million workers currently employed in the sector, more than 1.6 million additional workers will be needed by 2050 to maintain current coverage levels, even as the population aged 65+ is expected to grow by 23% by 2035, while projected care sector employment growth is only 7% (Cedefop, 2023; Pavolini and Marlier, 2024).

Working conditions remain challenging, with LTC workers earning 80% of the average hourly wage across the economy, dropping to just 69% for personal care workers. Moreover, 38% of LTC workers do not believe they can continue in their job until the age of 60 (Eurofound, 2020; Pavolini and Marlier, 2024) mainly due to job strain. This in turn also contributes to LTC workers experiencing mental health risks/problems (Eurofound, 2020; 2023). Similarly, many informal carers (who constitute 45% of the EU population) face significant physical and mental health burdens, such as depression and burnout. Moreover, 61% balance care duties with paid employment, and caregiving is associated with measurable reductions in life satisfaction, with 48% of informal carers reporting extreme loneliness (Eurofound, 2025).

The above situation has profound implications for LTC policies, which are increasingly focusing on endeavoring to improve the working conditions and the overall attractiveness of the LTC sector (Belmonte and Nedee, 2024). Indeed, the EU's care agenda, exemplified by the European Care Strategy (European Commission, 2022), places LTC services, informal carers, and LTC workers as central policy priorities across Member States. Given this context, strengthening support for both informal carers and LTC workers is crucial to improve their mental wellbeing and resilience.

The EU Horizon Europe funded WELL CARE project aims to address the above issues by improving the support available across Europe for LTC workers and informal carers, in order to increase their resilience and mental wellbeing. The project focuses on identifying good practices and developing innovative solutions that foster care partnerships, that is, the coordination, integration, and mutual recognition of care and caring activities performed by LTC workers and informal carers within a vision of integrated LTC. More specifically, a key aim of the WELL CARE project is to investigate practices that directly improve carers' mental health, as well as those which prevent or mitigate occupational risks (e.g. heavy workload, stressful working conditions, precariousness, ethical stress) as well as non-occupational risks (based on factors such as gender, age, migration background, socio-economic status, and the quality of care partnerships).

Aims of this Report

This Report presents the results of 10 case studies from across the five project partner countries (Germany, Italy, the Netherlands, Slovenia and Sweden) (at month 27; March 2026) conducted within Work Package (WP) 2 ("Review, selection and analysis of good practices") of the WELL CARE project. WP2 followed a structured sequence of research activities carried out during the first two years of the project: under Task 2.1 (M1-9; January-September 2024), a systematic review of both scientific (SLR) and grey literature (GLR) was conducted, examining interventions and practices implemented in Europe to improve carers' mental wellbeing and resilience. Under Task 2.2 (M10-12; October-December 2024) country partners, together with stakeholders participating in national Blended Learning Networks[2] (BLNs) in all five partner countries, identified, defined and agreed on inclusion/selection criteria to assess whether a practice implemented in LTC organisations/settings to promote informal carers' and/or LTC workers' resilience and mental wellbeing can be considered to be a good practice.

Task 2.3 involved three main research activities, coordinated by INRCA in cooperation with the Coordinator, and carried out by country partners: 1) expert interviews (M13-15; January-March 2025); 2) reporting good practices (M16-20; April-

August 2025); and 3) case studies (M21-24; September-December 2025). On the basis of the first two activities within Task 2.3, good practices were selected by project partners, using a rigorous evaluation procedure (by using the agreed selection criteria defined in Task 2.2) enriched by inputs from experts interviewed and stakeholders participating in national BLNs in each partner country, resulting in a total of 170 identified good practices. The top 40 highest-ranked practices were selected and presented in a Report submitted to the European Commission at month 20 (August 2025): D2.1 "Final report on 40 good practices in 5 European countries" (Socci et al., 2025).

This Report (D2.2) presents the results of the third specific research activity envisaged in Task 2.3 (i.e. case studies) and represents the final research activity of WP2. The specific aim is to report case study findings on a total of 10 good practices selected, with the help of stakeholders participating in national BLNs, together with country partners, and analysed by the five partner countries - both national research and advocacy partners - (Germany, Italy, the Netherlands, Slovenia and Sweden) from the overall list of the top 40 ranked good practices or (where relevant) from the list of the top 41-60 ranked good practices (information of which is available in the WP2 database).

Case studies in the context of WP2 and the WELL CARE project

In each of the five project partner countries, the findings of the top ranked identified good practices across Europe included in D2.1 were discussed in the national BLNs (a dedicated BLN session eight in September 2025, WP5), facilitated by prior preparatory work carried out by country partners. The two most effective and promising practices at country level were identified by project partners, in accordance with stakeholders participating in the national BLNs, by use of ad hoc criteria set up in agreement between the Coordinator (LNU) and WP2 leader (INRCA). Special attention in the selection of the good practices was devoted to the practices' transferability potential, and their adaptability and implementability in other (national and/or regional) contexts, and to their possible potential to foster care partnerships between informal carers and LTC workers (see paragraph 2.1 for more details on this process). It is important to note that with regards to the practices selected for and analysed via in-depth case studies, there are aspects related to and/or having the potential to foster care partnerships, and these do not necessarily adhere to the specific definition of care partnerships adopted by the project. This is likely due to the fact that the concept of care partnerships delineated in the project definition is relatively new in the literature, and it will be specifically pursued in developing solution prototypes in WP3, building on elements fostering care partnerships that emerged from the case studies.

Through desk research, analysis of available documentation and key informant interviews (with LTC workers' employers, informal carers organisations, health and care and mental health organisations representatives, LTC workers and informal carers, etc.), two in-depth case studies of two selected good practices were conducted in each partner country. Using common guidelines and methods (interviews/focus groups) the case study results were reported using a common template. The main findings of this task, namely all 10 completed and validated case studies (two per country), are included in this dedicated WP2 Report: D2.2 "Final report on 10 in-depth case studies in 5 European countries". This is a public deliverable of the WELL CARE project, finalised within WP2 at month 27 (March 2026). For more detailed methodological details, see Chapter 2.

Case studies: definition, and aims

A case study is a research approach that is widely used in the social sciences, and it is popular among researchers in a variety of disciplines and fields. According to some authors, a case study can be defined as an in-depth exploration from multiple perspectives of the complexity and uniqueness of a contemporary phenomenon ("the case") (e.g. a particular project, programme, practice, policy, system) in a "real life" context (Simons 2009; Yin, 2018).

By drawing on multiple data sources, case study research enables researchers to gain an in-depth and holistic view of the research problem, facilitating the description, understanding, and explanation of complex situations (Baxter and Jack, 2008; Tellis, 1997; Yin, 2018). According to Yin (2018), case study analysis involves making projections about the likely transferability of findings based on a theoretical analysis of the factors producing outcomes and the effect of context. This analytical generalisation is distinct from statistical generalisation, as it does not draw inferences from data to a population; rather, it compares case study results to previously developed theories. The generalisability of findings substantially increases when similar results are found across selected cases or when they are consistent with state-

of-the-art analysis (Yin, 2018). The multiple case study approach is particularly suited to exploratory analysis where sufficient systematic investigation of a phenomenon has not yet been conducted, emphasising the richness of context and ensuring findings are deeply grounded in varied empirical evidence (Edmonson and McManus, 2007; Eisenhardt and Graebner, 2007). Case study analysis is particularly suitable for uncovering practices, identifying challenges, and understanding how these challenges could be addressed (Starks and Brown Trinidad, 2007). To achieve this depth of understanding, case studies might typically draw on a wide variety of data collection methods, including interviews, focus groups, observations, and document analysis (Carolan, Forbat and Smith, 2016; Rule, 2024). More broadly, the case studies carried out and included in this report are in line with a realistic evaluation approach[3] adopted by the WELL CARE project within WP3 ("Developing resources, prototypes and ecosystems for improving resilience and wellbeing") (Glimmerveen et al., 2024, pp. 43-45).

The purpose of the case studies in WELL CARE is to integrate and enrich the analyses already performed during the previous phases of WP2 described in D2.1, "Final report on 40 good practices in 5 European countries"and to contribute (together with the findings of D2.1) to the next steps of the project (e.g. the development of: solution prototypes in WP3 "Developing resources, prototypes and ecosystems for improving resilience and wellbeing"; evidence-based and action-oriented recommendations for policy makers and stakeholders in WP4: "Policy analysis, evaluation and recommendations" and for the aims of WP6: "Dissemination, communication and exploitation"). Moreover, the results of D2.2 will also contribute to further advance knowledge and understanding with regards to promising and effective good practices aimed to strengthen the mental wellbeing and resilience of informal carers and LTC workers across Europe.

Contents of this Report

Chapter 2 provides detailed methodological information on how the research activity, for realising the case studies, was conducted (e.g. data sources and participants, data collection methods, data analysis) as well as the criteria and process that led to the selection of the two most promising good practices for the case studies in each partner country. Chapter 3 presents the results of this research work. After a description of the interview/focus group case study sample, it offers an overview of the key findings of the case studies. The final section provides some conclusions based on an overview of the main findings reported. Following the main Report itself, Annexes are also included which comprise all the 10 complete case study reports (two from each partner country), the topic guide used for interviews/focus groups and templates for reporting various types of information on the case studies.

2. Methodology

This Chapter provides information on methodological aspects related to the conduction of case studies, by presenting the criteria and process followed for selecting the two most promising good practices to investigate in each partner country via case studies, data sources and participants, data collection methods and data analysis, in addition to some difficulties/challenges eventually faced by project partners in this research activity (e.g. with recruiting key informants for the case studies or other related issues).

2.1. Process and criteria to select the most promising good practices for conducting the 10 case studies

The process followed for selecting the most promising good practices at country level for carrying out the case studies has been characterised by a close collaboration between WP2 and WP5. Indeed, after the BLN session seven (WP5, M19; July 2025), where BLN members discussed preliminary results of selected/identified good practices (among the practices previously retrieved through the SLR and GLR, and via expert interviews) as part of Task 2.3 for the purposes of D2.1, the aim of the BLN session eight (M21; September 2025) facilitated by two country BLN facilitators in each of the five partner countries, was, for BLN members, to discuss, provide inputs to and reach agreement on the two most promising good practices in their country for the two detailed country case studies that the country project team subsequently carried out during the Autumn 2025 (October-early December 2025, M22-M24).

The rationale for choosing the 10 promising good practices (bearing in mind differences and peculiarities related to the type of practice and national LTC contexts), is that the selected practices had the potential to achieve the goals of the project that is, to promote mental wellbeing and resilience of informal carers and LTC workers; to identify, recognise and empower informal carers; to strengthen care partnerships and to improve the quality of care provided to people with LTC needs.

In detail, country BLN facilitators provided their BLN members (one week-10 days prior to the BLN session eight) with a description (through accessible information and ppt slides) of the good practices implemented in their own country, from the list of the top 40 ranked good practices included in D2.1 and (where relevant) from the list of the top 60 ranked good practices (information of which is available in the WP2 database).

The criteria (key questions) for identifying and agreeing on the two most promising good practices for the in-depth case studies at country level, shared with BLN members by the WP5 leader (NKA) and agreed on by INRCA to facilitate the BLN 8 discussion and selection process in all 5 countries, were as follows:

- How well do you think the good practices help to address our core project aims of strengthening the mental wellbeing and resilience of informal carers and/or LTC workers?
- How well do you think the good practices help to foster care partnerships between informal carers and LTC workers?
- How high is the ranking of the identified good practices (preferably the chosen two practices are from the list of the top ranked 40 practices, or where relevant, the list of the top 60 practices)?
- In your opinion, how transferable or adaptable are the identified good practices to different care settings and different geographical areas of your country?
- More specifically, for the subsequent development work in WP3 in your country, how well do the identified good practices at country level (or elements of a good practice) match with the current ideas you and the country project team have for the development work of solution prototypes in your country?
- Are the good practices still running or not? (prioritising those still ongoing).

The BLN members in all partner countries discussed the good practices and, on the basis of the above criteria/key questions, either voted or reached a consensus on the two practices they wanted the national project team to do case studies on.

2.2. Data sources and participants

For each selected good practice to investigate via a case study design, information was gathered through the following multiple data sources:

- Semi structured, individual in-depth interviews with key informants of the practice (between two-four individual interview per case study);
- A focus group interview with key informants of the practice (involving at least four stakeholders and a maximum of eight stakeholders), as an alternative to individual interviews mentioned above;
- Additional available documentation (e.g. reports, factsheets, papers, especially of assessments and evaluations conducted and additional detailed descriptions of the practice itself, etc.) provided by key informants of the practice;
- Online data/information, e.g. available in a dedicated project website;
- Desk search, e.g. in the case of a good practice retrieved through the scientific literature review (SLR), searching potentially relevant sources for additional information, such as relevant national websites, repositories, advised by the key informant; or gathering additional details of the practice itself and any assessments, evaluations carried out and their main findings;
- Secondary data: solely for the Dutch case study, i.e. "Colourful Relief", data draws also on existing interview data carried out in the Summer 2025 for another project by the national Dutch research partner; thus, this particular case study report was written by using comprehensive and informative secondary data on that good practice (for more details on the rationale for this choice, see paragraph 2.3).

In detail, nine of the 10 case studies were conducted by carrying out individual interviews or a focus group interview with key informants having a relevant role in and/or in-depth knowledge of the selected good practice in question. Country partners employed different data collection approaches. Indeed, the choice to carry out individual interviews or a focus group interview for the purposes of the case study, was made by each national project team taking into account the characteristics of the good practice, the timeline of Task 2.3, and also according to what key informants of the practice considered most suitable and feasible amongst the available options.

Key informants involved in the case study (via interview or focus group) - depending on the characteristics of the good practice and on the availability of people to be interviewed - were sought from some of the following categories of stakeholders:

- LTC workers'/informal carers' employers
- Human Resources (HR) managers
- Health, care and mental health organisations representatives
- Trade unionists
- LTC workers
- Informal carers/patients' representative organisations.
- Other relevent key informants (e.g. representatives from the voluntary or community sector, etc.).

Single patients/carers were not directly involved in the case study due to ethical issues (namely, the possible need for formal ethics approval which was not feasible within the allotted short timeframe for the case studies). Nevertheless, relevant patients/carers organisations could be approached in their role as patient/carer representatives.

2.3. Data collection tool and methodological details of interviews/focus groups

In order to guarantee methodological consistency across the countries while still allowing for a degree of flexibility for exploring context-specific themes (McCracken, 1988), a common topic guide was developed by INRCA (WP2 leader) in collaboration with the Coordinator (LNU) and then finalised in agreement with country partners, for carrying out semi-structured interviews or focus groups with key informants, which consisted of the following four key sections (see Annex 1 for more details):

- Section A: Opening (to gather information on key informants' role and period of involvement in the practice/initiative);
- Section B: Start and status of the practice/initiative (to gather information on starting date, main reasons for commencing the practice/initiative; implementation steps practice/initiative still ongoing or terminated);
- Section C: Target group(s) and care recipients (to gather information on: the main target group/s of the practice/initiative - e.g. informal carers, LTC workers, other stakeholders; types of care recipients assisted by the target group/s);
- Section D: Overall characteristics of the practice/initiative (to gather information on: main outcomes; sustainability and transferable potential; strengths and weaknesses of the practice/initiative; potential to foster care partnerships, etc.).
- Additionally, a final section (Section E: Demographics) was aimed to collect socio-demographic data of interviewees.

Interviews and focus groups were conducted between months 22-23 of the project (October-November 2025). The only exception, as already mentioned, is the Dutch case study "Colourful Relief". Indeed, this particular case study built on existing data (of interviews carried out in the context of another project as already mentioned and further clarified below) that were re-analysed for the purposes of the WELL CARE project. The country partner team from the Netherlands chose to include this existing data, first, to prevent additional and avoidable burden to informal carers and LTC workers that were recently already interviewed between June and August of 2025 for a different study with a similar focus. Second, they considered this particular qualitative dataset to be a relevant addition to the other case studies as it captures perspectives of informal carers that are often underrepresented in scientific studies, i.e. carers with a migration background and carers with relatively low trust in the formal LTC system. While this means that the data was collected using different interview guides than in the other case studies, there was considerable overlap in the questions asked and issues explored. This made the data highly suitable for answering the key questions that guided the analyses of the other nine WELL CARE case studies.

First contact with key informants, pre-interviews/focus groups

The "official" contact with a key informant of the practice (e.g. coordinator, employer, HR manager, etc.) was via e-mail (including sending an invitation and information letter and the WELL CARE leaflet), followed by a 'phone call, if necessary, for gathering the willingness and availability of the key informant to take part in an interview or a focus group. With the help of the contacted key informant, additional key persons having a relevant role in the practice were identified, with the purpose to also invite them to take part in an in-depth individual interview alternatively to be part of a focus group interview. In the event that the contacted key informant was not available during the allotted time period, they were then asked to suggest other colleagues who could act as potential key informants to be eventually contacted and/or that could provide details of additional key informants to suggest for involvement in the case study activities (a so-called "snowball" recruitment method).

The identified key informants who agreed to participate in an interview/focus group received the following additional preparatory materials in their national language prior to the interview, from national project partners:

- an Informed consent form to be signed prior to the interview/focus group;
- a Topic Guide with proposed questions and topics for discussion;
- a Document/template describing the good practice with information collected in the previous phases of WP2:
- if the good practice was included within the top 40 ranked practices, the template was the one describing the good practice included in Annex G of D2.1;
- in the case the practice was among the top 41-60 ranked practices, a document/template was developed by gathering information available on the good practice within the WP2 database and/or on the basis of the information shared

to BLNs members about the good practice in the BLN session eight, WP5.

Procedure for the interviews/focus group

At least one or two WELL CARE country project partner(s) (i.e. research and/or advocacy partners) conducted each individual interview or focus group interview accordingly. For the individual interviews, if two team members of the country project partners were involved, one acted as the interviewer/facilitator, and the other as assistant facilitator and note-taker of the responses. In the case of a focus group interview, at least two country team members were involved, one acting as the lead interviewer and the second team member acting as an assistant facilitator, ensuring all participants' voices were heard and key non-verbal cues were picked up on, where feasible. Even though the case study activities are usually, mainly research focused, country research partners and national advocacy partners agreed and reached consensus in each country on how best to organise, coordinate and conduct fieldwork activities for realising the case study within the specified time period (October-November 2025, M22-M23).

The interviews/focus group were video-audio-recorded (upon permission/consent of the interview participants) for research purposes, to facilitate the transcription of the contents. The latter were analysed and summarised to contribute to the development of the case study report, together with relevant desk research and analysis of both online data and documentation on the practice provided by key informants. Each case study report aims to describe the good practice in detail, that will then be subsequently used to inform the next phases of the project, and in particular the WP3 work with the development, implementation and evaluation of the solution prototypes in all five project partner countries.

How the data will be stored

The recordings and transcriptions shall be stored for a period of 10 years in a password protected data server at the national responsible research partner's organisation. Only the relevant national WELL CARE project team members, and, where appropriate, the project's external designated Ethics Advisor will have access to the actual transcriptions. All treatment of personal data will be handled guaranteeing confidentiality and anonymity and according to the EU Data Protection Regulations (GDPR, 679/27 April 2016, article 6); this information was also clearly written in the Informed consent form.

2.4. Transcription of the interviews/focus groups and data analysis

Verbatim transcription of the interviews/focus groups (conducted in the respective national languages) was carried out by the interviewer(s)/facilitator(s). Once the transcription of the interviews/focus group was completed, country project partners were required to provide a "polished" text, that is making the spoken language more readable when presented in writing by refinement of the transcripts to enhance their fluency (i.e. removing several superfluous text elements - which naturally occur in spoken language - was considered as sufficient). The WP2 leader and Coordinator initially agreed that it was not necessary to translate the transcribed interviews into English, as the contents/information to be included in the template to be filled-in for writing the actual case study report was required to be written in English by the relevant national project team member/s (see Annex 2). Personal information of respondents was pseudonymised in the transcripts.

The topic guide sections (and related questions) for interviews and focus groups mirrored the sections of the template to be filled-in, in order to develop the case study report for the good practice. Thus, national country partners used (in the way they thought best appropriate according to their research experience/expertise) the content of the answers provided by the key informants to integrate/complete the information pertaining to the various corresponding sections of the template for the case study report. In this respect, no formalised content analysis of the transcriptions was needed.

Indeed, the case study reports were developed by national country partners on the basis of the analysis of the outcomes of the interviews/focus groups transcriptions as well as of relevant, additional data belonging to other sources (i.e. documentation - such as e.g. reports, factsheets, papers, etc. - provided by key informants of the practice; online data; desk research that gave additional details of the practice itself and any assessments, evaluations conducted and their main findings and outcomes). This in order to integrate the earlier template describing the good practice that was realised

in the previous phase of the project and included in Annex G of D2.1 and/or the template built by collecting information available on the good practice within the project database (and also sent to key informants prior to the interviews/focus groups, as mentioned above).

In the case study reports the WP2 leader (INRCA) also recommended country partners to include some relevant and illustrative quotations of key informants interviewed or who participated in a focus group, in the case they agreed about this in the Informed consent form (thus, some quotations are contained in most case study reports, by reporting the initials of first names and surnames of the key informants concerned). Each full draft case study report was sent by country project partners to key informants for their checking and validation (and for assuring the credibility of information collected). Then, all the validated and final case study reports were sent by country partners to the INRCA team (WP2 leader) and to the Coordinator (LNU) for their final checking and fine-tune editing. All the 10 case study reports are included within Annex 5 of this document.

2.5. Data collection and challenges faced in the case study work

As for the data collection, in detail, three focus groups (two in Italy, one in Slovenia) involving four-five participants and individual interviews with key informants were carried out, between October and December 2025, all in an online mode, by using a video-conferencing platform (mainly "Zoom", while in Germany "BigBlueButton" was used, and in the Netherlands "Teams" was employed). Also, for the Dutch case study "Colourful Relief" the original individual interviews, conducted in the context of another project by the national Dutch research partner, were carried out in the Summer of 2025 face-to face, and in one case online.

Except for the above Dutch case, the case study work was conducted by using exclusively online platforms rather than face-to face site visits as it was often a more viable and practical way to carry out interviews or focus groups with key informants living in different geographical areas, alternatively for optimising the timeline for the case study activities.

Each individual interview lasted between one hour and one and a half hours in duration (only one individual interview lasted 40 minutes), while focus groups lasted between one and a half hours and two hours. The original interviews for the case study "Colourful relief" lasted between 45 minutes to more than two hours (see Table 1).

Table 1: Data collection method for the case study activities, and characteristics

Country	Case study	Method (and participants)	Platform	Duration
Germany	Care and Live	Interviews (2)	BigBlueButton	60-80 mins each
Germany	Familial Care	Interviews (2)	BigBlueButton	60-80 mins each
Italy	Standard Format for the Individualised Care Plan (PAI)	Focus group (4)	Zoom	90 mins
Italy	Community House	Focus group (5)	Zoom	90-120 mins
The Netherlands	Community Circles	Interviews (2)	Teams	40-60 mins
The Netherlands	Colourful Relief*	Interviews (16)	Teams (1); 15 face-to-face	45-135 mins
Slovenia	Family Carers Training	Focus group (4)	Zoom	120 mins
Slovenia	E-Qalin - Quality Management Model	Interviews (2)	Zoom	40-60 mins each
Sweden	Assertive Community Treatment (ACT)	Interviews (3)	Zoom	75-90 mins each
Sweden	Carers' Outcome Agreement Tool (COAT)	Interviews (3)	Zoom	75-90 mins each

* Interviews carried out in the Summer 2025 with a different but compatible topic guide to the WELL CARE case study topic guide.

Overall, the recruitment of key informants did not raise any specific challenges or substantial difficulties, with some exceptions. For example (according to information collected in Annex 4), in Slovenia the recruiting of informants for the "E-Qalin" good practice proved to be challenging, as the relevant interviewees were heavily engaged with the implementation of the new national LTC legislation, so that it was needed to postpone and change the interview date four times with two of the key informants, over a period of three weeks. In Sweden, for the "ACT" case study finding participants was straightforward, though selecting whom to include required careful consideration given the variations in practice across different regional adaptations of the examined models. Moreover, for the Swedish case study "COAT", a focus group interview had originally been planned, but it had to be cancelled due to unforeseen circumstances. As no alternative date could be scheduled within the project's timeframe, individual interviews were instead carried out with a total of three key informants. In Italy recruitment did not raise specific challenges, although, there was a last-minute unavailability of a representative of the local health care authority who was invited to attend the focus group on the "PAI" to bring the health care perspective. In Germany recruitment of key informants presented no substantial difficulties, as the selected practices were well-established with clear contact persons available. The snowball sampling approach facilitated access to additional relevant informants. The only minor challenge concerned reaching representatives of the statutory health and LTC insurance funds, which typically operate through general hotline numbers. As for the Netherlands, concerning the case study "Community Circles", the main challenge was the difficulty to schedule the interview with one key informant due to existing work commitments, thus the interview was postponed until a slightly later date in time than originally anticipated.

Ethical considerations and an external ethical assessment of all 10 case study reports

After the WELL CARE General Assembly meeting held in Copenhagen in December 2025, the Coordinator (LNU), in agreement with partners, approached the project's external Ethics Advisor, to consult her with regards to an issue which emerged during the General Assembly meeting, in which a partner/s were involved to different extents and ways in a good practice/s that were selected for the case study reports. During the ethics consultation, Prof. Ingrid Hellström, Ethics Advisor, chair of the External Advisory Board of the WELL CARE project, decided to carry out an external review of all the 10 case studies reports, with a particular focus on the three case studies (one from NL: "Colourful Relief", one from SI: "Family Carers Training", and one from SE: "Carers Agreeement Tool") that involved at least one of the project partners to different extents in either the development, implementation or evaluation of the said good practices.

The external review, carried out by Prof. Ingrid Hellström, aimed to assess a potential conflict of interest regarding the case study reports and project partners with regards to the following aspects: personal relationships, professional relationships, economic and other dependency relationships. On the basis of the information available, the external review confirmed that there were no indications of any conflict of interest found that would compromise, or could reasonably be perceived to compromise, the objectivity or integrity of the research within D2.2.

The related decision is outlined in a Statement on Conflict-of-Interest Review of 10 February, 2026 sent by Prof. Ingrid Hellström to the Coordinator (LNU).

3. Results

This Chapter presents an overview of the 10 case studies from the five project partner countries. First, an overview of the 10 good practices chosen for the in-depth case studies is presented (3.1 below). Second, a description of the overall sample is provided, highlighting the aggregate socio-demographic characteristics of the participant key informants (3.2 below). This is followed by an overview of the key findings of the 10 good practices from the five project partner countries investigated through a case study methodology, by providing information on: general aims and specific objectives of the good practice; target group/s, and care recipients assisted by the target group/s; main outcomes; care partnerships aspects; sustainability and transferability potential (3.3 below). Please note that the 10 in-depth case study reports are presented in full within Annex 5.

3.1. Overview of the 10 good practices chosen for the in-depth case studies

All 10 cross-country good practices selected by the national BLN members (across all five partner countries) in agreement with country partners are still active, and nine were retrieved through the grey literature review (GLR) in the previous phases of WP2 (see Table 2).

Seven of them are ranked among the top 40 (1, 4, 6-10, listed in Table 2; see the first column) and three among the top 60 (2-3, 5), and seven good practices (2-4, 6, 7, 9, 10) were identified as having the potential to foster care partnerships. One additional good practice (5) was identified by the Dutch BLN members in agreement with country partners as promoting care partnerships, although it had not been classified as such in the initial stage of the identification process.

The selected good practices also reflect a rich diversity in focus and context. Some practices adopt a broad, cross-sectoral approach (1, 5, 7, 10), while others concentrate on more specific areas of health and social care, such as LTC services (4, 8), care transitions (2), support for people with mental illness/es (9), and care for individuals with intellectual disabilities (6) and older adults.

Furthermore, the chosen 10 good practices reflect the six types of good practices described earlier in the conceptual framework outlined in the Grant Agreement and also outlined in D2.1 "Final report on 40 good practices in 5 Eruopean countries".

The six types of practices comprise the following:

- **Type 1:** Primary, secondary and tertiary prevention interventions;
- **Type 2:** Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level;
- **Type 3:** Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives;
- **Type 4:** Integrated approaches and strategies for fostering partnerships for care collaboration and integration between informal carers and LTC workers;
- **Type 5:** Interventions and programs targeted at LTC workers and/or informal carers with pre-existing mental health conditions, or for favouring work-life balance for LTC workers who are also informal carers;
- **Type 6:** Community-based initiatives/measures.

Table 2: Overview of the 10 good practices chosen for the in-depth case studies by BLN members in agreement with country partners

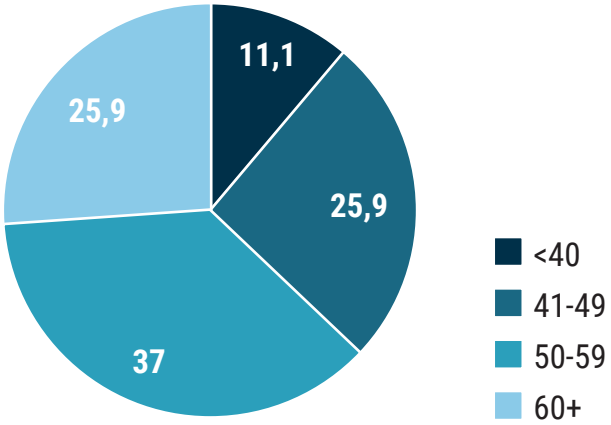
	Country BLN	Good practice	Short description	SLR or GLR	Type	Foster care partnerships	Rank (in the top 60 ranked list)	Context	Ongoing	Already reported in Socci et al. (2025) - D2.1[4]	Weblink
1	DE	Care and Live	Psychosocial counselling for informal carers	GLR	1	No	10	Online/Telephone; no delimitation	Yes	Yes (pp. 166-169)	
2	DE	Familial Care	Training and counselling for informal carers	GLR	1	Yes	54	Transition of care between hospital and home	Yes	No	None
3	IT	Standard Format for the Individualised Care Plan (PAI)	A professional team plan the care with the care recipient and their informal carer	GLR	1	Yes	45	Social and health services; people with LTC needs	Yes	No	
4	IT	Community House	An integrated organisation model	GLR	2, 6	Yes	33	A common building easily accessible for citizens	Yes	Yes (pp. 309-312)	
5	NL	Community Circles	Support by a limited group of neighbours	GLR	6	Yes*	43	Part of a neighbour-hood; no delimitation	Yes	No	
6	NL	Colourful Relief	Home support with an intercultural consultant	GLR	4	Yes	28	Ordinary homes; young adults with intellectual disabilities	Yes	Yes (pp. 274-278)	
7	SI	Family Carers Training	A course and a volunteer self- help group for informal carers	GLR	5, 3	Yes	3	An institute; no delimitation	Yes	Yes (pp. 122-126)	
8	SI	E-Qalin - Quality Management Model	A care quality system with the care recipient in the centre	GLR	2	No	7	Care homes for older people	Yes	Yes (pp. 144-149)	
9	SE	Assertive Community Treatment (ACT)	Comprehensive care and support by multi-professional teams from different sectors	SLR	2	Yes	11	Ordinary homes; people with severe mental illness	Yes	Yes (pp. 170-174)	
10	SE	Carers' Outcome Agreement Tool (COAT)	Structural assessment, support and evaluation of informal carers' needs.	GLR	4	Yes	26	Ordinary homes; no delimitation	Yes	Yes (pp. 264-269)	

* Yes, according to BLN members, in agreement with country partners

3.2. Sample description

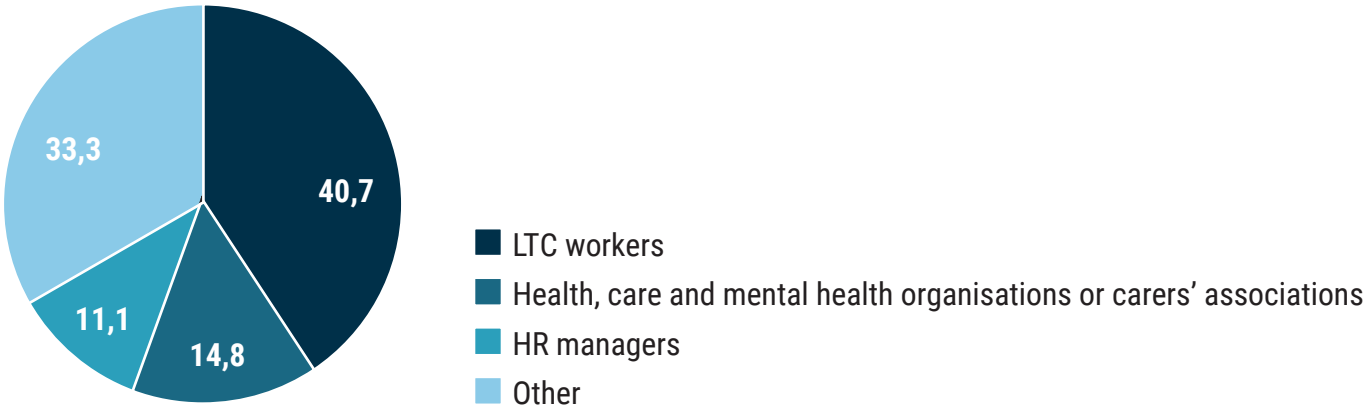
With the exception of the "Colourful Relief" case study (in which the qualitative data collection was carried out in the Summer 2025 as clarified above with a total of 16 participants), a total of 27 key informants participated in the WELL CARE case study data collection on the other nine selected good practices from across the five project partner countries. The WELL CARE sample comprised of a total of 13 participants in the focus group interviews and a total of 14 individual interviewees. The distribution of participants by country is as follows: Italy (nine participants), Sweden (six), Slovenia (six), Germany (four), and the Netherlands (two) (see Table 1 above). The WELL CARE sample showed a marked gender imbalance, with 88.9% female participants (n=24) and only 11.1% male participants (n=three). This distribution reflects the predominantly female composition of formal and informal carers across Europe (Eurofound, 2025). Participants' ages ranged from 25 to 79 years, with a mean age of 51.5 years (median: 53 years). The age distribution revealed a mature sample: 37% were aged 50-59 years, 25.9% were 60 years or older, 25.9% were 40-49 years, while younger age groups (under 40) represented only 11.1% of participants (Figure 1).

Figure 1: Age distribution of participants within the overall WELL CARE case study sample



All WELL CARE case study sample participants reported high educational attainment (tertiary education and beyond), and none reported a migration background. From a stakeholder representation perspective, the sample achieved a good mix of people belonging to different sectors. LTC workers comprised the largest group at 40.7% (n=11), followed by other relevant key informants (including e.g. representatives from the voluntary or community sector) at 33.3% (n=nine). Health, care and mental health organisations or carers' associations constituted 14.8% of the sample (n=four), while HR managers/project managers represented 11.1% (n=three) of participants (Figure 2).

Figure 2: Stakeholder typologies



Finally, participants represented a diverse range of organisational backgrounds, including public social services, public health care services, regional health authorities, municipal eldercare services, LTC residential facilities, academic institutions, non-governmental organisations (including carers' associations), and professional associations. Professional roles encompassed social workers, nurses, directors and managers, physicians, carer advocates, psychologists, and implementation support officers. The vast majority of participants (over 85%) had more than five years of experience in their current position or organisation, indicating substantial expertise in their respective fields. As for the Netherlands "Colourful Relief" case study, the existing qualitative dataset did not contain the same type or amount of information about

participants' socio-demographic background as gathered in the other nine cases, thus this is described separately from the rest of the WELL CARE sample case study participants. The main body of data consists of transcripts from 16 semi-structured interviews collected, as already mentioned, between June and August of 2025 by the Netherlands research partner (LG, VUA). This includes six interviews with informal carers of a relative with an intellectual disability: four parents (two fathers, two mothers) and two siblings (one brother, one sister-in-law). All but one of them had a migration background (four Moroccan, one Syrian). The other 10 interviews were conducted with employees (two male, eight female) of the care organisation responsible for the "Colourful Relief" program. Half of them had a migration background (three Moroccan, two Surinamese). They either worked in a management position (four), as a senior policy advisor (one), intercultural consultant (one) or in other frontline positions at a supported workplace, respite centre or ambulatory team (four).

3.3. Overview of the main findings from the 10 case studies

The following tables (Tables 3-12) provide an overview of the main findings of the 10 good practices from across the five project partner countries investigated through case studies within WP2 (3.3.1. below), by presenting information collected by project country partners using an ad hoc template (see Annex 4). Tables 3-12 include general information on the good practices (i.e. aims and specific objectives, target group/s, care recipients assisted by the target group/s), main outcomes, care partnerships aspects, sustainability and transferability characteristics/potential of the examined good practices. After the Tables, a brief summary analysis of the case study findings (3.3.2. below), as well as cross-cutting insights highlighting lessons learned, implications, and suggestions for practical interventions based on the main findings (3.3.3. below) are reported. Methodological strengths and weaknesses in realising the case studies are also presented (3.3.4. below).

3.3.1. Overview tables of the 10 good practices analysed through in-depth case studies: general information, main outcomes, care partnerships, sustainability and transferability potential

Table 3:

Case study 1 - Care and Live

1	**GENERAL INFORMATION** **AIMS AND SPECIFIC OBJECTIVES** Care and Live (Pflegen-und-Leben.de in German) is a low-threshold, anonymous psychological online counselling for informal carers. It aims to reduce psychological distress (stress, anxiety, depressive symptoms), strengthen self-efficacy, and prevent crisis escalation. Counselling focuses on emotional stabilisation and coping strategies rather than psychotherapy. **TARGET GROUP(S)** The service is intended for informal carers aged 18 and above. According to evaluation data, it is used predominantly by women between 50 and 79 years of age who have long-standing, often intensive caregiving responsibilities, frequently within the same household. The service also reaches carers who traditionally remain "invisible", including those who avoid in-person help due to stigma, time constraints, or geographic barriers. **CARE RECIPIENTS ASSISTED BY THE TARGET GROUP(S)** Mainly older adults with multimorbidity, dementia, neurological disorders, and other chronic conditions. Additional groups include persons with mental illness (e.g. depression, schizophrenia), ME/CFS or Long-Covid, and children with chronic or complex conditions. The initiative does not intervene in care provision itself but stabilises carers, indirectly supporting quality and continuity of care.
2	**MAIN OUTCOMES** The initiative measurably decreases care burden, stress, anxiety and depressive symptoms, and increases emotional stability and self-efficacy (Böttche et al. 2013). The eight-session counselling format provides a solid basis for emotional stabilisation, helping users feel understood, set boundaries, and manage difficult emotions. Anonymity promotes openness and allows early expression of strain before crises escalate. For the care system, the service strengthens the stability of home-based care arrangements and contributes to safer care situations. By reducing emotional overload and supporting clearer boundary-setting, the initiative also improves the quality of care provided, as carers are better able to respond calmly and appropriately to challenging behaviors. Interview insights further suggest that counselling can help prevent escalation and potential violence towards care recipients by improving emotional regulation and de-escalation skills. A key limitation remains when carers decide to pursue psychotherapy: despite counselling providing important initial support, many must wait months for treatment under SGB V[5]. This highlights a structural gap between SGB XI (counselling) and SGB V (psychotherapy), which cannot yet be bridged by the initiative.
3	**CARE PARTNERSHIPS** While the program does not formally coordinate services, counselling indirectly improves care partnerships by enhancing communication, boundary-setting and role clarity between informal carers and LTC workers. Carers are encouraged to reframe from professional services as partners rather than competitors. Improved emotional regulation often facilitates cooperation with ambulatory providers, respite care, and 24-hour carers. Stabilised carers are better able to engage constructively with support networks.
4	**SUSTAINABILITY** Long-term sustainability is ensured through stable funding under §45 SGB XI by four statutory long-term care insurance funds (Barmer, TK, DAK, HKK). The digital delivery model keeps costs predictable and scalable. The initiative has operated continuously since 2014, supported by professional supervision, quality assurance structures and strong institutional partnerships. Consistent user demand and positive evaluation outcomes further support sustainability.

5	**TRANSFERABILITY** The model is highly transferable to other regions and European contexts. Key components like digital access, anonymity, evidence-informed counselling, sustainable public funding, and trained psychologists can be adapted regardless of geography. It is particularly suitable for systems facing care burden, limited access to psychosocial support, rural-urban disparities, or long psychotherapy waiting times. Transferability requires a funding mechanism comparable to §45 SGB XI[6], integration with local care networks, and availability of qualified psychological staff.

Table 4:

Case study 2 - Familial Care

1	**GENERAL INFORMATION**

AIMS AND SPECIFIC OBJECTIVES

Familial Care (*Familiale* Pflege in German) aims to stabilise home care arrangements after hospital discharge by systematically involving informal carers in discharge and transition processes. Implementation is based on clearly defined intervention components delivered by care trainers in the participating hospitals. These trainers are experienced nursing professionals and act as key persons in transitional care management. The intervention includes:

- an initial consultation in the hospital to clarify the family situation, caregiving roles and support needs;
- bedside care training in the hospital, with practical instruction in relevant caregiving tasks;
- home-based care training during the first six weeks after discharge to support the transfer of skills into everyday care;
- care courses and group-based counselling formats.

Together, these hospital-based and home-based interventions strengthen caregiving competence and confidence, support role clarification within familial care networks, and improve the quality of discharge and transition management.

TARGET GROUP(S)

The intervention addresses informal carers of older care recipients involved in caregiving after hospital discharge. It involves not only a single main informal carer, but the wider familial network sharing responsibility for care, including spouses, adult children and other close persons involved in caregiving or decision making.

CARE RECIPIENTS ASSISTED BY THE TARGET GROUP(S)

The care recipients are primarily older adults who require support after hospital discharge and are cared for at home by informal carers. In practice, this mainly includes persons with chronic conditions, multimorbidity or cognitive impairments, such as dementia. While other age groups were not formally excluded, the programme predominantly addressed care situations involving older care recipients.

2 MAIN OUTCOMES

Across the evaluation period (2014-2017), three consistent outcomes were documented.

Improved caregiving competence and confidence

- Informal carers reported greater practical security in caregiving tasks aimed to provide support to care recipients (e.g. household maintainance, personal hygiene, mobility, etc.), clearer orientation after discharge, and increased confidence in their caregiving role. Quantitative evaluation data show that 96.3% of participants felt well prepared for home care through the programme; 99.1% rated the bedside training as understandable, and 99.3% rated the home-based training as understandable.

Stabilisation of the family care situation

Participation was associated with clearer role allocation within the family network and more stable caregiving arrangements after discharge. Evaluation results also report fewer family conflicts (80.4%) and increased mobilisation of additional helpers within the family and social network (81%).

Substantial reach and routine implementation during the model phase

- In the final model phase, the programme involved more than 400 hospitals and reached up to around 70,000 informal carers per year, indicating substantial scale for an intervention combining hospital-based training with home-based follow-up support.

3 CARE PARTNERSHIPS

Familial Care explicitly promotes care partnerships aspects between informal carers, hospital-based nursing staff and long-term care insurance actors. These partnerships are operationalised through the role of the care trainers, who are employed in the participating hospitals. As experienced nursing professionals, they coordinate transitional care by working directly with informal carers at the bedside and during home-based follow-up support, and by facilitating cooperation between families, hospital wards, discharge management and relevant community-based services.

Care is explicitly addressed as a networked task, rather than a dyadic relationship between one informal carer and one care recipient. The programme supports shared responsibility and mutual recognition of care activities by involving informal carers early in the hospital setting and clarifying roles within the familial care network.

4 SUSTAINABILITY

Long-term sustainability is ensured through regular financing by the statutory long-term care insurance funds under Section 45 of the German Social Code, Book XI. Since 2018, the programme has been part of routine care through direct contracts between long-term care insurance funds and participating hospitals and is currently implemented in four federal states: North Rhine-Westphalia, Schleswig-Holstein, Hamburg, and Bavaria.

At the same time, sustainability is associated with quality risks. With the transfer into routine care, the former scientific training programme provided by Bielefeld University for care trainers, after a prior period where it was mandatory, was largely discontinued), which is assessed as a major loss for consistent quality. As hospital participation is voluntary, the programme must be organisationally viable to be implemented and maintained. Under the current contract model, the program depends heavily on the individual institution and its willingness to ensure qualifying training independently. Thus, hospitals are responsible for local implementation, increasing variation between sites and potentially weakening standardisation and quality assurance.

5	TRANSFERABILITY
	Familial Care is generally transferable to other regions and settings. The intervention is based on clearly defined, modular components that can be integrated into existing hospital discharge processes. Transfer is facilitated by regular financing within the statutory long-term care insurance system and by the defined role of care trainers within hospitals. At the same time, transferability depends strongly on contextual conditions. In Germany's federal and decentralised health care system, implementation requires active commitment from long-term care insurance funds and individual hospitals. As participation is voluntary and decisions are made locally, successful transfer depends not only on formal eligibility for funding, but also on institutional willingness, local leadership and sustained regional engagement.

Table 5:

Case study 3 - Standard Format for the Individualised Care Plan (PAI)

1	**GENERAL INFORMATION** **AIMS AND SPECIFIC OBJECTIVES** The Standard Format for the Individualised Care Plan (PAI) is a tool used by all public, social and health services in the Emilia-Romagna Region to identify the needs of dependent persons, formally recognise informal carers (distinguishing between main and substitute carers), and assess their needs. Its purpose is to develop an Individualised Care Plan providing support for both the dependent person and the informal carer. A key innovation is the structured assessment of the informal carer, with particular attention to emotional stress and psychological needs, enabling a formal recognition of the family/informal carer together with an assessment and documentation of their needs and health risks so that a personalised support intervention can be designed. **TARGET GROUP(S)** The PAI assesses the needs of care recipients (people with long-standing health and/or care needs) and targets family/informal carers (including young carers, working-age carers not in paid employment, older carers, and working carers) or private care assistants. Professionals involved in drafting the PAI (social workers, nurses, physiotherapists, doctors, and other health, social and administrative staff) are also indirect beneficiaries. **CARE RECIPIENTS ASSISTED BY THE TARGET GROUP(S)** The PAI Standard Format is aimed at the general population of any age with physical disabilities (caused by frailty, accidents, illness, etc.), psychological/mental health problems (e.g. depression, anxiety, personality disorders, bipolar disorder, schizophrenia, etc.), cognitive disorders (e.g. Alzheimer's, dementia, etc.).
2	**MAIN OUTCOMES** The PAI Standard Format enables a paradigm shift in how carers are viewed from someone who merely provides assistance to someone with their own needs that must be identified and protected. The main relief and support measures available to family carers include: relief interventions, support initiatives in complex or emergency situations, psychological and socio-relational support programmes, information and training measures, and targeted measures for specific groups (e.g. young carers). The practice promotes integrated work between multiple social and healthcare professionals, creates productive relationships between key stakeholders (health and social services and the Third sector), and establishes a support network addressing both LTC needs of frail individuals and the mental wellbeing of their family and informal carers.
3	**CARE PARTNERSHIPS** The PAI Standard Format explicitly promotes care alliances between informal carers and long-term care providers through the signing of a shared project, where the PAI is drawn up by several parties to achieve objectives and respond to needs and mutual expectations. Social workers aim to keep this alliance alive through a mutual relationship of trust and esteem, working alongside vulnerable people and their families and supporting them in their life project. When PAIs for people with disabilities are drafted, there is an emphasis on co-development with families. Collaborations between services and Third sector actors further expand this territorial support network, pooling resources to meet the needs of carers and their families.

4	**SUSTAINABILITY** The PAI Standard Format is funded through the health system and national, regional and local public funds, including the Regional Fund for Non-Self-Sufficiency (FRNA), the National Fund for Non-Self-Sufficiency, the Caregiver Fund, the "Dopo di noi" Fund, and the Independent Living Fund. The tool's sustainability is generally assured as it can be offered to families at no additional cost. As stated above, the PAI Standard Format is a tool used in operational practice by all public social and health services and professionals (e.g. social workers) in the Emilia-Romagna Region and subsequently it was mentioned and envisaged by the Italian law through various regulations, thus it should be implemented throughout the country, guaranteeing its sustainability over time. Once a person has entered the service network, the PAI remains in place until new needs arise that require a review of the project. Even when funding is limited, the relationship of trust established with families through honest and transparent dialogue helps identify alternative strategies and manage critical issues, including those relating to fund availability.
5	**TRANSFERABILITY** Eight Italian Regions, including Emilia-Romagna, have legislation on family/informal carers, which may facilitate the adoption of the PAI Standard Format in these territories. At the national level, recent legislation reforming policies for older people (Law 33/2023 and Legislative Decree 29/2024) mentions the PAI as a tool for unified multidimensional assessment, further supporting the potential for broader adoption. The Standard Format supports professionals in assessing informal carer' needs alongside those of care recipients and guides them in planning responsive actions, making the practice scalable and adaptable to different contexts. The experience of operators using the tool has already been shared with the Union of Municipalities of the Reggio Emilia Plain and with the Liguria Region. However, successful transferability in other regional contexts requires adapting the tool to local realities and ensuring it is used as a participatory instrument rather than merely another form to fill in.

Table 6:

Case study 4 - Community House

1	**GENERAL INFORMATION** **AIMS AND SPECIFIC OBJECTIVES** Community Houses represent an organisational model for population proximity care. The model is designed as a physical and easily identifiable location where citizens can access services for their health and socio-health care needs. It constitutes a meeting and integration point for complex primary care units, functional aggregations of General Practitioners, Community Hospitals, Territorial Operations Centers (COTs), and pharmacies. Some examples of services present in and provided by Community Houses are the following: primary care services delivered through multi-professional teams, home care services, ambulatory specialty services for high-prevalence pathologies, nursing services, services for mental health, pathological dependencies, child and adolescent neuropsychiatry. **TARGET GROUP(S)** The Community House caters for the general population with health and/or care needs. Its key target groups are also informal/family carers. **CARE RECIPIENTS ASSISTED BY THE TARGET GROUP(S)** Community Houses are aimed at the general population of all ages with: physical disabilities (caused by frailty, accidents, illness, etc.); psychological/mental health problems (e.g. depression, anxiety, etc.); cognitive disorders (e.g. Alzheimer's, dementia, etc.).
2	**MAIN OUTCOMES** The various Community House activities and its network of community-based services for citizens and carers (supporting people of different ages, social backgrounds, and care needs, especially through training initiatives) highlights the ongoing collaborations in the area between professionals and carers. This promotes an ongoing cultural development and creates concrete opportunities for collaboration and exchange between professionals and informal/family carers. These interactions support the formation and functioning of care alliances between the two groups, improving the quality of care provided to care recipients and strengthening the resilience and mental wellbeing of both informal carers and professionals.
3	**CARE PARTNERSHIPS** The practice promotes care alliances through improved care coordination. Additionally, several Community Houses offer informal carer training programs led by long-term care professionals, creating valuable knowledge-sharing opportunities and fostering both a care alliance culture and concrete collaborations. Through skills training, carers feel supported while working alongside staff to deliver care, enabling patients to maintain quality of life at home or within the community.
4	**SUSTAINABILITY** The model integrates existing services and essentially does not create new ones, making it sustainable through ordinary funding

5	TRANSFERABILITY
	The Community House model, an ongoing initiative launched nationwide in 2022 (and thanks to the PNRR-Italy's National Recovery and Resilience Plan- investments aimed at expanding this type of service nationwide, in particular for the activation of at least 1,038 renovated Community Houses by mid-2026) has the potential to be transferable and scalable across a variety of contexts. The implementation standards are outlined in the Ministerial Decree 77/2022, in 2024 the National Agency for Regional Health Services published operational guidelines and in 2025, the Conference of Regions and Autonomous Provinces released the "Guidelines for the hourly activities to be carried out by physicians in the unified primary care role within Community Houses".

Table 7:

Case study 5 - Community Circles

1	**GENERAL INFORMATION** **AIMS AND SPECIFIC OBJECTIVES** The Community Circles aim to: • Enabling older people to live independently for as long as possible: enhancing self-reliance; • Strengthening informal support and community networks to postpone the need for formal care; Increasing community cohesion and connectedness, encouraging mutual support, and reducing loneliness. **TARGET GROUP(S)** Although Community Circles welcome participants "from young to old," most Circles tend to concentrate on adults aged 60 and above, as having a reliable support network becomes increasingly important with age (Netherlands Cares for Each Other-NLZVE, 2025). Beginning participation around age 60 is ideal: in the early years, individuals may primarily contribute support to others, while later in life they may rely more on the network themselves. Secondly, the Community Circles focus on local residents and volunteers who actively participate and offer support. They also aim - if needed - to connect welfare and care organisations as well as municipalities to the Circles so they can help facilitate and sustain them. Formal long-term care organisations are not replaced; rather, they may collaborate with a Circle – for example, when a social support need is identified that members of a Circle can address. **CARE RECIPIENTS ASSISTED BY THE TARGET GROUP(S)** The initiative mainly focuses on adults aged 60 and above who live at home and are in need of simple practice-based support.
2	**MAIN OUTCOMES** Community Circles provide social support and enhance people's self-reliance within their own environment. Local pilots and practical examples report increased community engagement, better insight into the needs of older adults, and practical relief for informal carers. NLZVE has documented several case studies (Emmeloord, Riel, Valburg, Eindhoven, Deventer, Almere, Land van Cuijk) and pilots that highlight positive experiences. Reporting and evaluations are conducted at the regional level, and nationwide quantitative impact measurements are still being developed.
3	**CARE PARTNERSHIPS** True care partnerships - in which members of a Community Circle work together with staff from professional care or welfare organisations - are still limited in practice. At the same time, first steps can be taken toward building such connections - between Community Circles and professional care providers (particularly home-care organisations), as well as with general practitioners and hospitals.
4	**SUSTAINABILITY** Sustainability is supported through community ownership, low-cost structures, freely available manuals, training, learning networks, and NLZVE's knowledge platform. The methodology is designed for transferability, allowing adaptation to different local contexts while maintaining core principles. Further development is needed to strengthen connections with formal care, ensure long-term funding, and monitor impacts on wellbeing, loneliness, and care use.

5	TRANSFERABILITY
	There is an extensive step-by-step methodology available which can be followed to set up a Community Circle. This methodology is extensively described in the book by its founder, Henk Geene (Geene, 2025, p. 64). It outlines, among other things, the three stages in the development of community circles: 1. Initiating community circles; 2. Developing community circles; 3. Linking community circles to existing social support and care structures. For the adoption of community circles in other regions, several phases can be distinguished (Geene, 2025, p. 56): • The first phase centers on raising awareness: helping older people recognise that they are increasingly reliant on themselves and that they must actively care for one another—with active, fit older people supporting more vulnerable people. • The second phase involves gathering experiences and needs from older residents, as well as identifying the opportunities and bottlenecks they encounter in the areas of Housing, Care, and Wellbeing. • The third phase focuses on implementing the projects related to Housing, Care, and Wellbeing. The methodology is explicitly designed to be transferable. NLZVE has published materials (scripts, invitations, visual guides) and there are concrete examples of local implementations in various municipalities, indicating strong transferability. While the approach requires local adaptation (culture, networks), it is relatively easy to reproduce.

Table 8:

Case study 6 - Colourful Relief

1	**GENERAL INFORMATION** **AIMS AND SPECIFIC OBJECTIVES** Colourful Relief (Kleurrijk Ontzorgen in Dutch) aims to support families caring for an adult relative with a learning disability, enabling these relatives to continue living at home while sustaining the wellbeing of informal carers. The initiative focuses on improving trust, communication and collaboration between families and Cordaan (a large long-term care provider organisation) staff and on filling service gaps by offering tailored, preventative support (e.g. an ambulatory team providing home-based assistance in various domains, an intercultural consultant working to improve trust and communication with participant families, extended day centre hours and overnight respite care, and workshops aimed at strengthening staff's intercultural competence). **TARGET GROUP(S)** Its primary target group consists of parents and siblings who provide intensive daily care at home, many with a migration background. **CARE RECIPIENTS ASSISTED BY THE TARGET GROUP(S)** The care recipients are adults with mild to severe learning disabilities who function at a younger developmental age and benefit from structured, reliable support in their home environment.
2	**MAIN OUTCOMES** Interviews with family members and care staff show examples of markedly improved relationships, characterised by more open, positive and frequent communication. Families report increased trust in formal care and greater recognition of their cultural preferences, particularly through the intercultural consultant. Uptake of respite services has risen, easing pressure on carers and supporting their wellbeing. Some parents and siblings describe renewed energy and restored balance at home. Care staff report stronger intercultural competence, greater confidence in approaching families and better understanding of their own cultural frames of reference. Quantitatively, emergency admissions appear lower among this group, suggesting strengthened home support systems and preventative impact.
3	**CARE PARTNERSHIPS** Colourful Relief explicitly promotes care partnerships by strengthening collaboration between informal carers and long-term care staff. Its approach recognises family members as experts on their relative's needs, fostering mutual respect. The intercultural consultant and ambulatory team invest time in building trust, improving communication and reducing barriers caused by cultural misunderstandings or previous negative experiences. Workshops further develop staff's intercultural and relational skills, enabling more constructive partnerships where concerns can be shared openly and support can be better aligned with each family's situation.
4	**SUSTAINABILITY** From the outset, the programme's long-term sustainability has been a core focus. Progress, achievements and challenges have been continuously discussed with funding and regulatory bodies, including the Ministry of Health, to determine how its activities might be structurally financed. While some components are now covered through regular long-term care funding, others -particularly the ambulatory support - still rely on temporary "experimental" funding, with decisions on structural funding expected from 2027 onwards. Internally, much effort has gone into embedding the programme within Cordaan, raising awareness of its value and strengthening organisational support to ensure that these activities remain integral to service provision.

5	**TRANSFERABILITY** While the programme is developed in a highly urban setting and primarily supports families with a migration background, its underlying mechanisms are not context-bound. The outreach support, relational approach, and emphasis on trust-building and partnership with family carers are considered equally valuable for families without a migration background. During the research, comparable promising practices were identified in different regions with different demographics, indicating that the programme's core principles can be applied elsewhere, provided they are adapted to local circumstances and needs.

Table 9:

Case study 7 - Family Carers Training

1	**GENERAL INFORMATION** **AIMS AND SPECIFIC OBJECTIVES** The aim is to empower carers with better competence, confidence, and wellbeing so that their care remains humane and sustainable. The group sessions are designed to blend practical skills, communication, self-care, navigation of services, and peer connection. The culture is participatory, such that participants are not passive listeners, but actively approach the topic with their own situation and experiences. That culture legitimises the messiness of real life and allows difficult topics, such as continence care, boundary-setting with siblings, grief, to surface without shame. As the audience is mixed, specific objectives are expressed in accessible terms: safer mobility and transfers; better understanding of assistive aids and home adaptations; clearer ways to ask for and use home nursing and home help; and the confidence to speak with professionals and relatives about sharing responsibilities. **TARGET GROUP(S)** The principal target group are family and other informal carers, that is, people who care for family members or older people in their home environment without formal payment or as part of an informal network. This focus acknowledges the reality of how care is organised in most communities: families carry a major share, and friends or neighbours often step in during crises or as part of everyday neighbourliness. It is estimated that more than 70% of training users are informal carers, 20% are not yet carers and at least 10% are formal carers, some of whom are also included in some cohorts, such as district nurse, physiotherapist, or care assistant. The family member is also able to hear how services work from the people who deliver them, and on the other hand, the professional hears what daily life looks like outside the structured hours of a shift from an informal carers' perspective. Depending on the local systems, stakeholders, such as doctors, associations, pharmacies, etc. are also invited to join the trainings. **CARE RECIPIENTS ASSISTED BY THE TARGET GROUP(S)** Older people, chronically ill, or disabled and those who live at home.
2	**MAIN OUTCOMES** The training for family and other informal carers has several effects. First, it helps carers feel better and more resilient, less alone and less overwhelmed, so that they cope more easily with their caring role. The regular meetings give them a space to talk openly about guilt, tiredness and difficult decisions, and to feel understood by others in a similar situation to their own. Over time, they feel more knowledgeable and more confident about what they're doing. The training also changes how local services work together. It brings in different actors, such as municipalities, homes for older people, health services and community organisations, and puts them in the same room with carers. This makes it easier for people to know who is responsible for what and where to turn when new problems arise. In some areas, the training is written into municipal plans and partly funded, which helps it become a stable part of local practice rather than a one-off project. It also helps people to stay involved afterwards as volunteers or group leaders. For the care receiver, the quality of care can improve as well. Carers learn small but important changes in how they talk to and support their relatives, especially when dementia or mobility problems are involved. Practical exercises help them imagine what the other person is going through. They also pick up concrete skills, like safer ways of helping someone move or use aids which can make everyday life safer and more comfortable. Follow-up groups after the course mean carers still have somewhere to turn to when the person's condition changes. The training tends to strengthen community support around care. From 2005 onwards, ATI (Anton Trstenjak Institute) and local authorities co-developed community-based cycles, piloted and evaluated them, and then scaled them across Slovenia, with some dissemination done in Croatia. The core logic, of community-based cycles is to identify needs of the people in the community, test in practice, evaluate and refine. It can encourage more volunteering and informal help, and the feedback collected from participants gives local services a clearer picture of what carers are dealing with and what they need.

3	**CARE PARTNERSHIPS** Care partnerships are built into how the training is designed and delivered. Each cycle brings together informal carers, at least one ATI facilitator, and local professionals such as district nurses, physiotherapists, pharmacists, dementia associations or social workers. Whenever possible, these professionals are drawn from the same community where carers live, so that people meet the actual staff they might later contact. In many groups there are also formal carers among the participants themselves, which means that, from the start, informal and formal carers are learning and talking together. The training room is treated as the place where partnerships begin. Sessions are run with the idea that "all teachers are students", i.e. professionals are not the only experts, and there is constant exchange of experience between carers and staff. Over 10 meetings, people get to know each other by name and share stories. This often turns a one-off encounter into an ongoing relationship – carers finish the course with 'phone numbers and a clear sense that they can call someone they already know when problems arise, which they describe as invaluable. Partnerships are also planned to continue after the formal course ends. Training course graduates are supported to form a "group of relatives" that runs for at least a year, led by two trained carers from those having a professional back-up (e.g. district nurses, physiotherapists, pharmacists, etc.). These groups act as small hubs in the local care system: new carers can join, former participants can return with fresh problems, and the group can invite district nurses, physiotherapists, pharmacists or associations to specific meetings. In this way, collaboration between informal carers, long-term care workers and other stakeholders is kept alive in everyday, low-threshold contact, rather than being limited to formal referrals or crises. Finally, the partnership logic is mirrored at system level. The ATI co-develops and runs the program with municipalities and local organisations, and in some municipalities the training is written into municipal action plans and co-funded from local budgets. This kind of institutional backing makes it more likely that the relationships formed in the training room translate into longer-term cooperation between families, service providers and local authorities.
4	**SUSTAINABILITY** This practice stands on quite solid ground in some ways, but it is not fully "guaranteed" and depends a lot on policy and funding decisions. It has already been running continuously since 2001 and has gradually moved from being hosted mainly by homes for older people into a community-based programme delivered with municipalities across Slovenia, which shows that it can survive changes in context and keep its basic structure intact. Financially, the model rests on a mix of national and local money. For around fifteen years it has been partially co-financed by the Ministry, while co-financing by municipalities is described as "essential," with an ideal scenario where municipalities cover about 80%, and in some cases up to 90%, of the total cost of a cycle. A full round, including 10 meetings, literature, trainers' time and travel, and a year of support for the relatives' group with leader training, comes to roughly six to seven thousand euro, so this municipal share is significant but still manageable for many local budgets. In several places, the training is written into municipal action plans and approved by municipal councils, which gives it formal status and makes it more likely that funding is renewed rather than negotiated from scratch each time. At the same time, everyone involved is aware that this arrangement is vulnerable to shifts in national policy and local priorities. If the Ministry were to withdraw its developmental co-financing, or if municipal budgets tightened, the current balance could be upset quite quickly. The true long-term sustainability would require clearer, more stable formulas for co-financing that explicitly keep this kind of preventive, community-based training open to all carers. There is also a kind of "social sustainability." The practice builds local capacity by training volunteer leaders, seeding ongoing relatives' groups, and encouraging volunteering and even movement into formal care jobs. The model is seen as easily transferable to other municipalities if there is coordination and political will and could be organised on a national level because the issue of family caregiving is shared by the whole country.
5	**TRANSFERABILITY** Practitioners consider the model transferable, especially if there is good coordination and will at a municipality level. It could also be organised at a national level as it is a nation-wide issue. The combination of a clear goal, one co-designed session, and a year of group support gives other regions a template that is simple to adopt and adapt.

Table 10:

Case study 8 - E-Qalin - Quality Management Model

1	**GENERAL INFORMATION** **AIMS AND SPECIFIC OBJECTIVES** The main aim is to improve the everyday quality of life and care for residents, as well as the working environment for staff. It seeks to help organisations look regularly and honestly at how they work, and to turn that reflection into practical improvements. Through a structured self-evaluation, based on a set of clearly defined criteria, E-Qalin encourages homes for older people to review their structures, daily procedures and results in a systematic way and to track progress over time. A key objective of E-Qalin is to actively involve everyone who is part of the care community, i.e. residents, their relatives, frontline staff and management, in assessing what works well and what needs to change, so that services are shaped together instead of being decided only "from above". It also aims to strengthen the personal responsibility and initiatives of staff, support teamwork across different professions and levels of the organisation and build a culture where learning and quality improvement are part of everyday practice. Another specific objective is to provide a recognised certification that makes the quality of care visible and comparable, while still being adapted to the reality of long-term care settings such as nursing homes and services for people with disabilities, and not copied from industrial quality models. **TARGET GROUP(S)** The practice mainly focuses on residential long-term care organisations, mostly on all homes for older people and institutions for adults with disabilities, that decide to introduce a structured quality management system. Within these organisations, its key target groups are managers and frontline long-term care workers (nurses, care assistants, social care staff, therapists and other support staff) who take part in the self-evaluation and continuous improvement process. At the same time, E-Qalin deliberately involves residents and their family members as important target groups, inviting them to contribute to assessments, feedback activities and improvement projects so that changes are grounded in their day-to-day experiences. In Slovenia, this includes homes for older people and disability institutions that are working with or already certified under E-Qalin. **CARE RECIPIENTS ASSISTED BY THE TARGET GROUP(S)** Care recipients are mainly older people living in homes for older people and other long-term care facilities that use the E-Qalin system, as well as adults with physical, intellectual or sensory disabilities who live in residential homes or use day, and community services run by these organisations.
2	**MAIN OUTCOMES** The E-Qalin model leads to the following improvements on several levels at once. Staff feel more included and listened to, because they can bring their own suggestions into the quality groups and then actually see changes happen in practice. This tends to boost their sense of meaning at work, strengthens team spirit and makes them more confident to speak up, which in turn supports their mental wellbeing and resilience over time. At the organisational level, homes for older people report that everyday work processes are more clearly structured and less chaotic as there is a shared system for how things are done, regular self-assessment, and a rolling cycle of small improvements. Leadership gets a more realistic picture of where the institution is doing well and where it needs to improve, helped by regular satisfaction surveys of staff, residents and relatives. For residents and their relatives, this shows up as more resident-centred care and better cooperation with the home. Residents' wishes and habits are taken more seriously in discussions about routines, and relatives are invited to join quality groups and participate in development decisions. Homes for older people report more satisfied and emotionally stable residents, fewer complaints from families and a gradual shift in culture towards seeing quality as a shared responsibility between staff, residents and relatives, rather than something managed "from above".

3	**CARE PARTNERSHIPS** Residents and their relatives are formally invited into quality work through their own quality groups and through representation in the central development group, where they sit alongside managers and staff and help decide which proposals are taken forward. Meetings with residents take place at a slower pace and are adapted to address their needs, and relatives can organise their own group, so that both have a realistic chance to speak and be heard. Relatives are also regularly included in satisfaction surveys, and their feedback is treated as part of the institution's picture of quality, which strengthens the sense of "working hand in hand" between families and the home for older people. So far, the focus is on partnerships within institutional care, but the director of a nursing home for older people explicitly mentioned plans to extend E-Qalin structures to home care in the future, so that informal carers at home can be invited into the same kind of shared decision-making process.
4	**SUSTAINABILITY** E-Qalin is set up as a continuous quality cycle rather than a short-term project. It has three-year certification cycles that repeat one after another, with regular self-assessment and external reviews, such that the work on quality never really ends but becomes part of how the home for older people is run. It is a permanent structure and a pillar of the home, supported by periodic updates of the model at European level so that the model can respond to new problems and trends. Nevertheless, sustainability depends on several conditions. Committed leadership and stable process managers are crucial, as changes in directors or key staff have, in some places, led to E-Qalin slowing down or being discontinued. The fact that there is no dedicated funding or quality posts also makes the model vulnerable, since staff often work on E-Qalin alongside their regular duties. There are arguments for stronger national recognition of the model and a quality program that would put E-Qalin on an equal footing with ISO, in order that homes for older people are not forced to run two parallel systems.
5	**TRANSFERABILITY** The E-Qalin quality model, that originated in Austria, is also currently disseminated in the following countries in addition to Slovenia: Croatia, the Czech Republic, France, Germany, Italy, Luxembourg and the United Kingdom. It was introduced in Slovenia in the mid-2000s. E-Qalin is already being used beyond the original setting of homes for older people, which shows that it transfers quite well. In Slovenia it has been adapted for sheltered workshops for people with disabilities, for home help services and for Training, Work, and Protection Centres (CUDV), each time with its own tailored catalogue of criteria. Even though social work centres discontinued it after a reorganisation, their earlier involvement also points to the model's flexibility across different social-care services. It was suggested that the model could also be transferred to other countries as a form of quality framework.

Table 11:

Case study 9 - Assertive Community Treatment (ACT)

1	**GENERAL INFORMATION** **AIMS AND SPECIFIC OBJECTIVES** The aim of Assertive Community Treatment (ACT), and its adaptations, Flexible Assertive Community Treatment (FACT) and Resource Group Assertive Community Treatment (RACT) is to address fragmentation and disconti nuity in mental health care and provide continuous, community-based, multidisciplinary support for individuals with severe and persistent mental illness. Specific objectives include reducing unnecessary hospitalisations, preventing homelessness, promoting social inclusion, supporting daily functioning, and enhancing recovery. FACT allows flexible intensification of care when needs increase, while RACT emphasises user-centered goal setting, shared decision-making, and active collaboration with the service user's network. **TARGET GROUP(S)** ACT and its adaptations focus primarily on the recovery of the care recipient themselves with severe mental illness/es. However, the care recipient's network, namely, family, and friends are regarded as an essential part of the recovery process. In FACT, family members are seen as essential partners and a resource for recovery of mental health issues, while also potentially needing support themselves. Their knowledge of the participant's daily life and challenges is vital, and they are actively included in planning and reviewing care once consent is given. FACT recognises that relatives may occasionally need to step back, allowing them to resume natural roles and supporting their wellbeing. In RACT, family collaboration is deemed to be central. Relatives are active partners who contribute important knowledge about the participant's needs and context. The model aims to reduce care burden, help relatives regain balance, and foster meaningful cooperation between formal and informal carers, with relatives always included in the care process. **CARE RECIPIENTS ASSISTED BY THE TARGET GROUP(S)** Care recipients are people whose mental illness significantly impairs their ability to manage everyday life independently and who require integrated medical, psychological, and social support. They are at risk of repeated hospitalisations, social isolation, and disruption in daily functioning without coordinated, long-term interventions. Recipients are usually aged 18-65 and have complex needs that cannot be addressed by conventional psychiatric and social services alone.
2	**MAIN OUTCOMES** Research shows that FACT improves service collaboration, continuity of care, and recovery outcomes for individuals with complex mental health needs. FACT may also reduce staff strain through clarified roles and shared responsibilities. RACT has been associated with improved functioning, greater wellbeing, and stronger engagement in care. Both models recognise and support the role of family and informal carers, enhancing their involvement as partners and improving person-centered care.
3	**CARE PARTNERSHIPS** Care partnerships involving the multi-disciplinary health and social care team, care recipients and their relatives are central to both models. FACT views relatives as essential partners who provide insights into daily life and contribute to recovery. RACT formalises collaboration through a resource group consisting of the service user, relatives, and professionals, who regularly meet to plan, implement, and evaluate interventions. Shared decision-making and collaboration across formal and informal care systems are key principles.

4	**SUSTAINABILITY** FACT and RACT build on Assertive Community Treatment (ACT), originally developed in the United States in the 1970s by Marx, Stein, and Test at the Mendota Mental Health Institute in Wisconsin. FACT has gained substantial institutional support in Sweden, promoted by the Swedish Association of Local Authorities and Regions (SALAR) since 2012, with many psychosis teams transformed into FACT teams. RACT experienced strong early implementation in Sweden in the early 2000s, but continuity has varied across regions; however, its principles continue to influence recovery-oriented care. Sustainability for both models depends on organisational anchoring, stable staffing, committed management, and formal agreements between sectors.
5	**TRANSFERABILITY** FACT is currently used in several countries, including the Netherlands, Denmark, and Norway. As a formalised model, RACT is most thoroughly documented in Sweden, but its foundational principles are reflected in international practices under related concepts such as Integrated Psychiatry, Case Management, and Resource Group Methods. Both FACT and RACT are community-based and transferable in principle to other settings where individuals have complex care needs are where multidisciplinary teams involving informal carers are valuable. Successful implementation requires adaptation to local health and social care structures, financing, and governance. Core principles such as continuity, interdisciplinary collaboration, and inclusion of family and significant others remain broadly applicable and central to effective, person-centered, long-term mental health care.

Table 12:

Case study 10 - Carers' Outcome Agreement Tool (COAT)

1	**GENERAL INFORMATION** **AIMS AND SPECIFIC OBJECTIVES** COAT (Carers' Outcome Agreement Tool) was developed around 2003-2005 to respond to the growing burden on family members providing care for relatives, particularly in the context of decreasing resources in healthcare and municipal eldercare. Its aim is to strengthen both informal carers' quality of life and their ability to provide good care to older or ill relatives. The tool facilitates individual structured conversations and meetings between professionals (e.g. carer advocates employed by the municipalities) and informal carers (at informal carers'own homes or in the office of the professional), in order to identify carers' needs and potential support measures, guided by the priorities and improvement areas most meaningful to them. COAT promotes dialogue, mutual understanding, and partnership between carers and professionals. **TARGET GROUP(S)** The primary target group consists of informal carers, including spouses, adult children, or other family members, who provide regular support to older or ill relatives in their own homes. These carers often face increasing responsibility for long-term care while formal support remains limited, highlighting the need for structured assessment and follow-up of their needs. **CARE RECIPIENTS ASSISTED BY THE TARGET GROUP(S)** Care recipients are mainly older adults over the age of 65 who require help with activities of daily living due to illness, disability, or reduced functional ability. Their LTC needs vary from personal care and meals to cleaning, shopping, and social support. Some receive municipal services in addition to family support, while others rely entirely on informal carers or civil society.
2	**MAIN OUTCOMES** Evaluations of COAT show positive effects for both carers and staff. Informal carers report feeling seen, heard, and taken seriously, while also being able to reflect on their own situation and express needs that might otherwise be overlooked. Professionals working in the municipality such as carer advocates and Needs Assessors, gain a deeper understanding of carers' circumstances, which improves communication, trust, and the quality of support provided. Field trials and international experience indicate that COAT fosters equitable collaboration, person-centered dialogue, and informed, individualised support plans.
3	**CARE PARTNERSHIPS** COAT explicitly promotes partnerships between informal carers and professionals. Structured conversations provide a platform for mutual understanding and joint planning, recognising experienced carers as experts regarding their own caring situations. The approach ensures that carers' voices are central to identifying support needs and that interventions are agreed upon collaboratively. Staff report that COAT strengthens trust, participation, and legal certainty in the provision of support, fostering effective cooperation across formal and informal caregiving networks.
4	**SUSTAINABILITY** Sustainability is supported through political decisions and institutional implementation, such as in Jönköping municipality, where all carer advocates/consultants are required to use COAT. Its structured framework and proven effectiveness contribute to long-term use. It is recognised that ongoing training and relevant updates of the instrument would help to maintain relevance and applicability across healthcare and social care staff. The approach has been successfully implemented in several Swedish municipalities, demonstrating its capacity to be maintained over time.

5	TRANSFERABILITY
	COAT is transferable to other contexts where informal carers play a central role in providing long-term care. Its structured methodology, emphasis on dialogue, and adaptable framework allow it to be applied in various contexts. International experience, including from Canada, shows that the tool can support equitable collaboration between carers and professionals and enhance individualised support planning beyond the Swedish context.

3.3.2. Summary analysis of the main case study findings

The 10 good practices from across the five project partner countries analysed using a case study methodology, reflect diverse yet complementary approaches to supporting carers, strengthening care networks, and enhancing the quality of life of care recipients. These initiatives span a spectrum of interventions, including psychological support, transitional care, community-based engagement, individualised care planning, quality management, and mental health-focused interventions, as outlined below. Despite differences in national context, target populations, and implementation mechanisms, several thematic patterns emerge regarding aims, target groups, outcomes, care partnerships aspects, sustainability, and transferability.

Aims and specific objectives

The primary objective shared across all practices is the support of mainly informal carers, who constitute a critical yet often under-recognised segment of the LTC workforce in Europe. The German initiative "Care and Live" provides low-threshold, anonymous online psychological counselling aimed at reducing infornal carer stress, anxiety, and depressive symptoms, while strengthening carers' self-efficacy. "Familial Care" focuses on stabilising home care arrangements following hospital discharge by systematically involving informal carers in transition processes. The Italian initiative "Standard Format for the Individualised Care Plan (PAI)" emphasises structured assessment of informal carer and care recipient needs, supporting the development of individualised care plans and "Community House" facilitates access to integrated health and social services. In the Netherlands, "Community Circles" foster broader community engagement and social cohesion to promote independent living among older adults, while "Colourful Relief" focuses on culturally sensitive support for families caring for adults with learning disabilities. The Slovenian practice "Family Carers Training" emphasises skill development and self-care of informal carers and participatory learning, whilst "E-Qalin - Quality Management Model" focuses on quality management within residential care settings. In Sweden, "Assertive Community Treatment (ACT) adopts a comprehensive mental health support approach involving care recipients, informal carers and a range of health and social care professionals. Finally, the "Carers' Outcome Agreement Tool (COAT)" focuses on structured engagement by municipal carer advocates with informal carers to enhance continuity of care and person-centered outcomes (COAT).

Collectively, these practices share an emphasis on improving primarily informal carers' wellbeing while simultaneously enhancing care recipient outcomes. They target both practical care skills and psychological resilience, recognising that supporting the informal carer is directly linked to the quality, safety, and sustainability of LTC provision.

Target groups and care recipients

Even though we were interested in initiatives supporting resilience and the mental wellbeing targeted at both informal carers and LTC workers, across all practices analysed, the primary target group found is informal carers, encompassing family members, close friends, and other unpaid carers. Thus, LTC workers are mainly indirectly targeted, or their role is related to the potential of practices to promote care partnerships, or elements of care partnerships, between informal carers and LTC workers. This highlights a knowledge gap within the existing literature on practices focused on LTC workers as a primary target group (as also emerged in the systematic review of scientific and grey literature carried out in Task 2.1), a topic that should be addressed by future research.

In the German practice "Care and Live", users are predominantly women informal carers aged 50-79 providing intensive

home-based care. "Familial Care" engages familial networks post-hospital discharge, including spouses, adult children, and other close relatives in Germany. Both Italian practices "Standard Format for the Individualised Care Plan (PAI)" and "Community House" target a broad population, from young carers to older adult carers, with interventions designed to address both physical and mental health needs, as well as cognitive impairments of care recipients. The Dutch initiatives "Community Circles" and "Colourful Relief" emphasise local community participation, focusing on older adults and families caring for adults with learning disabilities, including those from migrant backgrounds. In Slovenia, practices "Family Carers Training" and "E-Qalin - Quality Management Model" reach informal carers, formal LTC staff, and organisations, supporting both practical caregiving and system-level quality improvements. The Swedish practice "Assertive Community Treatment (ACT)" targets care recipients with complex mental health needs, their family members (informal carers) and a range of health and social care staff. The second Swedish practice, "Carers' Outcome Agreement Tool (COAT)" targets informal carers of older people and dedicated municipal staff- carer advocates- who work directly to support informal carers by a negoitatied approach to support planning.

Care recipients across these initiatives include older adults, people with multimorbidity, cognitive impairments, psychological disorders, chronic illnesses, disabilities, and those requiring post-hospital discharge care. The breadth of targeted care recipients illustrates a shared understanding of care as a relational process involving both carers and care recipients.

Main outcomes

Outcomes are consistently positive across all initiatives, both at the individual and systemic levels. "Care and Live" demonstrates reductions in infomal carer stress, anxiety, and depressive symptoms, increased emotional stability, and enhanced self-efficacy. "Familial Care" reports improved caregiving competence and confidence, clearer family role allocation, stabilisation of care arrangements, and reduced family conflicts. "Standard Format for the Individualised Care Plan (PAI)" enables a paradigm shift in carer recognition through formal assessments and individualised care planning, while "Community House" fosters collaboration between carers and multiple healthcare providers, enhancing the quality of care. "Community Circles" and "Colourful Relief" show increased social engagement, enhanced self-reliance, reduced loneliness, and improved trust between families and care organisations, with "Colourful Relief" also demonstrating preventive impacts on emergency admissions. "Family Carers Training" improves informal carers' resilience, practical skills, and communication, while "E-Qalin - Quality Management Model" enhances organisational processes, teamwork, and resident-centered care. Swedish initiatives, "Assertive Community Treatment" (ACT) and the "Carers' Outcome Agreement Tool (COAT)" enhance continuity, recovery outcomes (ACT), structured collaboration, and shared decision-making, benefiting both carers and care recipients. Across cases, these outcomes reveal that carer-focused interventions generate secondary benefits for care recipients, enhancing care quality, safety, and relational dynamics.

In a few cases, LTC workers also benefit directly from implemented initiatives. For example, the "E-Qalin - Quality Management Model", supports mental wellbeing and resilience over time of its main target group, i.e. care managers and frontline LTC workers of nursing homes, as they feel more included and listened to within the continuous quality improvement process in providing care within such organisations. Moreover, Flexible Assertive Community Treatment (FACT) may reduce health professional strain, through clarified roles and shared responsibilities in the process aimed to provide support for individuals with severe and persistent mental illness.

Care partnerships

The potential to foster care partnerships is evident across all practices which formed the ten case studies. In "Care and Live", counselling indirectly strengthens collaboration between informal carers and formal services through improved emotional regulation. "Familial Care" directly involves informal carers, hospital staff, and insurance actors in transition care planning. "Standard Format for the Individualised Care Plan (PAI)" and "Community House" emphasise co-development and shared responsibility between informal carers and professionals. "Community Circles" and "Colourful Relief" promote informal-professional collaboration at the community level, fostering knowledge exchange, trust, and shared care responsibilities. The Slovenian practices ("E-Qalin - Quality Management Model" and "Family Carers Training") respectively embed partnerships within training cycles and ongoing peer support, while Swedish initiatives ("Carers' Outcome Agreement Tool" and "Assertive Community Treatment") respectively institutionalise structured dialogues between informal carers and municipal carer advocates and between care recipients, informal carers and health and social care professionals via resource groups (RACT).

Overall, these practices illustrate a continuum of partnerships, from indirect facilitation to more formalised collaborations. Common features include trust-building, recognition of experienced informal carers as experts, and the promotion of mutual learning and joint decision-making between informal carers and professionals.

Sustainability

Overall, the case studies highlight that sustainability is strongly influenced by institutionalisation, funding stability, and community engagement. "Care and Live" relies on statutory insurance and digital scalability; "Familial Care" is integrated into hospital contracts and supported by insurance funds. Italian initiatives leverage national, regional, and local public funds alongside participatory engagement. Dutch initiatives combine low-cost, community-driven models with knowledge networks and manuals. Slovenian practices emphasise municipal co-financing and social sustainability through volunteer leadership. The "Assertive Community Treatment (ACT)" practice depends on health care region policy support and financing, institutional adoption, and ongoing training whilst the "Carers' Outcome Agreement Tool (COAT)" is contingent on high-level political decision-making within the municipality concerned. Across contexts, sustainability is enhanced when programs are legally recognised, financially secure, and embedded within existing structures, demonstrating the importance of systemic alignment for long-term success.

Transferability

Most case study practices exhibit a strong potential for transferability across regions and countries. Digital counselling ("Care and Live"), modular hospital interventions ("Familial Care"), standardised care plans ("Standard Format for the Individualised Care Plan-PAI"), "Community House", "Community Circles", relational support ("Colourful Relief"), training programs ("Family Carers Training"), quality management system ("E-Qalin - Quality Management Model"), and structured methodologies (characterising Swedish practices- Assertive Community Treatment", ACT and the "Carers' Outcome Agreement Tool, COAT) all allow adaptation to new contexts, while some have already been proven to be transnationally relevant (e.g. ("E-Qalin - Quality Management Model" and the ACT model both of which are implemented in several European countries and internationally). It was evident from the case studies that successful transfer depends on attention to local culture, workforce capacity, regulatory frameworks, and funding structures. The emphasis on structured methodologies, evidence-informed approaches, and participatory engagement was seen to enhance replicability while maintaining fidelity to core principles.

3.3.3. Cross-cutting insights: lessons learned, implications, and suggestions for practical interventions

There will now follow some cross-cutting insights, main lessons learned, as well as implications, and general practical suggestions for policymakers, practitioners, decision makers and care organisations on the basis of the WELL CARE case study analyses.

Recognising and supporting informal carers as central actors

A consistent theme across all 10 practices, which formed the focus for the WELL CARE case studies, is the recognition of informal carers as essential partners in care. Traditional LTC systems often focus primarily on care recipients or formal providers, overlooking the central role informal/family carers play in daily care and wellbeing of care recipients. Several initiatives exemplify the benefits of interventions that directly address informal carer needs, including psychological support, practical skills, self-efficacy, and resilience. By explicitly valuing carers' expertise, these programs help to reduce stress, prevent burnout, and enhance caregiving competencies. The centrality of informal carers in successful LTC systems has profound implications for policy design. Health and social care systems must formally recognise informal carers, provide structured assessment of their needs, and integrate carer support into routine care planning. Without such

recognition, care arrangements risk becoming unsustainable, and informal carers may experience high levels of stress, jeopardizing their own mental wellbeing and, in turn, care quality.

Dual benefits: informal carer wellbeing and care quality

An additional key finding is the dual impact of carer-focused interventions. Programs that strengthen carers' skills, confidence, and emotional resilience also indirectly improve care recipient outcomes. For example, hospital-based training and home-based follow-up can stabilise familial care networks, reduce family conflict, and improve continuity of care post-discharge. Similarly, other practices highlight the importance of structured care planning and integrated service delivery, which simultaneously support carers and ensure that care recipients' needs are comprehensively addressed. This dual benefit underscores the importance of holistic approaches in LTC. Policymakers and service designers should consider carer support not simply as an ancillary component, but rather as a central strategy to improve care quality, prevent crises, and sustain home-based and community care models.

Importance of structured, evidence-informed interventions

A feature of the practices analysed is the use of structured and evidence-informed methodologies. Programs based on quality management systems, systematic assessment, structured planning, and monitoring ensure consistent outcomes for care recipients, informal carers and involved LTC/health and social care staff. Structured approaches provide several advantages: they facilitate evaluation, enable adaptation across contexts, support scalability, and allow organisations to maintain high standards over time.

Structured interventions also support transparency and accountability. They allow informal carers, professionals, and organisations to track progress, identify gaps, and make informed decisions about resource allocation and service design. Evidence-informed frameworks ensure that interventions are not ad hoc but are guided by empirical insights and best practices.

Care partnerships as a mechanism for success

Care partnerships represent another key success factor underpinning the effectiveness of the initiatives. Findings highlight that collaborative models (where informal carers, formal professionals, and community organisations work together) enhance communication, role clarity, and build trust. Importantly, care partnership aspects extend beyond carer-care recipient relationships. Many programs promote multi-stakeholder collaboration, connecting families, health and social care professionals, social services, and local authorities. Networked approaches help to reduce isolation, improve care coordination, making care systems more resilient and responsive to changing needs. While in general within the initiatives, carers are mainly recipients of support (e.g. training, advice, support), recognising carers as equal partners and encouraging shared decision-making could foster mutual learning and more effective care delivery.

Community engagement and social capital

Several initiatives highlight the value of community-based engagement in supporting carers and recipients. Local networks and community structures can strengthen informal care support, enhance social cohesion, and promote independence among older adults. Community-oriented approaches provide low-cost, sustainable solutions, particularly in contexts with limited formal care resources. Community engagement also enhances social capital. By mobilising volunteers, fostering mutual aid, and creating shared responsibility for care, these initiatives generate collective resilience. Importantly, community-based approaches complement formal care services rather than replacing them, creating a balanced and more integrated care ecosystem.

Sustainability requires multi-level support

Sustainability emerges as a critical determinant of the long-term impact of the analysed good practices. Initiatives supported by institutional embedding, legal frameworks, and stable funding demonstrate greater durability. Sustainability is further strengthened when practices incorporate social and community mechanisms, ensuring continuity even amid policy or funding shifts. Multi-level support - combining policy alignment, organisational integration, continuous professional training and quality monitoring - ensures continuity of the initiatives.

Transferability and adaptation across contexts

The 10-case study good practices collectively illustrate that effective practices are transferable across contexts when core principles are maintained and contextual adaptations introduced. Key factors for allowing effective transfer include cultural relevance, regulatory compatibility, available workforce, sutainable funding provisions, and organisational capacity. Also, well defined methodologies, clear implementation guidance, participatory approaches involving relevant stakeholders and training protocols facilitate replication while enabling local tailoring, ensuring that interventions remain relevant, effective, and sustainable.

Specific policy and system level implications and suggestions for practical interventions drawn from the findings are now presented.

Policy and system-level implications

The cumulative insights from these practices point to several policy implications:

- Formal recognition of informal carers is essential, including needs assessment, psychological support, and training integration.
- Integration of carer support into routine care systems enhances both care quality and system sustainability.
- Investment in structured, evidence-informed interventions ensures consistency, replicability, and scalability.
- Promotion of care partnerships and community networks strengthens collaboration, trust, and resilience.
- Sustainability planning should combine stable funding, institutional embedding, and social/community mechanisms.
- Transferable frameworks require clear protocols, adaptable methodologies, and mechanisms for local contextualisation.

Suggestions for practical interventions

Based on the case study analyses, possible suggestions for practical interventions to support carers in the context of LTC include:

- Developing policies that embed carer support within statutory LTC systems.
- Promoting initiatives targeted at LTC workers, to support their mental wellbeing and resilience, and also for further strengthening care partnerships with informal carers.
- Supporting digital and community-based interventions to expand access, particularly in rural or underserved areas.
- Encouraging co-development of care plans and participatory decision-making with carers.
- Implementing training on quality management systems in LTC settings to ensure consistency and measurable outcomes.
- Fostering multi-stakeholder care networks that integrate formal and informal care provision.
- Establishing monitoring, evaluation, and knowledge-sharing mechanisms to support continuous learning and adaptation of initiatives for both informal carers and LTC workers, to contribute to support their resilience and mental wellbeing.

3.3.4. Methodological considerations in realising the case studies

Overall, the data collection carried out for realising the 10 in-depth case study reports on good practices to support carers' mental wellbeing and resilience, has the main strength of having involved a wide number of key informants belonging to different sectors (i.e. representatives from the voluntary or community sector, LTC workers, healthcare and mental health organisations, carers associations, HR managers/project managers, LTC workers). They also represent a broad range of organisational backgrounds (e.g. public, social, healthcare services, LTC residential facilities, academia, carers' and professional associations, patient/carer representatives, citizens and volunteers organisations) and professional roles (e.g. physicians, nurses, psychologists, social workers, managers, carer advocates, etc.). This specific profile of participant key informants allowed project partners to gain a multifaceted and holistic set of inputs and information useful to describe in detail the good practices, by enriching the knowledge on how they work and highlighting their potential in terms of transferability, sustainability and fostering care partnerships.

Another strength of this work is based on the methodological choice to select the good practices for carrying out case studies through a participatory approach, by involving various stakeholders participating in the national BLNs in the five project country partners. This guaranteed the possibility to select good practices of different types and of relevance in the various national contexts, characterised by diverse LTC systems and belonging to different geographical areas across Europe.

However, we also acknowledge some methodological limitations in developing the case studies. First, for ethical reasons (i.e. the potential need for formal ethics approval which was not possible to obtain within the tight timeframe for realising the case studies), we did not involve individual informal carers or care recipients as key informants within the case study interviews or focus groups conducted. However, relevant patients/carers organisations were approached in their role as patient/carer representatives, and they represented/reported a general point of view of carers/care recipients about the implementation of the selected good practices for the case study reports.

Moreover, also, due to time constrains, it was deemed expedient to carry out interviews and focus groups online, rather than face-to-face, such that onsite visits for making a participant observation was not realised. These aspects limited the possibility to gain a more nuanced and holistic set of information for describing and analysing the good practices, even though, as mentioned above, the wide and different composition of key informants involved in the fieldwork in an online modality assured a good quality of information collected to produce the case study reports.

4. Conclusions

This Report is a public deliverable (D2.2 "Final report on 10 in-depth case studies in 5 European countries") of the WELL CARE project, finalised at month 27 (March 2026), the overall aim of which is to report case study findings of a total of 10 selected promising good practices aimed to support the resilience and mental wellbeing of informal carers and LTC workers in the five projectpartner countries, i.e. Germany, Italy, the Netherlands, Slovenia and Sweden.

It is based on the results of the third specific research activity envisaged in Task 2.3 (case studies; M21-24; September-December 2025) and represents, the final research activity of WP2 ("Review, selection and analysis of good practices") of the WELL CARE project. More specifically, the Report presents the case study analyses of a total of 10 promising good practices from across the five project partner countries, carefully identified by project partners - in accordance with stakeholders participating in the national BLNs, by use of ad hoc agreed criteria - from among the top highest-ranked practices selected and previously presented in D2.1 "Final report on 40 good practices in 5 European countries" (month 20; August 2025) and (where relevant) from the list of the top 60 ranked good practices (information of which is available in the WP2 database). In the selection of the good practices to investigate through in-depth case studies (two in each partner country) particular attention was devoted to the practices' transferability, adaptability and implementability potential in other contexts, and to their possible potential for fostering care partnerships between formal and informal carers.

As already mentioned, the results of this Report have three main goals: i) to integrate and enrich the findings of the previous reasearch phases of WP2 as described in D2.1; ii) to contribute (together with the findings of D2.1) to the next steps of the project (e.g. the development of solution prototypes in WP3) and iii) to contribute to further advance knowledge and understanding concerning promising and effective good practices aimed to strengthen the resilience and mental wellbeing of informal carers and LTC workers across Europe.

In the previous sections, we have presented the main activities carried out, providing methodological details, and highlighting the overall main results of the investigated good practices through case studies.

The analysis carried out of the 10 good practices reported in the Results chapter highlighted several insights that can help to inform policy, practice, and the broader design of LTC systems. These practices demonstrate how structured, evidence-informed, and participatory approaches can effectively support (mainly) informal carers and LTC workers, enhance care recipient outcomes, strengthen care partnerships, and provide potential transferable models for different national and regional contexts in Europe.

The 10 cross-country practices collectively illustrate a paradigm shift towards holistic, participatory, and systemically integrated approaches to LTC. By focusing on informal carers, fostering care partnerships, leveraging community resources, and institutionalising structured methods, these initiatives address both the practical and emotional dimensions of informal caregiving. Importantly, they demonstrate that carer support is not merely an ancillary component but a strategic lever for enhancing the quality, safety, and sustainability of LTC systems.

As emerged from the case studies, care partnership potential/aspects and collaborations between informal carers and LTC workers are promoted or are key aspects of most of the investigated good practices. This, apart from highlighting concrete and actual mechanisms of cooperation between these two groups of carers already in place, could also promote a debate among stakeholders and policy makers to contribute to a cultural and operational shift towards strengthening these types of care alliances. It is a potential key ingredient to support both formal and informal carers' wellbeing, by sharing knowledge, experiences and alleviation of care burden, leading also to an improvement in care quality for the benefit of the care recipient. The insights gained from the combined case study reports will help to inform the next phase of the WELL CARE work, namely the development of solution prototypes for supporting the mental wellbeing of informal carers and LTC workers, by promoting effective care partnerships (i.e. in line with the definition adopted in the WELL CARE project).

Furthermore, there is a need for more research on interventions and practices primarily targeting LTC workers for supporting their resilience and mental health in different settings. On the one hand, this could help to fill a knowledge gap in the iterature (e.g. as revealed by our systematic review of scientific and grey literature) and, on the other hand, it could provide further useful ideas for building and strengthening effective care partnerships with informal carers.

In conclusion, the practices analysed provide robust evidence that well-designed interventions can simultaneously strengthen carer wellbeing, improve care recipient outcomes, foster collaborative partnerships, and offer scalable,

transferable solutions adaptable across diverse European contexts. Policymakers, practitioners, and organisational stakeholders/leaders can draw upon these insights to design care systems that recognise, empower, and sustain informal and formal carers, while ensuring high-quality, resilient, and inclusive care for people in need of LTC.

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Annexes

Annex 1:
Topic Guide for interviews or focus group with Key Informants

SECTION A: OPENING

A1. Which is your role in the practice/initiative?

A2. How long have you been involved in the practice/initiative?

SECTION B: START AND STATUS OF THE PRACTICE/INITIATIVE

B1. When did the practice/initiative commence (month and year)?

B2. What were the main reasons to start the practice/initiative?

POTENTIAL PROBES:

- What factors led to the development of the practice/initiative (the background or context for the practice/initiative)
- How was the practice/initiative actually initiated?
- Which stakeholders/key actors took the initiative and what are/were their roles and contributions in its implementation?
- Which were the main steps in the implementation of the practice/initiative overtime?

B3. Is the practice/initiative still ongoing? If it is terminated, when and why?

SECTION C: TARGET GROUP(S) AND CARE RECIPIENTS

C1. Which are the main target group(s) of the practice/initiative (e.g. informal carers, LTC workers, other stakeholders)?

POTENTIAL PROBES:

- Which are the main socio-demographic characteristics of the target group(s) (e.g. gender, age, educational level, socio-economic status, migration background)?
- Have/are target groups been actively involved in the practice/initiative design or in its ongoing development/ implementation and if so, how?

C2. Which are the care recipients assisted by the target group(s)?

POTENTIAL PROBES:

- Which are the main socio-demographic characteristics of the care recipients assisted by the target group(s) (e.g. gender, age, educational level, socio-economic status, migration background)?
- Is there a specific focus on older people, disabled people, people with chronic illnesses with long term-care needs?

- Which are the main health issues of the care recipients assisted by the target group(s) (e.g. physical disabilities, psychological/mental health issues, cognitive impairments, other chronic illnesses/long-term health conditions)?

SECTION D: OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE

D1. What are the aims and specific objectives of the practice/initiative?

POTENTIAL PROBE:

What are the main innovative aspects of the practice/initiative and why?

D2. Could you describe how the practice/initiative operates on the ground, and with which resources?

POTENTIAL PROBES:

- How many people and with which roles/professional background are involved as staff to implement the practice/ initiative?
- Which are the current funding sources and their amount/s to implement and/or sustain the practice/ initiative?

D3. What are the main outcomes of the practice/initiative (e.g. in relation to improving/sustaining LTC workers' and/or informal carers' mental wellbeing and resilience, improving organisational practices, improving the quality of care provided)?

POTENTIAL PROBES:

- Are the outcomes of the practice/initiative regularly measured/assessed?
- How does (might) the practice/initiative improve/sustain LTC workers' and/or informal carers' mental wellbeing and resilience?
- If the response to one or both of the above is "yes", then ask if there is supportive documentation (evaluation, assessments) available

D4. To what extent and how are care partnerships[7] between informal carers, LTC workers or other stake-holders explicitly foreseen and promoted by the practice/initiative?

POTENTIAL PROBES:

- If any, what type of care partnership is promoted by the practice/initiative (e.g. sharing care, sharing knowledge, relationship characterised by mutual recognition, appreciation, and reciprocal emotional support, supportive relationships and interactions)?
- Are LTC workers and/or informal carers supported (e.g. by means of dedicated tools) and trained/educated to foster/ promote care partnerships? And if so, how?
- Have patients/care recipients benefitted from care partnerships between informal carers and LTC workers related to the practice/initiative, if any and if so, in what ways?
- How could care partnerships between LTC workers, informal carers and other stakeholders (including patients/care recipients) be further developed and/or strengthened (or which are the main barriers hampering it)?

D5. How is the long-term sustainability of the practice/initiative guaranteed?

D6. To what extent and how is the practice/initiative transferable or potentially transferable to other set-tings/regions/contexts?

D7. What are the main strengths of the practice/initiative (and its implementation) in your opinion and why?

POTENTIAL PROBE:

- Are there any particular elements of the practice/initiative that work particularly well that you didn't initially expect to do so? If so, please specify.

D8. What were/are the main weaknesses/drawbacks/limitations of the practice/initiative (and its implementation) in your opinion and why?

POTENTIAL PROBES:

- Are there any particular elements of the practice/initiative that didn't work as well as you had first envisaged and why?
- How have you sought to overcome these identified weaknesses/drawbacks if feasible over the years?

D9. What were/are the main challenges you and/or your team have experienced over the years, if any? If so, could you specify them? Could you also explain how you have strived to overcome these identified challenges?

D10. What could be useful to improve the practice/initiative (e.g. organisational structure, subsidies/incentives, legislation) with regards to supporting the mental wellbeing and the resilience of LTC workers and informal carers, and to foster care partnerships?

CONCLUSION

Looking back at the practice/initiative, since its inception, what are your main lessons learned over the years that you would like to share with us?

If you were to start this practice/initiative up today, would you do anything differently? If so, how and why?

Do you have anything else you wish to share with us that you think could be relevant for us to know and/or learn about the practice/initiative that we haven't touched on during the interview?

SECTION E: Demographic data of the interviewed persons

Name	
Country	
Gender	
Age	
Education	
Socio-economic status (e.g. high, middle, low)	
Migration background (yes/no; if yes, please specify)	
Organisation	
Profession/role	

Please specify how long the interviewee has been working at the organisation and in the current position (e.g. less than 1 year, 1-2 years, 3-4 years, more than 5 years)	
Representative from:	
LTC workers/informal carers' employers	
HR managers/project managers	
Informal carers/patients' organisations	
Health, care and mental health organisations or carers' associations	
Trade unions	
LTC workers	
Other relevant Key Informants (e.g. representatives from the voluntary or community sector)	
E-mail	
Telephone number	

Annex 2:
Template for reporting the case study, with sources of information from the Topic Guide (for Interviews/Focus group)

	ABSTRACT
1	**INTRODUCTION (GENERAL INFORMATION)**
	Name of the practice/initiative in English and national language
	Country of implementation
	Leader organisation(s) [organisation(s) in charge of coordinating the initiative: name in original language and in English (when possible)]
	Contact details [name of the contact person, address, phone number, e-mail]
	Website
	Date of data collection [month when the case study template has been filled-in]
	Describe the organisational structure
2	**START AND STATUS OF THE PRACTICE/INITIATIVE**
	Indicate when the practice/initiative commenced (month and year) (B1)
	Describe the main reasons for starting the practice/initiative (B2)
	Describe if the practice/initiative is still ongoing, or if it is terminated, when and why (B3)
3	**TARGET GROUP(S) (ON WHICH THE PRACTICE/INITIATIVE FOCUSES)**
	Describe which are the main target group(s) of the practice/initiative (e.g. informal carers, LTC workers, other stakeholders) (C1)
4	**CARE RECIPIENTS**
	Describe which are the care recipients assisted by the target group(s) (C2)

5	**OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE**
	Describe what are the aims and specific objectives of the practice/initiative (D1)
	Describe how the practice/initiative operates on the ground, and with which resources (D2)
	Describe what are the main outcomes of the practice/initiative (e.g. in relation to improving/sustaining LTC workers' and/or informal carers' mental wellbeing and resilience, improving organisational practices, improving the quality of care provided) and with supportive documentation where available (D3)
	Describe to what extent and how care partnerships between informal carers, LTC workers or other stakeholders are explicitly foreseen and promoted by the practice/initiative (D4)
	Describe if and how the long-term sustainability of the practice/initiative is guaranteed (D5)
	Describe to what extent and how the practice/initiative is transferable or potentially transferable to other settings/ regions/contexts (D6)
	Describe what are the main strengths of the practice/initiative (and its implementation) and with supportive documentation where available (D7)
	Describe what were/are the main weaknesses/drawbacks/limitations of the practice/initiative (and its implementation) and with supportive documentation where available (D8)
	Describe what were/are the main challenges experienced over the years, if any (D9)
	Describe what could be useful to improve the practice/initiative (e.g. organisational structure, subsidies/incentives, legislation) with regards to supporting the mental wellbeing and the resilience of LTC workers and informal carers, and to foster care partnerships (D10)
6	**CONCLUSIONS**
	Describe the major lessons learned arising from this initiative
	ACKNOWLEDGMENTS
	Reporting details on Key Informants contributing to data collection, if they agree
	REFERENCES

Annex 3:
Template for reporting concise information/details about the 2 country case studies

Country: _____

Length: A4 single-spaced, 11 font size Times Roman half a page approximately

1	**METHOD/S OF DATA COLLECTION** (i.e. individual interviews and/or focus group)
2	**GROUPED DESCRIPTION OF THE INTERVIEW PARTICIPANTS** (socio-demographic data)
3	**DESCRIPTION OF ANY DIFFICULTIES/CHALLENGES EVENTUALLY FACED** (e.g. with recruiting key informants for the case studies or other related issues)

Annex 4:
Template for reporting concise key findings about the 2 country case studies

(To fill-in 1 template for each country case study)

Country: _____

Name of the practice investigated via Case Study _____

Length: A4 single-spaced, 11 font size Times Roman, 1 page approximately

1	**GENERAL INFORMATION OF THE PRACTICE/INITIATIVE** • aims and specific objectives • target group(s) (on which the practice/initiative focuses) • care recipients assisted by the target group(s)
2	**MAIN OUTCOMES** (e.g. in relation to improving/sustaining ltc workers' and/or informal carers' mental wellbeing and resilience, improving organisational practices, improving the quality of care provided)
3	**CARE PARTNERSHIPS** (e.g. describe if and how care partnerships between informal carers, ltc workers or other stakeholders are explicitly foreseen, promoted, or planned by the practice/initiative)
4	**SUSTAINABILITY** (describe if and how long-term sustainability of the practice/initiative is guaranteed)
5	**TRANSFERABILITY** (describe to what extent and how the practice/initiative is transferable or potentially transferable to other settings/regions/contexts)

Annex 5:
Templates reporting the complete 10 case studies

Good practice	Country
Care and Live (pflegen-und-leben.de)	DE 1
Familial Care (Familiale Pflege)	DE 2
Standard Format for the Individualised Care Plan (PAI) (Format Unico per il Piano Assistenziale Individualizzato - PAI)	IT 1
Community House (Casa della Comunità)	IT 2
Community Circles (Voorzorgcirkels)	NL 1
Colourful Relief (Kleurrijk Ontzorgen)	NL 2
Family Carers Training (Usposabljanje za družinske in druge neformalne oskrbovalce)	SI 1
E-Qalin - Quality Management Model	SI 2
Assertive Community Treatment (ACT)	SE 1
Carers' Outcome Agreement Tool (COAT)	SE 2

Endnotes

1 Throughout the Report, the terms informal carers and family carers are used synonymously and refer (as well as when only the term carers appear) to persons who (according to the Grant Agreement) provide - usually - unpaid care to someone with a chronic illness, disability or other long-lasting health and/or care need, outside a professional or formal framework. Moreover, the terms LTC workers, formal carers and (healthcare/LTC) professionals are used as synonyms, to refer to professional people providing LTC, including (as specified in the Grant Agreement) primarily qualified nurses and personal care workers, either employed by a LTC provider (in home or residential settings) or directly by the care recipient/family (i.e. live-in carers, mainly in home settings); the latter also includes migrant care workers.

2 BLNs are carried out within WP5 "Blended learning networks (BLNs) and include informal carers, LTC workers and their organisations and other key stakeholder groups" (M1-48; January 2024-December 2027).

3 Realistic Evaluation does not only assess whether an intervention works, but also asks how it works, for whom, and under what circumstances (Pawson and Tilley, 2014).

4 In this column, where "No" appears, it means that the related practices were among the list of top 41-60 good practices selected within Task 2.3 of WP2, while the other good practices reporting "Yes" in this column were among the top 40 good practices reported in D2.1 (Socci et al., 2025). For such good practices, the page numbers of D2.1 where they are described are also reported.

5 SGB refers to the German Social Code Book- for more details see the full case study 1 report in Annex 5.

6 §45 SGB XI refers to Section 45 of the German Social Code Book XI, which regulates benefits for the support of informal carers within the statutory long-term care insurance system. It provides funding for low-threshold counselling, training and relief services aimed at stabilising and supporting family carers.

7 Definition of care partnerships: in the WELL CARE project, by care partnerships, we mean the coordination, integration (i.e. working together), and mutual recognition of care and caring activities performed by LTC workers and informal carers, in a vision of integrated LTC, strengthening the mental wellbeing and resilience of both groups.

1. Care and Live (pflegen-und-leben.de)

ABSTRACT

The Psychological online counselling for family carers (pflegen-und-leben.de; *Care and Live*) is a nationwide online counselling service offering low-threshold psychological support to informal carers in Germany. The service is free of charge for participating family carers. Developed by Zentrum ÜBERLEBEN gGmbH, the initiative addresses one of the most persistent challenges in long-term care systems: the high emotional burden carried by family carers and their limited access to specialised support. Drawing on cognitive-behavioural and systemic principles, the service provides structured psychological counselling while remaining clearly distinct from psychotherapy. It offers a safe, anonymous and flexible environment where carers can articulate concerns that are often difficult to share in traditional settings.

The platform is funded through §45 SGB XI[1] by four statutory long-term care insurance funds: Barmer, Techniker Krankenkasse, DAK-Gesundheit and Handelskrankenkasse (hkk), and delivered by a team of five psychologists (one full-time and three part-time). Professional supervision ensures consistent quality. Over the past three years, 1,659 carers voluntarily provided demographic information, confirming that the service reaches a diverse user base, predominantly women between 50 and 79 years old who are caring for relatives with moderate to high care needs, often for two years or longer and frequently in the same household.

The counselling aims to reduce stress, anxiety, and depressive symptoms, strengthen self-efficacy and provide early emotional stabilisation. Evaluations indicate meaningful improvements in psychological wellbeing and a strong sense of being understood. Some users who complete the full counselling cycle are identified as needing psychotherapy, yet many face long waiting periods, highlighting a systemic gap between psychosocial counselling under §45 SGB XI and therapeutic care under SGB V.

The initiative indirectly supports care partnerships by helping carers reframe their interaction with professional care workers and by encouraging earlier acceptance of formal support. Its digital, evidence-informed model is highly transferable across regions and care systems. Overall, *pflegen-und-leben.de* demonstrates the value of integrating psychosocial counselling into long-term care and offers an adaptable approach to strengthening the resilience of informal carers in Europe.

[1] §45 SGB XI refers to Section 45 of the German Social Code Book XI, which regulates benefits for the support of informal carers within the statutory long-term care insurance system. It provides funding for low-threshold counselling, training and relief services aimed at stabilising and supporting family carers.

INTRODUCTION

Name of the good practice: pflegen-und-leben.de – Psychological online counselling for family carers (pflegen-und-leben.de – Psychologische Online-Beratung für pflegende Angehörige).

Country of implementation: Germany.

Implementation level: National.

Leader organisation: Zentrum ÜBERLEBEN gGmbH (Center Surviving, non-profit organisation).

Contacts: Jana Toppe, Head of Psychological Online Counselling, Psychologist (M.Sc.) and Systemic Therapist (DGSF), j.toppe@pflegen-und-leben.de.

Website: https://www.pflegen-und-leben.de/.

Date of data collection: WELL CARE case study interviews November 2025; internal evaluations conducted by Zentrum ÜBERLEBEN gGmbH during the pilot phase (2011-2013) and through ongoing voluntary evaluation data collected between 2022 and 2025 (see References).

Description of the organisational structure of the practice:
pflegen-und-leben.de is a nationwide online counselling service that provides low-threshold psychological support for informal carers in Germany. Developed and coordinated by Zentrum ÜBERLEBEN gGmbH, a Berlin-based non-profit organisation specialising in trauma treatment, violence prevention, migration support and psychosocial services, the initiative addresses a persistent gap in the long-term care landscape: the emotional and psychological strain experienced by family carers and the limited access to specialised support structures. Zentrum ÜBERLEBEN gGmbH employs approximately 129 permanent staff and 116 freelance professionals across its various programmes. Informal carers often delay help-seeking due to shame, fear of judgement or logistical barriers. The counselling service was therefore designed from the outset to offer anonymous, flexible and stigma-free access to professional psychological support.

The origins of the initiative lie in an interdisciplinary working environment within Zentrum ÜBERLEBEN gGmbH, which functions as an umbrella organisation bringing together trauma therapists, psychologists, migration counsellors, a research division and a care training centre. constellation of expertise enabled the team to identify the specific psychological burden associated with family caregiving: "*It was a unique constellation of expertise under one roof, and that combination created the idea*" (IW).

Based on these insights, the team developed a concept for preventive, structured and accessible psychological counselling tailored to the caregiving context. The approach draws on cognitive-behavioural and systemic principles yet is clearly positioned as counselling rather than

psychotherapy. The focus is on emotional stabilisation, resource activation and managing stressors related to the daily realities of caregiving. Clinical diagnosis or therapeutic treatment are explicitly excluded, in line with the legal framework of Section 45 of the German Social Code Book XI (statutory long-term care insurance). In 2011, the concept was presented to the Federal Ministry for Family Affairs and selected for a three-year federal pilot project under the Bundesaltenplan (national aging plan). This funding enabled the development of a professional online platform, a secure counselling infrastructure and an evidence-informed methodological framework. From the beginning, the service was intended to operate nationwide: "*It was always intended to be a nationwide service, because the internet cannot be regionalised*" (IW).

After the pilot phase ended in 2013, *pflegen-und-leben.de* transitioned into regular provision through §45 SGB XI, supported by four statutory long-term care insurance funds: Barmer, Techniker Krankenkasse, DAK-Gesundheit and Handelskrankenkasse (hkk). This stable and innovative funding model reflects the increasing recognition of psychological support as an essential component of sustainable long-term care. Over the years, the counselling service has become a reference point for digital psychosocial support in Germany.

The team currently consists of four psychologists: one full-time counsellor (40 hours per week) responsible for coordination, administration, negotiations and reporting, and three part-time psychologists (20 hours each), with recruitment underway to meet rising demand. Weekly internal case discussions and regular external supervision ensure adherence to professional standards and consistent quality. The anonymity and written format of the counselling allow users to express thoughts and emotions that might otherwise remain unspoken. Family carers can contact the service at any time through the online platform, while responses are provided by the counselling team within their regular working hours. As one counsellor described: "*People can reach out at any hour, from any place, and that makes a difference when daily routines are shaped entirely by the care situation*" (JT).

In addition to interview insights, voluntary evaluation data from 1,659 carers collected over three years (internally collected by the service provider via a voluntary online questionnaire with closed-ended demographic and care-related items) provide a clearer picture of who uses the service. Most users are women between 50 and 79 years of age who provide long-term, often co-resident care for relatives with moderate to high support needs. This reinforces the central relevance of the service for a population that is both highly burdened and structurally under-supported.

Public visibility and credibility have increased through continuous outreach, cooperation with local advisory structures and national recognition, including awards such as Deutschland – Land der Ideen (Germany – Land of Ideas). These factors have supported the integration of pflegen-und-leben.de into the long-term care system and contributed to its sustainability.

Taken together, the conceptual foundations, interdisciplinary origins and evolving user profiles of the initiative form the basis for understanding how it operates within the broader long-term care landscape. The following section describes in more detail the origins, development and current status of the practice.

START AND STATUS OF THE PRACTICE/INITIATIVE

WHEN DID IT START

The origins of *pflegen-und-leben.de* date back to 2009-2010, when an interdisciplinary team at Zentrum ÜBERLEBEN gGmbH recognised that informal carers faced substantial emotional strain yet had limited access to support tailored to their needs. The organisation's unique combination of trauma-focused psychological services, migration counselling, a research unit and a care training centre created an environment in which the specific burdens of family caregiving became increasingly visible: "*We had trauma services, migration services and a care school under one roof, and that made us pay attention to the hidden burden of caregiving*" (IW).

From these observations emerged the idea of creating a preventive, low-threshold digital counselling offer that would help stabilise carers emotionally and reduce the risk of overload and escalation in home-based care. Early concept development focused on providing structured psychological counselling, not psychotherapy, using evidence-informed methods such as cognitive-behavioural and systemic interventions, which support psychological relief, orientation and reflection on carers' roles, relationships and interaction patterns within the care situation. The aim was to create a format that carers could access discreetly, flexibly and without bureaucratic barriers.

In 2011, the team presented the concept to the Federal Ministry for Family Affairs, which selected it for funding as a three-year federal pilot project under the Bundesaltenplan. This support enabled the development of the counselling infrastructure, the integration of a secure online platform and the establishment of methodological standards. The pilot phase confirmed the relevance and feasibility of the approach and demonstrated that carers were willing to use digital psychological support when other pathways felt inaccessible.

Following completion of the pilot project in 2013, the team sought long-term financing, which required extensive outreach: "We contacted every long-term care insurer through cold acquisition, sending printed reports and project summaries, and surprisingly, it worked" (IW).

The first breakthrough came when Barmer expressed strong interest in continuing the service. In cooperation with Barmer, additional statutory long-term care funds: Techniker Krankenkasse, DAK-Gesundheit and HKK joined and developed a stable funding framework under §45 SGB XI. This funding model uses a fixed base amount rather than case-based billing, ensuring continuous availability regardless of fluctuations in demand. It also reflects the growing recognition among insurers that the psychological wellbeing of carers is essential for maintaining sustainable long-term care arrangements.

Since its integration into regular care provision in 2014, *pflegen-und-leben.de* has operated without

interruption. The counselling team now consists of four psychologists: one full-time (40 hours per week) and four part-time (20 hours each). Weekly case discussions, external supervision and a structured counselling protocol ensure consistent quality. Rising demand has recently led to longer response times, and recruitment for an additional psychologist is underway: "*We have reached a point where demand is higher than what the team can handle comfortably, and additional staff are urgently needed*" (JT).

The service has also achieved national visibility through partnerships with advisory centres, social media outreach and recognition through awards such as *Deutschland – Land der Ideen* (Germany – Land of Ideas). These factors, along with positive evaluation findings, reinforce the relevance and stability of the initiative within the long-term care system.

Today, *pflegen-und-leben.de* is an established and continuously developing component of psychosocial carer support in Germany. Its long-term sustainability is anchored in statutory financing, its operational structure and its demonstrated ability to reach carers who often remain invisible in traditional support settings.

REASONS FOR STARTING

Family carers in Germany often experience psychological strain, yet few ones access mental health support due to stigma, lack of awareness, and geographical barriers. Early practice-based insights and observations from counselling and pilot work indicated high levels of stress, guilt, and isolation among carers, particularly those balancing work and care or living in rural areas. The initiative was created to offer easily accessible, evidence-based counselling that reduces stress and strengthens self-efficacy.

TARGET GROUP(S)

The primary target group of *pflegen-und-leben.de* consists of informal carers aged 18 and older who provide support to relatives, partners, friends or neighbours across a wide range of care situations. The service is explicitly designed for adults, as counselling under §45 SGB XI must remain within professional and legal boundaries that exclude the counselling of minors, given the additional legal, ethical and safeguarding responsibilities involved in working with children and adolescents. From the outset, the initiative aimed to reach family carers who experience psychological strain but face substantial barriers to accessing support: "*We always knew that carers were an underserved group who rarely reached out for help, even when they were close to crisis*" (IW).

The counselling is intended for carers regardless of the care recipient's level of dependency or official care status. No proof of a care level is required, and many users contact the service before entering the formal long-term care system. This structure allows the programme to support a wide

range of caregiving constellations: from early-stage caregiving and intermittent support to complex, high-intensity care arrangements.

Voluntary evaluation data from 1,659 participant family carers collected over the last three years, internally collected by the service provider (*pflegen-und-leben.de*, offer detailed insight into the demographic profile of the users. The data show that the majority of carers accessing the service are women, followed by a significant number of men and a small proportion of users identifying as diverse. Most carers are between 50 and 79 years old, with the largest cluster in the 60-69 age group. Younger carers aged 18-29 and older carers aged 90 and above are also represented, though in smaller numbers. These patterns indicate that the service predominantly reaches individuals in midlife or older adulthood, many of whom carry multiple responsibilities such as paid employment, household management and long-standing care duties.

The marital status of users suggests that caregiving frequently involves partner or spousal care: married carers represent the largest group among respondents. However, substantial numbers of single, divorced or widowed carers also seek support, indicating that adult children caring for ageing parents and individuals caring for non-parent relatives form a considerable portion of the user base.

Educational backgrounds are highly varied. Many carers report secondary or vocational qualifications, while a substantial proportion have completed higher education. A significant number selected the category “other qualification”, which likely reflects international or non-standard educational pathways. This diversity indicates that *pflegen-und-leben.de* reaches a wide social spectrum, including carers with migration or biographical backgrounds that differ from the dominant German educational profile.

Carers contact the service in connection with a broad range of care recipients. These include older adults with chronic physical illnesses, multimorbidity, dementia or cognitive impairments; partners with neurological conditions such as Parkinson’s disease or post-stroke complications; relatives with psychiatric conditions such as depression, bipolar disorder, psychosis or addiction; individuals affected by post-viral syndromes such as Long Covid or ME/CFS; as well as infants, children and adolescents with congenital disorders, developmental delays or chronic illnesses requiring long-term care: “*Over the years, we saw everything from small babies to very old seniors*” (IW).

The evaluation data highlight that most carers have been providing support for two years or longer, confirming that the service largely accompanies long-duration, high-burden care situations. Many care recipients live in the same household as the carer, while others live nearby or at greater distances, which can introduce additional organisational and emotional challenges that are reflected in counselling sessions.

A further important subgroup consists of carers who provide support despite the absence of an officially recognised care level. These individuals may be navigating early-stage health decline, fluctuating psychiatric conditions or complex social situations that have not yet been formally assessed by the statutory care insurance system. The digital accessibility of the service ensures that these carers - who are often invisible in formal structures - can still access professional support.

The counselling is also used by carers who have not previously sought psychological assistance, either because they lacked time or because they felt ashamed to express their emotional strain. The anonymous format lowers these barriers significantly. As one counsellor observed: "*People can write about things they would never say out loud, and anonymity makes that possible*" (JT).

Overall, the target group is broad and heterogeneous, encompassing carers from different age groups, educational backgrounds, family constellations and care intensities. The service reaches individuals providing care within the home, across short distances and over long geographical separations. It is accessed by carers of people with physical, cognitive and psychiatric conditions, including children and adolescents with long-term health needs. What unites this diverse population is the psychological burden associated with caregiving and the need for timely, low-threshold emotional support. The following section describes the characteristics of the care recipients supported indirectly by the initiative.

CARE RECIPIENTS

Care recipients supported indirectly through *pflegen-und-leben.de* represent a highly diverse group, reflecting the broad range of caregiving situations in Germany. Although the service focuses exclusively on carers, the characteristics of the people they support shape the counselling process and the types of emotional and organisational challenges that arise. The initiative therefore targets the psychological wellbeing of carers while indirectly influencing the stability and safety of the care arrangements in which they are embedded.

Most care recipients are older adults, including individuals with chronic physical illnesses, multimorbidity, frailty or mobility impairments. Many present degenerative neurological disorders such as dementia, Alzheimer's disease or Parkinson's disease. These situations are often marked by behavioural changes, disorientation or fluctuating levels of dependency, all of which place sustained emotional pressure on carers: "*Dementia is one of the most dominant themes in our counselling cases and often one of the most exhausting situations for families*" (JT).

Care recipients also include adults with mental health conditions such as depression, anxiety disorders, bipolar disorder, psychosis or substance-use disorders. These cases present specific challenges around emotional co-regulation, safety, unpredictability, and crisis risk. Carers in such contexts frequently report feelings of isolation, emotional exhaustion and insecurity about how to respond to escalating symptoms: "*People care for relatives with severe psychiatric conditions and often feel they have to manage everything alone*" (JT).

In addition to older adults and adults with psychiatric or chronic physical illnesses, the service reaches carers responsible for children and adolescents with long-term support needs. These include infants and young children with congenital disorders, developmental delays, neurological conditions, rare diseases or chronic illnesses requiring continuous medical attention. Although minors are not counselled directly under §45 SGB XI, carers in these situations account for a noticeable proportion of users. Their counselling needs often relate to emotional overload, complex coordination tasks and the difficulty of balancing employment, parenting and caregiving responsibilities: "*Over time, we saw an increasing number of parents of children with chronic or severe conditions contacting the service*" (IW).

The evaluation data from 1,659 carers reinforce the broad range of care recipients reached by the service. Most carers have been providing support for two years or longer, suggesting long-term and high-intensity care arrangements. The majority report that the care recipient lives in the same household, which is associated with high emotional and physical demands, constant availability and limited personal space. Significant numbers also provide care across short or long distances, which can introduce additional organisational demands, time pressure, and feelings of guilt or inadequacy.

The distribution of care levels reported by users indicates that many care recipients have moderate to severe support needs. Care levels two, three and four are most frequently represented, reflecting situations of regular, complex or intensive care, as defined within the German long-term care insurance system, where higher care levels indicate increasing degrees of functional impairment and support needs. However, a notable proportion of users care for relatives without an officially recognized care level. This may point to early-stage health decline, fluctuating psychiatric symptoms, or barriers to accessing formal assessment. These cases highlight the importance of low-threshold counselling pathways for carers who may not yet be linked to the broader long-term care system.

Mental health and behavioural aspects of care recipients frequently surface in counselling, even when carers initially describe the situation in purely practical terms. This includes behavioral symptoms associated with dementia, refusal of help, aggression, communication difficulties or emotional withdrawal. Many carers express fear of escalation and uncertainty about how to maintain safety and boundaries in the home. Counselling helps them understand these dynamics, regulate their own reactions and stabilise the care relationship: "*Preventing escalation protects both sides – the caring person and the care recipient*" (IW).

Other care recipients include individuals affected by Long Covid or myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). These cases often involve profound fatigue, cognitive impairment, fluctuating symptom patterns and unpredictable progression, which can lead to frustration, misunderstanding and chronic stress within families. Counselling provides carers with space to articulate their concerns, validate their emotional strain, and identify coping strategies.

Taken together, the care recipients indirectly supported through *pflegen-und-leben.de* span all age groups and clinical categories: from infants to the very old, from chronic physical illnesses to cognitive impairments, psychiatric conditions and rare diseases. What unites these diverse situations is the sustained emotional load placed on carers, who often manage complex care responsibilities with limited support. By stabilising carers psychologically, the initiative contributes to safer, more resilient and more sustainable care arrangements across the full spectrum of long-term care needs.

OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE

AIMS

The initiative aims to reduce psychological distress among informal carers by offering early, structured and low-threshold psychological counselling tailored to the caregiving context. The counselling is based on cognitive-behavioural and systemic principles but remains strictly within the professional scope of counselling under §45 SGB XI, not psychotherapy. The focus lies on emotional stabilisation, stress regulation and the development of coping strategies that help carers manage the emotional and organisational demands of their situation.

Further objectives include strengthening carers' self-efficacy, enabling them to recognize personal limits and identify early warning signs of overload. The service also seeks to normalise help-seeking and reduce the stigma associated with psychological support in caregiving contexts. As one of the interview partners explained: "*The idea was to create a place where carers could seek psychological relief long before a crisis occurs*" (IW). The initiative's overarching aim is to support sustained resilience among carers while improving the stability and safety of care arrangements.

HOW DOES IT OPERATE

The service operates through a secure digital counselling platform that provides confidential, one-to-one psychological support. Counselling is delivered primarily in an asynchronous written format via a protected inbox system. This allows carers to articulate concerns at any time of day, accommodating the unpredictable rhythms of caregiving. Video sessions are available as an optional format for individual counselling for those who prefer real-time interaction. As one counsellor noted: "*People can stay anonymous and many feel safer writing than speaking, especially when it comes to difficult or shame-laden topics*" (JT).

Counselling follows a structured process grounded in cognitive-behavioural and systemic

approaches, focusing on emotional stabilisation, goal clarification, resource activation and managing complex relational dynamics within caregiving situations. The intervention explicitly excludes diagnosis or therapeutic treatment. The counselling is provided free of charge and consists of up to eight individual sessions. Sessions are offered in a flexible format, allowing carers to choose between written counselling, telephone consultations or video-based individual sessions.

The counselling team comprises five psychologists: one full-time staff member (40 hours per week) responsible for operational coordination, administration, negotiations, reporting and counselling, and four part-time psychologists (20 hours each). Quality is ensured through weekly internal conferences and regular external supervision. As one counsellor described: "*It always touches the boundary between counselling and therapy, but we cannot cross that line*" (JT).

The service is funded by four statutory long-term care insurance funds (Barmer, TK, DAK, HKK) under §45 SGB XI, using a fixed base funding model that ensures continuous availability independent of the number of users.

MAIN OUTCOMES

Evaluations conducted during the pilot phase, consisting of structured pre- and post-assessments of psychological burden and self-efficacy, as well as continuous user feedback collected during routine service provision, show that the service reduces psychological burden among carers and supports emotional stabilisation, understood as a reduction of acute emotional distress, improved emotional regulation and increased coping orientation within the caregiving situation.The original evaluation demonstrated measurable improvements: "The results show a significant decrease in care burden, stress, anxiety and depressive symptoms, and a significant increase in self-efficacy from pre- to post-assessment" (Böttche et al., 2013).

Carers often report that the counselling helps them articulate emotions they have suppressed or felt ashamed to express. Many users describe a sense of feeling understood: "*People often tell us that they feel understood for the first time because we know the caregiving context in detail*" (JT).

Evaluation data from 1,659 carers show that most users have been providing care for two years or longer, often for relatives with care levels two-four. For this group, emotional stabilisation and support in boundary-setting are particularly meaningful, as these carers frequently face chronic stress and limited personal time.

Some carers complete all eight available individual counselling sessions and are then identified as needing formal psychotherapy. Many, however, face long waiting lists in the statutory system, which reveals a structural gap between psychosocial counselling under §45 SGB XI and psychotherapy under SGB V.: "*There are clients who clearly need psychotherapy, but they remain stuck on waiting lists for months, and we cannot bridge that gap*" (JT).

Indirect outcomes for care recipients include improved relational stability, understood as more consistent and manageable day-to-day interactions between carers and care recipients, a reduced risk of escalation of conflicts or emotional overload within the caregiving relationship, and better acceptance of formal support services.

CARE PARTNERSHIPS

While the initiative does not directly coordinate formal-informal care partnerships, it indirectly supports them by helping carers rethink their relationship with professional support services. Many carers initially view professional help as a sign of failure or loss of control. Counselling encourages them to reframe this perspective. As one counsellor explained: "*We often tell people to view the care service as a partner, not as competition*" (JT).

Evaluation data show that many carers provide long-term, high-intensity care, frequently in the same household. In these cases, emotional clarity and improved communication can significantly influence the quality of collaboration with formal care providers. A striking example involved a culturally aligned 24-hour carer: "*When the carer found a 24-hour worker who shared the father's cultural background, everything changed and it became a real partnership*" (JT).

Through emotional stabilisation and boundary-setting, the counselling supports the prerequisites for effective care partnerships, even if formal coordination is not part of the programme's mandate.

SUSTAINABILITY

The long-term sustainability of *pflegen-und-leben.de* is ensured through its stable funding under §45 SGB XI by multiple statutory long-term care insurers. The use of a base funding model rather than case-based reimbursement enables consistent availability regardless of fluctuations in demand.

The service has operated continuously since 2014 and maintains strong institutional partnerships. Its digital format ensures low overhead and scalability. The sustained use of the service - evidenced by 1,659 voluntary evaluation responses over three years - demonstrates ongoing relevance and user need.

National recognition, including awards such as *Deutschland – Land der Ideen* (Germany – Land of Ideas), further supports its legitimacy and visibility.

TRANSFERABILITY

The model is highly transferable due to its digital structure and evidence-informed counselling approach. Its digital, low-threshold counselling format and evidence-informed psychological approach address challenges that are common across many European care systems, including high care burden, limited access to psychosocial support and delayed help-seeking.

At the same time, transferability is closely linked to the specific funding and regulatory framework within which the service operates. In Germany, counselling is delivered under §45 of the Social Code Book XI, which provides a legally defined and publicly funded framework for low-threshold support for informal carers. This framework enables anonymous access, limits documentation requirements and clearly delineates counselling from psychotherapy.

Transfer to other contexts would therefore require functionally equivalent arrangements, such as stable public or insurance-based funding, clearly defined scopes of practice, trained psychological staff, professional supervision and integration with local care and support infrastructures. Without such system-level conditions, the model cannot be transferred as a routine service, but only as a time-limited pilot or project-based intervention.

STRENGTHS

Key strengths of the initiative include:

- low-threshold, anonymous access suited to carers who avoid in-person services
- professional counselling delivered by qualified psychologists
- evidence-informed methodology with documented reductions in psychological distress
- strong reach among carers providing long-term, high-intensity support
- digital format that allows flexibility for carers with limited time
- continuous supervision and stable funding
- broad target group, including carers of people with physical, cognitive and psychiatric conditions
- bridging function for carers waiting for psychotherapy.

WEAKNESSES/CHALLENGES

Limitations include:

- the digital format requires literacy and internet access, potentially excluding some older carers
- the service is available only in German, limiting accessibility for carers with migration backgrounds
- capacity constraints have led to longer response times
- counsellors cannot provide psychotherapy or diagnosis under §45 SGB XI
- systemic gaps remain due to long waiting lists for psychotherapy under SGB V
- as a voluntary counselling service, uptake depends on awareness of the offer, self-identification as a family carer and willingness to disclose psychosocial strain, which creates structural access barriers independent of service quality or capacity
- these structural access barriers particularly affect younger carers and carers of people without a formally recognised care level, limiting outreach to these groups.

POTENTIAL IMPROVEMENTS

Areas for improvement include expanding staffing capacities to reduce waiting times, offering multilingual versions of the counselling service, and developing bridging modules for carers awaiting psychotherapy. Improved structural integration with the therapeutic care system could strengthen continuity of support. Outreach efforts could be expanded to include younger carers and those with limited digital literacy. Enhanced links with local care services could support more explicit care partnerships.

Rather than numerical expansion alone, further scaling of the service would primarily depend on strengthening organisational capacity, securing sustainable funding arrangements and embedding the model more firmly within existing care and support infrastructures.

CONCLUSIONS

The case of *pflegen-und-leben.de* demonstrates how a digital, low-threshold counselling service can effectively address a persistent gap in long-term care: the emotional and psychological burden of informal carers. The initiative was created in response to the observation that carers often experience high levels of strain but have limited access to specialised support. Over the past decade, the service has evolved into a stable and professionally structured component of the German long-term care system, offering tailored psychological counselling rather than psychotherapy, and providing early emotional stabilisation for individuals in demanding care situations.

The service reaches a broad and diverse group of carers, as evidenced by voluntary evaluation data from 1,659 users over three years. Most carers have been providing care for at least two years, many in co-resident arrangements and often for relatives with moderate to high care needs. This user profile underscores the importance of the initiative, as carers in long-term, high-intensity arrangements are at particular risk of emotional overload, isolation and cumulative stress. Through structured counselling, *pflegen-und-leben.de* supports them in articulating emotions, strengthening resilience, recognising personal limits and managing the relational challenges intrinsic to caregiving. At the same time, the overall number of users remains small in relation to the total population of family carers in Germany, reflecting structural access barriers and the voluntary nature of psychosocial support rather than limited relevance or effectiveness of the service.

The initiative also reveals important insights into the functioning of care partnerships. Although it does not directly coordinate formal and informal care, it indirectly facilitates more constructive collaboration by helping carers reframe professional support as a resource, rather than as a sign of personal inadequacy. Stabilising carers emotionally creates better conditions for cooperation with home-care services, 24-hour carers and other actors within the long-term care landscape. As one counsellor described: "*We often tell people to view the care service as a partner, not as competition*" (JT).

One of the key lessons emerging from the case is the importance of early intervention. Carers often delay help-seeking until their situation becomes critical, and many only reach the service after years of accumulated burden. This highlights the need for improved outreach strategies and stronger integration of psychosocial support within the long-term care system.

The initiative also exposes a structural gap between counselling under §45 SGB XI and psychotherapy under §5 SGB V. Some users complete the full counselling cycle and are clearly identified as needing formal psychotherapy; yet many remain on waiting lists for months. As noted by an interviewed: "*There are clients who clearly need psychotherapy, but they remain stuck on waiting lists for months, and we cannot bridge that gap*" (JT). This gap calls for systemic solutions that improve continuity of psychological care, including better integration between psychosocial counselling and therapeutic services, and the development of bridging interventions.

The digital nature of the service makes it resilient, scalable and adaptable to different contexts, including geographic distance, limited mobility and time constraints. Its core components - structured psychological counselling, anonymity, professional standards and cooperation with statutory insurers - make the model transferable to other regions and countries facing similar challenges in informal caregiving.

Overall, *pflegen-und-leben.de* shows that supporting the mental wellbeing of carers is essential for the sustainability and quality of long-term care systems. The initiative contributes to safer, more stable and more resilient care arrangements by addressing the psychological dimensions of caregiving that are too often overlooked. Its long-term integration into the German care system, combined with strong evaluation results, suggests that similar approaches could benefit carers across Europe.

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2. Family Care (Familiale Pflege)

ABSTRACT

The Familiale Pflege *(Family Care)* programme is a care and education initiative developed in North Rhine-Westphalia to systematically support informal carers during the transition from hospital to home care. The aim of the programme is to close a clearly identifiable gap in discharge management by involving relatives at an early stage, providing practical guidance and strengthening them psychosocially. Implementation took place within a triangular agreement between the University of Bielefeld (Faculty of Educational Science), participating hospitals across several German regions (notably Westphalia, Rhineland, Hamburg and Schleswig-Holstein), and statutory long-term care insurance funds. In the final phase of the model project, around 70,000 relatives were reached each year.

The intervention comprises four standardised components: an initial consultation to clarify the family situation, bedside care training in the hospital, home-based care training during the first six weeks after discharge, as well as initial care courses and group sessions for relatives. These components were delivered by specially trained family care nurses ("Pflegetrainerinnen") in both the hospital and the home environment, and were financed through § 45 of the German Social Code XI.

Effectiveness was examined throughout the entire duration of the programme using a multi-level evaluation design (2014, 2015 and 2017). This included annual quantitative surveys of informal carers and family care nurses, qualitative case analyses, written feedback and narrative qualitative materials. The data consistently show that participating relatives gain confidence, expand their care skills, define roles more clearly and experience reduced family strain. A large proportion report an expansion of support networks and a marked stabilisation of the home caring situation.

Key limitations include the fact that hospital participation is voluntary, resulting in uneven nationwide diffusion. Following the transition into regular care, the previously mandatory scientific training for family care nurses was discontinued, which may affect the consistency of quality across institutions. Furthermore, implementation depends heavily on the commitment of individual leaders, which complicates structural sustainability and large-scale transfer.

INTRODUCTION

Name of the good practice: Family Care (Familiale Pflege).

Country of implementation: Germany. Its main focus lay in the federal states of North Rhine-Westphalia, Rhineland, Schleswig-Holstein and Hamburg. Bavaria joined at a later stage of the project.

Implementation level: Regional (implemented in selected regions across four federal states, not nationwide and not in all municipalities).

Leader organisation: AOK NordWest, regional statutory health and long-term care insurance fund within Germany's federal AOK system, responsible for the regions of Schleswig-Holstein and Westfalen-Lippe.

Contacts: There is no central contact person.

Website: There is no central website. The project is being continued in individual hospitals.

Date of data collection: WELL CARE case study interviews, November 2025, qualitative expert interviews conducted in November 2025 with the academic lead who initiated the programme and with senior management of AOK NordWest as the former project partner and implementing organisation.

Description of the organisational structure of the practice:
The scientific conception, leadership and evaluation of the project were carried out by Bielefeld University (federal state of North Rhine-Westphalia), Faculty of Educational Science, Working Group 7 "Pedagogical Counselling", under the direction of Prof. Dr Katharina Gröning. The central practice partners were the long-term care funds AOK Rheinland/Hamburg and AOK NordWest, which provided the financial basis for the model project and, together with the university, organised its implementation in numerous hospitals.

One of the earliest practice experts, who later became a research associate within the project, was Prof. Dr Dorothee Lebeda. In the interview, she describes her role as follows: "*I initially developed the role of one of the first family care trainers and later joined the university as a nursing scientist in order to further develop the project*" (DL).

This perspective illustrates the close interconnection between practical knowledge, scientific development and organisational transfer.

“Familiale Pflege” followed a model-based, three-tiered structure:

1. Scientific coordination (Bielefeld University)

Bielefeld University developed the theoretical and conceptual foundations of the project, coordinated the scientific monitoring and carried out the following functions:

- further development of course, counselling and training concepts;
- scientific training of the family care trainers;
- development of standardised documentation and evaluation instruments;
- regular development and annual review meetings with participating hospitals quality assurance of the programme components (e.g., initial consultation, care course, home-based training).

This scientific supervision was closely interlinked with the practical implementation and ensured continuous implementation research over a period of 15 years.

2. Funding and contractual structure (AOK)

The long-term care funds AOK Rheinland/Hamburg and AOK NordWest were the central contractual partners:

- they financed the educational and counselling services provided within the framework of long-term care insurance (Social Code Book XI, Long-Term Care Insurance, SGB XI), which regulates statutory benefits for people in need of care and their relatives in Germany, including preventive, educational and support services for family carers;
- they were responsible for the annual approval and continuation of the model phase;
- they ensured through contractual agreements that hospitals allocated staff for family-oriented care education.

A notable aspect was the funding of care-pedagogical services within the hospital setting, which was structurally new in this context.

3. Operational level: hospitals and family care trainers

Practical implementation took place in the participating hospitals. The family care trainers working there formed the core of the programme. They were generally:

- registered nurses with professional experience;
- trained through scientific continuing education programmes;
- active in discharge management, on the wards and in the home environment.

Their tasks included:

- conducting the care-pedagogical initial consultation;
- providing individual bedside care training;
- delivering initial care courses;
- offering counselling and support for entire familial networks;
- documenting activities and providing feedback to the project coordination.

The family care trainers acted as an interface between hospital care, long-term care funds and families. They made informal carers visible within the hospital setting and established a systematic form of support during the transition from hospital to home.

In addition, the project's network structure should be highlighted. The Family Care programme was based on a broad network consisting of:

- seven external education partners (responsible for designing and delivering care courses, further training and qualification programmes);
- Angehörigenschulen (education and counselling services for informal carers);
- nursing course instructors and qualified family care trainers;
- municipal and outpatient cooperation partners (home care services, social services and counselling centres).

This network structure facilitated the long-term consolidation of the programme and enabled regional transferability.

START AND STATUS OF THE PRACTICE/INITIATIVE

WHEN DID IT START

The development of the programme began in the mid-2000s and can be divided into a preliminary phase and a formal start-up phase. Between 2001 and 2004, exploratory preliminary studies were carried out in which familial care situations were examined empirically. Bielefeld University analysed who provides care within families, how roles are negotiated and what strains arise.

This early phase is described as follows: "The beginning … was actually in 2005, with the first studies that examined who actually provides care in families (…) and that the available support, such as educational offers, practical instruction and spaces for reflection, were essentially lacking" (DL).

On this basis, the project was formally launched in 2004-2005, initially funded by the Ministry of Health of North Rhine-Westphalia (MAGS). From 2006 onwards, its practical implementation was carried out in cooperation with AOK Rheinland/Hamburg and AOK NordWest; hospitals in the East Westphalia region were the first practice sites.

The initiative developed over a period of 15 years into a large-scale model programme with continuous scientific supervision. Throughout its duration, new hospitals were successively integrated, annual evaluation and development meetings were conducted, and quality assurance instruments were established.

After 15 years, the model programme was transferred into regular care in 2018. The triangular agreements between the university, the long-term care funds and the hospitals came to an end. Since then, hospitals have concluded direct contracts with the long-term care funds, and the services have been available to insured persons of all funds.

However, the previous scientific continuing education largely ceased; institutions now organise qualification processes themselves. This is identified as a weakness*:* "*There is no longer any scientific continuing education (…) this is a real problem, as the family care trainers keep saying*" (DL)*.*

Overall, it is now an established practice model implemented across several federal states, anchored in many hospitals and still in use:

- The central structure (family care trainers in hospitals, counselling and education for informal carers, support over several weeks) remains in place;
- The services have in some cases been expanded (e.g., renewed contact between relatives and the hospital beyond the original six-week period);
- Funding under §45 of the Social Code Book XI (Long-Term Care Insurance) remains stable; this provision establishes the statutory basis for publicly funded low-threshold counselling, education and support services for family carers in Germany.

REASONS FOR STARTING

Several structural problems led to the development of the programme. The interviewed expert and the documents consistently identify three main reasons:

1. Lack of educational, counselling and reflective support for families

The preliminary studies showed that informal carers typically take on care responsibilities without being prepared for them. Opportunities for education, practical training and psychosocial support were largely absent: "*There were few educational offers, little practical instruction and few spaces for reflection (…) and that was the starting point in 2005*" (DL).

This gap concerned both practical care skills and the development of familial roles, decision-making processes and gender equality.

2. Changes in the healthcare system due to Diagnosis-Related Groups (DRGs) and shorter hospital stays

With the introduction of G-DRGs between 2003 and 2007, hospital discharge processes accelerated. This created a new and barely structured transition for families: "*With the introduction of the DRGs, patient flows changed (…) there were transfer forms for residential and outpatient facilities, but no transfer to informal carers*" (DL).

In practice, patients were often "*discharged into the family*" without relatives being prepared for their new responsibilities.

3. Absence of structured support during the transition from hospital to home

Many hospitals reported so-called "*revolving door effects*", meaning rapid readmissions caused by overburden in the home environment. This led to a demand for stabilising forms of support: "*It is often not the medical diagnosis, but the overburdening of relatives. A family care trainer was often able to ease the situation and provide explanations*" (DL).

These gaps in care highlighted the need for a systematic programme of counselling, education and follow-up support. The initiative thus emerged from the combination of scientific insights, changing care structures and the urgent need for assistance for families during the transition from hospital to home care.

TARGET GROUP(S)

The initiative is primarily aimed at informal carers, understood in the sense of an expanded familial concept. This does not refer solely to individual main carers, but to all those who feel responsible and are involved in a care relationship with the person in need of care. This includes not only

traditional family members such as spouses, children or siblings, but also other close persons, such as friends, neighbours or informal supporters.

This broader understanding is based on the sociological concept of "familial". It was deliberately chosen to avoid restricting the intervention to biological or legally defined kinship: "*'Familial' in our concept does not refer to biological or legal family ties, but rather to all those who are connected through a sense of responsibility and mutual commitment*" (DL).

Accordingly, the model project does not position itself as an offer for a single informal carer, but as an approach that strengthens entire familial networks. The aim is to reach several people simultaneously and to promote shared responsibility. The common focus on only one main carer (as found in long-term care insurance) is explicitly criticised within the project, as it narrows the perception of burden and increases the risk of isolation: "*Familiale Pflege does not select one main carer (…) instead, we address all those who feel responsible. Care should be a family project, not a dual care arrangement that leads to isolation*" (MV).

This network-oriented approach is also reflected in the educational and counselling formats offered. Family care trainers support informal carers in clarifying roles, sharing responsibilities and realistically assessing their own limits of strain. The initiative is based on the assumption that care is not only a practical task but also a family-dynamic developmental process. For this reason, informal carers were not only recipients but also contributors to the continuous further development of the programme. Their input primarily took the form of systematic feedback collected during counselling and training sessions, as well as through accompanying evaluations. This feedback informed the ongoing adaptation of formats, content and delivery structures.

This results in a clearly defined picture of the target group:

- informal carers in an expanded, relational familial sense;

individuals involved in familial networks rather than isolated single carers; people who take on, or are expected to take on, care responsibility within these networks.

This conceptual orientation is supported by quantitative evaluation data from the most recent comprehensive programme evaluation (2017). Depending on the indicator, item-specific sample sizes vary across programme formats, ranging approximately between 1,300 and 2,700 respondents.

The evaluation shows that the initiative reaches a broad range of informal carers across different relational roles. Participants included spouses or partners, adult children, siblings, in-laws and other relatives, as well as a smaller proportion of friends and neighbours involved in caregiving networks. In individual care trainings, spouses or partners constituted the largest group of participants

(approximately 51%), followed by carers of parents (around 37%). In group-based initial care courses, adult children accounted for about 31% of participants, while spouses or partners represented roughly 29%.

Women formed the majority of participants (approximately 72-76%), while men accounted for around one quarter (22-26%) of users. Participants spanned a broad age range. Care recipients were predominantly older adults, with a mean age of approximately 77-80 years across programme formats. A substantial proportion of informal carers were of working age, although more than half were not in paid employment at the time of participation, often due to retirement. *(Based on evaluation report 2017.)*

Role of the informal carer/family target group in the development of the programme:

- continuous involvement in evaluations, surveys and interviews; during the model and evaluation phase of the programme (2014-2017), including repeated feedback collected through accompanying evaluations and a learning-effects study;
- identification of typical crises, strains and learning situations;
- contributions to further developments, such as dementia modules, medication studies and training concepts;
- reflection of familial atmospheres to improve counselling processes.

In summary, the initiative is therefore not directed at "the informal carer" alone, but at care arrangements as a whole within the broader family and relational context, spanning the transition from hospital to home. It creates structures that make informal carers visible, offer orientation and enable them to manage the care task jointly and sustainably.

CARE RECIPIENTS

The support services are directed at care recipients of all age groups who are cared for by informal carers. During the project period, the focus lay particularly on very old adults, as care dependency is most common in this group and is often associated with complex care situations and significant strain for informal carers.

In practice, the family care trainers encountered a wide spectrum of care needs: acute impairments following hospital stays, chronic illnesses, dementia-related developments, and situations in which both partners were very old and caring for one another. The project documentation shows that these individuals were particularly likely to experience insecurity during the transition from hospital to home and had a heightened risk of becoming overburdened.

In addition to the dominant group of very old adults, children and adolescents were also included as care recipients, albeit to a lesser extent. A dedicated pilot project focused on care transitions in neonatology, where determining care dependency is more complex and requires specific expertise.

Overall, the target group of supported care recipients includes:

- older adults in advanced old age (main focus of practice);
- individuals with chronic or acute care needs following hospital discharge;
- people with dementia or cognitive impairments;
- care-dependent children, particularly in pilot contexts such as neonatology;
- as the programme was delivered mainly in German, it primarily reached families with sufficient German language skills.

OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE

AIMS

The core aim is to strengthen informal carers during the transition from hospital to home care and to stabilise familial care arrangements in the long term.

Other objectives are:

1. Empowerment of informal carers:

The initiative provides practical care competencies – initially through care courses, later through bedside training and home-based training – as well as psychosocial orientation for family decision-making processes: "*We really need to start at the bedside (…) before we can begin training, we need to understand the family*" (DL).

2. Safeguarding discharge and transition management:

In response to shortened hospital stays and the absence of structured handovers to relatives, the programme introduced structured initial consultations, systematic involvement of relatives within the hospital, and follow-up support in the home environment in order to prevent overburden and avoid readmissions.

3. Strengthening familial networks:

The focus is not on individual main carers but on all those who feel responsible. Key elements include clarifying roles, sharing responsibilities and preventing isolating care constellations. As the

AOK states: "*Care should be a family project (…) not a dual care arrangement that leads to isolation*" (MV).

Many innovations emerged from the feedback of the family care trainers, who acted as practice-oriented "co-researchers" and provided insights into needs and necessary adaptations.

HOW DOES IT OPERATE

The implementation of the Family Care programme is based on a structured cooperation between long-term care funds, the university and hospitals. Its central element is the family care trainers, who support informal carers throughout the entire transition from hospital to home care.

1. Operational procedures:

The intervention consists of four clearly defined components that were implemented in all participating hospitals:

- an initial consultation to clarify the family situation, sources of strain and role expectations;
- bedside care training in the hospital, in which practical care skills are taught and practised together;
- home-based care training during the first six weeks after discharge, supporting the transfer of skills into everyday routines;
- initial care courses and group sessions for informal carers, offering basic care competencies, orientation and psychosocial support.

2. Resources and roles:

The family care trainers are experienced nursing professionals employed by the hospital and working independently within discharge management. They have many years of professional practice and are responsible for delivering all components (from the initial consultation and courses to bedside training and home visits).

3. Financial framework:

During the model phase, the project was based on triangular agreements between long-term care funds, the university and hospitals: the long-term care funds (financing courses, training sessions, initial consultations and home-based instruction under § 45 SGB XI); Bielefeld University (development of the programme components, training of the family care trainers and evaluation); and the hospitals (deployment of the family care trainers).

Since 2018, direct contracts have existed between long-term care funds and hospitals; the services have been maintained, while the scientific supervision has ceased.

MAIN OUTCOMES

The available evaluations combining quantitative survey data and qualitative feedback, consistently demonstrate a clear strengthening of informal carers as well as lasting improvements in the transition from hospital to home care. The findings are based on accompanying multi-level evaluations conducted during the model phase, including repeated standardised surveys of participating informal carers and qualitative feedback from counselling sessions, training formats and interviews (University of Bielefeld, 2015; 2016; 2018).

Strengthening informal carers (competence, self-efficacy, orientation):

Informal carers gain practical confidence, orientation during transitions and trust in their own role. Their empowerment becomes visible in the ability to manage acute strains, take on new tasks in a structured way and organise care independently. AOK describes this as follows: "*Education helps to cope with crises (…) a family can find its bearings again*" (MV).

The evaluations conducted over several years confirm this effect (based on evaluation reports by the University of Bielefeld, published in 2015, 2016 and 2018):

- The evaluations conducted between 2014 and 2017 confirm this effect. Standardised participant surveys among informal carers taking part in bedside training in hospital and home-based follow-up training show consistently high satisfaction ratings. In 2017, 99.1% of participants reported that the bedside training in hospital was easy to understand (n = 543-1,030, varying by item), and 99.3% reported the same for the home-based training after discharge (n = 431-842, varying by item).
- Participants in these evaluations were predominantly informal carers of older relatives with moderate to high care needs, many of whom were engaged in care over longer periods and often alongside employment.

Role clarification and familial stabilisation:

The initiative supports informal carers in adopting new roles and in sharing the responsibilities of familial care arrangements. The learning effects study shows that relatives most frequently identify role learning as a key benefit:

- clarifying their own role as a caring person,
- positioning themselves within the family,
- developing a strengthened identity as a "caring family".

Improved transition quality and reduced overburden:

The combination of an initial consultation, bedside training and home-based support reduces typical overburdening situations following discharge. Evaluations show that informal carers are able to carry out care tasks more safely after receiving guidance.

Relief of family conflicts and development of support networks:

Family counselling conversations have a stabilising effect on intra-family processes. The evaluations document: reduction of family conflicts (80.4%) and the development of additional supporters within the network (81%), as reported by participating informal carers. This strengthens not only the immediate care situation but also long-term coping mechanisms.

Organisational learning within the hospital:

The model leads to the systematic involvement of relatives in discharge management, establishes a clear role for family care trainers and improves coordination between wards, social services and families. Continuous feedback from practice resulted in the development of new components (e.g., initial consultation, home-based support), which were later incorporated into regular care.

CARE PARTNERSHIPS

The initiative uses the term "*care networks*" rather than "*care partnerships*", but it pursues functionally similar approaches: family care trainers work at the interface between the hospital and the family and systematically involve relatives in discharge management. The aim is to establish stable care arrangements and to manage the care situation jointly.

Care is understood as a network task, not as a dual relationship between one carer and one person in need of care.

The family care trainers support informal carers in clarifying roles, managing everyday life, building support circles and coordinating with professional actors. The extent to which this collaboration is embedded varies between institutions: in some hospitals it is systemically anchored, while in others it depends more strongly on individual trainers.

SUSTAINABILITY

The initiative has been part of regular care since 2018 and is implemented on an ongoing basis through contracts between long-term care funds and hospitals. Funding continues to be provided through § 45 SGB XI, enabling stable refinancing of course, training and counselling units. As a result,

the model is structurally anchored and is offered continuously in North Rhine-Westphalia and in the other participating federal states.

However, with the transition into regular care, the originally mandatory scientific continuing education for family care trainers was discontinued. Lebeda describes this as a key weakness in terms of sustainability: whereas family care trainers previously received systematic qualifications in nursing science, pedagogy and family dynamics, today any nursing professional appointed by the hospital can assume the role. This means that a standardised curriculum and clear qualification requirements are lacking. Lebeda summarises this as follows: "*We no longer have a structured curriculum (…) any nurse can take on the function. This is a weakness for the future*" (DL).

Thus, while the initiative is financially and organisationally stable, its long-term quality depends heavily on the individual institution and its willingness to ensure qualifying training independently.

TRANSFERABILITY

The model programme demonstrates a high degree of transferability. This is evident both in its actual expansion to several federal states and in the structural factors that facilitate its transfer to other regions.

1. Demonstrated transferability (actual transfer within Germany):
    - Initially introduced in the East Westphalia-Lippe region, followed by expansion across the whole of North Rhine-Westphalia;
    - Subsequent extension to Hamburg and Schleswig-Holstein (through the merger of the AOK funds and targeted continuing education structures);
    - More than 400 participating hospitals and around 70,000 relatives reached per year demonstrate a stable, scaled transfer practice across regions;
    - The concept is currently being taken up in Bavaria, representing a further transfer to an additional federal state.
2. Factors enabling transfer:
    - Strong arguments and research findings demonstrating benefit, effectiveness and improvements in care provision;
    - Financial incentives provided by the long-term care funds (SGB XI / § 45); funds must be clearly identifiable and accessible;
    - Leadership figures within hospitals or care funds who actively support the programme and make implementation decisions;
    - Large-scale events and network meetings that provide motivation and professionalisation for staff working in discharge management and in the support of informal carers; according to Lebeda, such events often act as catalysts for regional introduction.

3. Structural features facilitating transfer:
    - Standardised instruments that can be combined in modular ways (initial consultation, bedside training, home-based training, quality checks, care courses, etc.);
    - An established triangular model between the AOK, hospitals and the university, which clearly regulates financial and organisational responsibilities; this model is fundamentally replicable.
4. Challenges and limitations:
    - Lack of a standardised curriculum in current regular care; training requirements are not regulated consistently across institutions, which may weaken the quality and consistency of transfer;
    - Economic orientations within hospitals (arguments about profitability, staff shortages) limit decision-making scope; individual hospitals or care funds require committed decision-makers to enable implementation.

STRENGTHS

Many strengths have already been presented elsewhere in the case study report. The following therefore provides only a very concise summary of the central aspects:

- High effectiveness and satisfaction:

Very high feedback regarding the comprehensibility and usefulness of the training sessions (99% in the hospital, 99.3% at home). Reduction of family conflicts (80–81%) and development of supportive networks (81%);

- Evidence-based and practice-tested components:

The intervention combines clearly structured elements such as the initial consultation, bedside training, home visits, family counselling, quality checks and courses (all interconnected);

- Lifeworld-orientated and family-oriented approach:

The model integrates psychosocial, care-related and familial aspects and strengthens everyday competencies, role clarification and intergenerational coping processes;

- Sustainable qualification through scientific continuing education (model phase):

During the project phase, a systematic and interdisciplinary continuing education programme for family care trainers ensured high quality and professional confidence;

- Widespread implementation and high reach:

More than 400 participating hospitals and around 70,000 relatives reached annually represent an exceptionally high degree of implementation;

- Strong integration into discharge management:

The model addresses a relevant gap in the transition from hospital to home care and reinforces interface work between professional groups;

- Continuous development through evaluation:

Regular analysis of feedback from informal carers, project data and practical examples led to ongoing adjustments and improvements.

WEAKNESSES/CHALLENGES

Despite its wide implementation, the documents and the interview highlight several structural *weaknesses and challenges*:

- Lack of binding qualification requirements (central weakness):

With the transition into regular care, the mandatory curriculum for the further training of family care trainers was discontinued: "*The contracts do not state that one must be qualified (…) this is the weakness. As a result, the quality of implementation today depends heavily on the individual hospitals*" (MV).

- Limited visibility of family care trainers in everyday ward routines:

Prof. Lebeda reports that family care trainers regularly had to "*make themselves known*" (DL) on the wards, as not all professional groups involved them systematically. This reveals a coordination problem in day-to-day interprofessional work.

- Variation in organisational integration across hospitals:

Whether family care's trainers function as an integrated part of discharge management or as "lone fighters" varies considerably. This leads to uneven structures and affects the quality and consistency of implementation.

- Dependence on individual leadership and motivation:

Transfer often depends on individual decision-makers (e.g., hospital management, AOK staff with personal experience of caregiving). This makes widespread adoption more difficult in federal states with less institutional support.

- Structural access limitations for seldom-heard groups:

Access to the programme depends on its local implementation within participating hospitals as part of discharge management; where the programme is not offered, access is not available. In addition, as the service is delivered primarily in German, language barriers may limit accessibility for some informal carers. The available evaluation reports do not provide differentiated data on migration experiences or language needs.

The challenges that emerged during the model and regular phases have been fully described in the previous sections (from “Sustainability” to “Weaknesses/Challenges”). Beyond these, no additional difficulties were identified in the available documents or in the interview.

The main challenges concerned the inconsistent organisational integration of family care trainers, the absence of mandatory qualifying training, and structural differences between institutions and federal states.

The experiences described in the available documents and in the interview can be condensed into a small number of key lessons learned. No further independent or new insights appear that are not already presented in sections from “Sustainability” to “Weaknesses/Challenges”.

POTENTIAL IMPROVEMENTS

Key lessons learned from the overall project are:

- Education as a key component:

qualified instruction, spaces for reflection and ongoing continuing education for family care trainers are crucial for quality and impact;

- Regular networking:

exchange formats and large-scale events strengthen motivation, professionalism and transferability;

- Structural embedding is necessary:

the initiative is most effective when family care trainers are organisationally anchored and visible within interprofessional structures;

- Transfer requires incentives and leadership:

research findings, financial incentives and supportive leadership figures promote implementation in further regions.

- Expanding reach to seldom-heard groups:

improving reach to informal carers who are less likely to be addressed through hospital-based, German-language services, including carers with migration experiences, for example through multilingual materials and stronger cooperation with community-based support structures.

CONCLUSIONS

The major lessons learned from this long-term initiative have been outlined in detail throughout the previous sections (particularly “Strenghts” onwards). Taken together, four overarching insights became evident:

1. Qualified staff education is essential:

Systematic training in family dynamics, communication and pedagogical approaches is crucial for enabling staff to support informal carers effectively. Without a structured curriculum, the quality of implementation varies substantially.

2. Continuous professional support is needed:

Regular exchange formats, case discussions and supervision help staff handle complex family situations (including palliative crises, poverty, migration or neonatal challenges) and sustain their own resilience.

3. Strong organisational integration improves outcomes:

The role of the family trainer works best when it is clearly embedded in the discharge process, supported by leadership and recognised by all professional groups involved.

4. The initiative does not spread automatically:

Despite its proven effectiveness and successful adoption in several federal states (North Rhine-Westphalia, Hamburg, Schleswig-Holstein and, more recently, Bavaria), the model has not diffused nationally. Its expansion depends heavily on the initiative of individual federal states and committed key actors within hospitals or health insurance funds. Many regions remain unaware of the programme, indicating that transfer requires proactive dissemination and political support.

Together, these lessons underline that the effectiveness and sustainability of the initiative rely on professional qualification, structural embedding, continuous support and active efforts to promote transfer and adoption beyond the initial implementing regions.

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We also gratefully acknowledge the contribution of Maik Vonau (MV), Head of the Long-Term Care Department, AOK NordWest**,** who participated in the expert interview and provided valuable perspectives on the contractual structure, implementation processes and organisational requirements from the viewpoint of the care insurance fund. His expertise substantially enriched the understanding of system-level conditions enabling this initiative.

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3. Standard Format for the Individualised Care Plan (Progetto Assistenziale Individuale - PAI)

ABSTRACT

The practice described in this case study is the Standard Format for the Individualised Care Plan (PAI) of the Union of Terre d'Argine (Province of Modena). This standardised format is used by all public, social and health services to identify the needs of the dependent person, recognise the informal carer (distinguishing between main and substitute carers), and assess their needs. Its purpose is to develop an Individualised Care Plan providing support for both the dependent person and the carer.

A key innovation of the Standard Format is the structured carer assessment, with particular attention to emotional stress and psychological needs. This enables formal recognition of the carer, assessment and documentation of their needs and health risks. The identification of main support needs, and the design of personalised support interventions are also considered.

The initiative aligns with longstanding regional policies aimed at recognising, valuing, and supporting family carers. Emilia-Romagna was the first Italian Region to approve legislation supporting carers in 2014. With law nr. 5/2024, Lazio Region also adopted a similar measure.

The Standard Format for Individualised Care Plans, as implemented by the "Social Services – Older and Disabled People" sector and the Home Care Support Desk of the Union of Terre d'Argine (administrative union of four municipalities: Campogalliano, Carpi, Novi di Modena and Soliera) can be considered a positive practice. This area is notably advanced in recognising the rights of family carers of frail and dependent persons. The tool's relevance to care partnerships is also evident, as it facilitates collaboration between formal providers and informal carers and encourages tailored care pathways benefiting all the involved parties.

INTRODUCTION

Name of the practice/initiative: Standard Format for the Individualised Care Plan (PAI) of the Emilia-Romagna Region in the experience of the Union of Terre d'Argine (Province of Modena) - in Italian: Format Unico per il Piano Assistenziale Individualizzato (PAI) della Regione Emilia-Romagna nell'esperienza dell'Unione delle Terre d'Argine (Provincia di Modena).

Country of implementation: Italy, Emilia-Romagna Region, Union of Terre d'Argine (Province of Modena).

Implementation level: Local/Regional.

Leader organisation(s): "Social Services - Older and Disabled People" sector of the Union of Terre d'Argine (which includes four municipalities in the Province of Modena: Campogalliano, Carpi, Novi di Modena and Soliera) (Settore "Servizi Sociali - area Anziani e disabili" dell'Unione delle Terre d'Argine).

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Website:
For regional information (Emilia-Romagna) on the Standard Format for Individualised Care Plan (PAI), see Regional Determination/Resolution 15465/2020 "Approval of forms and technical tools for the recognition and support of family carers" (Approvazione schede e strumenti tecnici per il riconoscimento e sostegno del cargiver familiare):

https://www.regione.emilia-romagna.it/caregiver/operatori/caregiver-per-operatori/determina_15465-2020_strumenti_cf.pdf.

For further information and to download the relevant forms relating to the PAI and carers:

https://caregiver.regione.emilia-romagna.it/.

For information at national level, see Law 33/2023 "Delegation of powers to the Government in the field of policies in favour of older people", which mentions (Article 1, paragraph 1, letter d, and in the notes to Article 1) "individualised integrated care plans (PAI)":

https://www.gazzettaufficiale.it/eli/id/2023/03/30/23G00041/SG.

Date of data collection: WELL CARE focus group interview November 2025. In addition, for realising the case study report, information retrieved from the references listed at the end of this document have been analysed, mainly those included in Emilia-Romagna Regional Determination/Resolutions (of 2017, 2019, 2020), as well as in other sources (e.g. ANFFAS, 2023).

Description of the organisational structure of the practice:
The Standard Format for Individualised Care Plan (PAI) used in the Union of Terre d'Argine (Province of Modena) represents a particularly advanced local initiative, supporting family carers in the Emilia-

Romagna Region, a highly active Region in promoting the approach throughout its territory. The case study also aims to highlight strengths and weaknesses of the practice's operation. Precisely, this practice aligns with longstanding regional policies aimed at recognising, valuing and supporting family carers. Indeed, in 2014 Emilia-Romagna was the first Italian Region to approve a law supporting carers[2].

The content of this report is based on the analysis of online documents (listed in the "Bibliographical references" section) complemented with data collected during a focus group conducted via videoconference on 10 November 2025. Participants included the representative and two social workers from the "Social Services – Older and Disabled People Area" of the Union of Terre d'Argine, as well as the social worker representative of the Union's Home Care Support Desk, managed by the "Anziani e Non Solo" social cooperative to represent an example of service using the PAI model in its practice. The text also includes information on the national Standard Format/PAI model as contextual background, along with selected quotes from the focus group discussion; participant initials are indicated at the end of each quote. The "Acknowledgements" section lists the focus group participants' names and affiliations.

The Standard Format for the Individualised Care Plan (PAI) was first introduced by the Emilia-Romagna Region through the Regional Council Resolution 2318/2019 "Measures to Support Carers". Subsequently it was mentioned and envisaged by the Italian law through various regulations, the most recent of which are the aforementioned Law 33/2023 (Article 1) and its implementing Legislative Decree 29/2024 (Article 39) (for further details on the various regulations, see the following section).

This standardised form must be used by all public social and health services to identify the needs of the dependent person, recognise the informal carer (distinguishing between the main carer and any substitutes, where present), and assess their needs. Its purpose is to develop an Individualised Care Plan (PAI) (ANFFAS, 2023) that provides support for both the dependent person and the carer.

One of the most significant innovations of the Standard Format concerns the structuring of the carer assessment, with particular attention to the emotional stress and psychological needs of the carer. Specifically, the section dedicated to carers includes:

- An "Identification Form" including carer's personal details;
- Results of the carer stress assessment (using various tools: the Zarit scale for first-level assessment; the Caregiver Burden Inventory-CBI, Parenting Stress Index, and Perceived Stress Scale for second-level specialist in-depth assessment);

[2] Regional Law No. 2/2014 "Regulations for the recognition and support of family carers (persons who voluntarily provide care and assistance)".

- A summary of carer's needs;
- Support objectives for the carer;
- Activities and interventions for the carer.

Therefore, this section enables carer's formal recognition, the assessment and documentation of their needs and health risks, the definition of their main support requirements, as well as the design and implementation of personalised support methods.

Where a private family assistant/migrant care worker provides care to the dependent person, his/her recognition from the services is required. They also need to assess their needs and stress levels. If necessary, services should also identify support objectives and implement specific support and training interventions (including information and training initiatives, mentoring, and coaching). In practice, the social workers involved in implementing the practice collaborate closely and in an interdisciplinary manner with other professionals and services, including:

- The integrated social and health unit for multidimensional assessment (Unità di Valutazione Multidimensionale-UVM), in which various professionals (such as doctors, nurses, and social workers) first meet independently to assess the strengths of the frail person and develop an initial support plan. Eventually, they meet with the family to share the assessment, discuss and agree on the support objectives;
- The Home Care Support Desk, which is the public service aimed to support informal carers living in the area of the Union of Terre d'Argine. The service, while being integral part of the local public social service system, is managed by the social cooperative "Anziani e Non Solo" as a contractor of the Union of Terre d'Argine.

The latter, as reported by its representative who participated in the focus group, provides "home support for family carers of frail, older or disabled people, who are accompanied in their orientation and access to services" (AM). According to another focus group participant: "For some time, our approach has been characterised by integrated work between multiple social and healthcare professionals" (ST).

START AND STATUS OF THE PRACTICE/INITIATIVE

WHEN DID IT START

The introduction of the Standard Format for the Individualised Care Plan (PAI) is part of a regulatory process initiated by Emilia-Romagna Regional Administration that, since 2014, has progressively recognised the role of the family carer as an integral part of the social and health care of the older, disabled or frail person being cared for. The aforementioned Regional Law 2/2014 of Emilia-

Romagna was the first in Italy to introduce this approach, expressly referring, in Article 2, to the recognition of carers within the PAI.

This was followed by other regional (Emilia-Romagna) and national regulations. The most important are:

- The implementation guidelines set out in Regional Council Resolution 858/2017, which stipulate that family carers must be formally identified and actively involved in the process of defining, implementing and evaluating the life and care plan for the person being cared for;
- Regional Council Resolution 2318/2019, which, as already noted, provides for the development of a Standard Format for the drafting of the PAI containing a section dedicated to the carer;
- Law 234/2021, which establishes (Article 1, paragraph 163) that the PAI must contain "an outline of support measures calibrated to the intensity of need, specifying the responsibilities, tasks and work methods of the health, social and care workers involved, as well as the contributions of family members and other collaborating parties".

REASONS FOR STARTING

Over time, various models and tools have been developed to assess the needs, requests and resources of carers within the Individualised Care Plan (PAI) framework for frail persons. This has brought greater consistency to the recognition and of support to family carers, starting from the multidimensional assessment of the care recipient and extending to dedicated needs assessments and support measures for carers themselves. These aspects, set out in Resolution 15465/2020 of the Emilia-Romagna Region, were also highlighted by a participant in the focus group: "*The Standard Format for drafting the PAI is a response to the need to regulate the questions asked by family carers*" (AM).

Specifically, Resolution 15465/2020 approved a standardised package of forms and technical tools for the recognition and support of family carers in accordance with Regional Council Resolution 2318/2019, including the following:

- A standard format for drafting the personalised assistance and care plan containing a clear explanation of its essential elements, with clear identification of the carer's needs in a specific section;
- A format for the aforementioned "carer section" containing identification data and relevant information on the caregiving commitment, family and social network, stress assessment, needs analysis and identification of objectives and support measures for the carer;
- A family carer recognition form (in the form of a self-declaration by the carer) as a functional tool to facilitate the carer's access to health, social and educational services.

Recently, a national legislation aimed at reforming policies for older people (Law 33/2023; Implementing Legislative Decree 29/2024) mentions PAI as a tool for a nationally unified multidimensional assessment designed to ascertain older care recipients and their families' needs (including carers). Nonetheless, a national standard format has yet to be developed for this purpose.

TARGET GROUP(S)

The PAI and its Standard Form target two main groups: the non-self-sufficient population and their family/informal carers (including young carers, working-age carers not in paid employment, older carers, and working carers) or private care assistants/migrant care workers. Carers receive dedicated services to support them in their caring role.

Professionals involved in drafting the PAI (such as social workers, nurses, physiotherapists, doctors, and other health, social and administrative staff) are also indirect beneficiaries of this practice.

Regarding those accessing the "Social Services – Older and Disabled People" department of the Union of Terre d'Argine, which manages the Standard Form through the Home Care Support Desk, a focus group participant raised concerns about the growing number of people with care needs. Issues span all areas of intervention but particularly involve behavioural disorders, including among people with disabilities who are ageing and "*need greater social and health care*" (ST).

Another participant adds that one of the typical targets has always been families of people with disabilities since birth, who face care situations that are "*complex from both a health and care point of view, putting pressure and stress on the family system*" (EB). In such cases, family members "*think of themselves as parents, fathers, mothers, brothers or sisters*" just like other families, and find it very difficult to "*become aware that they are carers*" (EB). This awareness mainly occurs when the disabled person becomes an adult and remains in the family.

A shift over time has been observed among families accessing services. In the past, these were often extended families with large informal networks and a strong capacity to care for frail relatives. Today, families increasingly "*turn to services to request recognition of their rights and support, in order to prolong their role as carers able to provide assistance*" (EB).

Many families seeking support also include ageing carers, whose primary concern is the fate of their family member when they become too old to provide care or are "*no longer there*" (EB).

Another target group comprises lower-middle-class families who require formal support to organise care and ease the burden on carers. Unlike wealthier families, who typically engage services less frequently and arrange care privately, these families depend on formal assistance.

A further emerging group accessing the Home Care Support Desk is young carers (such as siblings or grandchildren of frail persons) who contribute to the care of a loved one. They are receiving growing attention as awareness increases that, beyond the main carer, "*there is a whole 'family system' that plays a significant role and struggles to provide care*" (AM).

The Support Desk is also seeing more frequent visits than in the past, albeit still a minority, from people of foreign origin, usually well integrated and with children aged 0-8 with disabilities, who seek "*recognition of their role as family carers*". However, for families of foreign origin who are less integrated or have lower levels of education, access to services is reduced. A social worker highlights the risk that "*children with after-school care needs stay at home with mothers who do not work and who have a limited circle of people with whom to interact*" (EB).

CARE RECIPIENTS

The PAI Standard Format is aimed at the general population of any age with:

- physical disabilities (caused, for example, by frailty, accidents, illness, etc.);
- psychological/mental health problems (e.g. depression, anxiety, or those involving significant limitations on autonomy, such as personality disorders, bipolar disorder, schizophrenia, etc.);
- cognitive disorders (e.g. Alzheimer's, dementia, etc.).

One participant highlighted how the types of pathology and disability among service users have changed over the past 20-30 years. Whereas cognitive or motor disabilities were once more common, behavioural disorders now predominate, affecting not only younger age groups but also older people. This includes people with psychiatric conditions who, as they age, "*require a completely different approach to the one that services were used to providing*" (ST). A related development is the growing number of service users "*with disabilities who are seniors, around 70 years old, who are beginning to experience significant health problems and healthcare needs*" (EB).

For minors with severe disabilities since birth, a notable difference exists between health and social services. Health services provide support based on needs. However, families have "*more difficulty even understanding what can be asked of [social services], also changing the points of reference to turn to*" (EB). One example involves vulnerable minors, for whom the child neuropsychiatrist serves

as the sole point of reference. When these young people reach adulthood, "*this figure disappears*" and families become disoriented, as "*they no longer know who to turn to*". The situation is even more challenging for foreign families who face communication barriers due to limited Italian language skills (EB).

OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE

AIMS

The PAI is the tool through which professionals compile the Standard Format plan based on elements emerging from the UVM's multidimensional assessment. This plan defines objectives, interventions, available resources, other parties involved, and the timing and methods for verification. The carer section enables formal recognition of the carers whilst identifying their needs, health risks, and personalised support measures.

The representative of the Home Care Support Desk of the Union of Terre d'Argine clarifies that the Standard Format's objective "*is to broaden the view of the 'family context' that provides care, highlighting its role*" beyond the mere taking charge of the person by services. A paradigm shift has occurred in how carers are viewed, from "*someone who does things, who provides assistance, to someone with their own needs*". These needs must be identified and protected "*before the whole care system collapses, because if the carer is no longer able to provide assistance, it is a big problem*" (AM). If the carer's physical and mental health are compromised, the conditions necessary to continue home care are no longer met.

During the focus group, the representative of the Social Services of the Union of Terre d'Argine emphasised how this geographical area has always been "*very virtuous in responding to various care needs, various targets, various requirements, and attentive to listening to care needs. It is proactive, even in questioning itself and experimenting with new approaches*" (ST), including the PAI. These considerations highlight the innovative potential of the Standard Format experience, both locally and across Emilia-Romagna. As noted, this was the first Italian Region to develop policies recognising the needs and priorities of family carers, an approach still evolving in other Regions and at the national level.

A further development is the establishment of productive relationships between key stakeholders in the Terre d'Argine area, including health and social services and the Third sector. This creates a support network addressing not only the long-term care needs of frail individuals but also the mental wellbeing of their family and informal carers.

HOW DOES IT OPERATE

The PAI is a standard format developed by the Emilia-Romagna Regional Administration in use in all public social services across the Region. Having been adopted formally with Regional Determination nr. 15465 of 10/09/2020, since then it was progressively introduced in the practice of social workers. In the year 2021 the Region has organised webinars to present the model and its use to professionals employed in local services.

Regarding UVM organisation and daily procedures, social workers from the "Social Services – Older and Disabled People" sector describe the various forms contained in the Standard Format. Several have been developed for the non-self-sufficient population, such as the Barthel scale (Mahoney et al., 1965), which measures the degree of dependency, and the Zarit scale (Chattat, et al., 2011), which evaluates carer stress.

Completing these forms requires operators to have thorough knowledge of the family, as well as sensitivity in asking certain questions, as some of which may be difficult for carers to answer, particularly when caring for people with disabilities. For example, asking the parent of a person with a disability since birth how much they feel limited by their family member "*is like blasphemy*". Operators must therefore explain that these questions are primarily designed for older people, and that carers should give the answer "*that most closely reflects how they feel*" (EB).

According to social workers, completing these forms for older people represents "*a kind of sharing of plans*" (EB). The needs of frail individuals are assessed by various UVM professionals, while requests from families are handled by Social Services. Collaboration between the two structures makes it possible to "*outline together what constitutes a support plan for the person*" (CB).

When drafting the PAI for people with disabilities, there is an emphasis on sharing it with families to achieve a form of co-development: "*we can create the best care plan in the world, but if the family does not agree with it, because it is not what they imagined or they have other ideas, there is a problem*" (EB). The aim is to "*allow family members to continue to have their own living and working spaces*", with the security that "*a specific, separate and independent pathway for their family members with care needs exists*" (EB).

The representative of the Home Care Support Desk explains how carers complete the self-declaration form: "*people can come to us spontaneously to ask to be recognised as carrs, putting into practice a sort of 'political' act of awareness*; *or they are sent to our Support desk by other people, but completely unaware of their rights*" (AM). In the latter case, operators explain to carers all the support service options before completing the form. This is "*an entirely voluntary tool, as it*

is a self-certification, i.e. it is not a sine qua non condition for accessing the Support desk" (AM). Carers can also complete forms themselves on paper or via the Region's website. However, focus group participants noted that operator assistance is preferable, as some questions are not immediately clear.

For example, regarding the Zarit scale, one operator noted how carers "*generally tend to mask and downplay their real emotional state*", often expressing "*distrust, shame, embarrassment and guilt*" when answering, especially when they are old themselves and unable to provide the care they would like (CB).

According to focus group participants, the main funding source for the PAI Standard Format is the Regional Fund for Non-Self-Sufficiency (FRNA). This covers all needs, services and projects for older people and people with disabilities, including home care support and access to day and residential social welfare services.

Additional funds used to finance the initiative include:

- National Fund for Non-Self-Sufficiency an instrument established in Italy (Law 296/2006) to finance services and economic contributions intended for non-self-sufficient people (elderly and severely disabled) and their carers, with the aim of supporting their permanence at home and preventing institutionalization, through integrated social and health interventions managed by the Regions.
- After us Fund, a national fund aimed to support initiatives for severely disabled persons who lack family support after the death of their parents.
- Independent Living Fund, for the promotion of independent living and social inclusion of people with disabilities.

MAIN OUTCOMES

Regarding measurement and evaluation, while comprehensive national-level assessment is not yet available, the Emilia-Romagna Region, General Directorate of Personal Care, Health and Welfare Social and Health Integration Area - Non-Self-Sufficiency has evaluated the use of resources and tools for carer recognition and support (including the Standard Format) for 2020-2021, in compliance with Resolution 15465/2020.

The regional report revealed significant territorial differences in implementation as at 31 December 2021 (Emilia-Romagna Region, 2020). In some local health authorities, all districts had begun using the forms and tools, including the carer recognition/self-declaration form, the standardised personalised project format, and the carer section with needs and Zarit forms. Actions were also undertaken to involve social workers responsible for the case (ASRC) and other professionals (e.g. nurses, psychologists, etc.), with whom the aims and instructions for using the tools were shared; these are now attached to service files and documentation. In other local health authorities, only some districts had fully integrated the tools into their access and care pathways. In certain areas, the recognition and Zarit forms were not yet in use, and the number of personalised plans with a carer section remained low.

Overall, the report highlighted a fragmented situation across the Region regarding use of the tools approved by Resolution 16465/2020, including the PAI Standard Format. It also outlined the main relief and support measures available to family carers to improve their mental wellbeing and resilience: relief interventons, support initiatives in complex or emergency situations (at home), psychological and socio-relational support programmes, information and training measures, and targeted measures for specific groups (e.g. young carers).

CARE PARTNERSHIPS

According to focus group participants, the PAI Standard Format has the potential to promote care alliances between informal carers and long-term care providers (including sometimes also Third sector actors) in various ways.

On one hand, the process leading to the definition of the PAI supports the development of a partnership between the care recipient, the informal carers/families and the social workers.

While the alliance is built through the signing of a shared project with the family, the objective pursued by focus group participants and the services in which they operate is to "*keep this alliance alive and strengthen it in a mutual relationship of trust and esteem. Social workers are very good at working alongside vulnerable people and their families, being present, monitoring the situation, supporting and accompanying them in their life project so that it can increasingly respond to their needs and characteristics*" (ST).

First and foremost, the alliance built with the family allows for "the signing of a shared project", in that "the PAI is drawn up by several parties (family doctor or pediatrician, nurses, social workers, the patient or his/her legal representative, etc.) in order to achieve the objectives, respond to needs and, in some way, also to the mutual expectations" of the family and the operators (ST).

Secondly, when social workers participate in UVM activities, they first inquire about the availability of funds and resources to provide immediate responses to the care needs of vulnerable users and their carers, at least for emergencies. However, it is not always possible to provide a concrete response or immediate relief to families' explicit requests in a short time, due to actual resource availability. In this regard, one participant states that "*alliances are more or less strong depending on the need to which a concrete response is given*" (ST). In such cases, social workers help families understand which needs can be met immediately and which later, proposing alternative solutions and support opportunities in the meantime.

On the other hand, the development of the PAI is also an opportunity to develop organisational partnerships between different professionals and services, both involved directly in the assessment of carers needs through the UVM or later, in the implementation phase. Indeed, social workers can also refer families to initiatives promoted by Third sector associations, such as "*respite weekends, summer holidays, parties, dinners, cinema trips*" financed with available funds (ST). These collaborations between services and Third sector actors create an expanded territorial support network that pools resources to meet the needs of carers and their families.

SUSTAINABILITY

Long-term sustainability was also discussed. The PAI Standard Format is funded through the health system and national or regional/local public funds, and its sustainability is generally assured since services can submit it to families at no additional cost. However, funds for implementing support actions (e.g. respite, psychological support) are one-off and available only until exhausted, with no guarantee of future allocation.

A social worker confirms that "*the issue of funding is one that may play a somewhat particular role in the actual implementation*" of this initiative. However, the objective pursued by the Social Services of the Union of Terre d'Argine "*is broader in scope*". Even when immediate responses are not possible, "*the relationship of trust that is established with families, based on honest and transparent dialogue, remains in place and makes it possible to find other strategies or to manage any critical issues that arise*" (EB), including those relating to fund availability. Another participant added that "*if a person has entered the service network, the PAI is sustainable in the long term, until new social and welfare needs arise that require a review of the project itself*" (ST).

TRANSFERABILITY

Regarding potential transferability, eight Italian Regions (including Emilia-Romagna) have legislation on family/informal carers, which may facilitate the adoption of the PAI Standard Format elsewhere. The practice also has broader national potential, particularly if similar forms are developed under recent legislation reforming policies for older people. This legislation mentions the PAI as a tool for unified multidimensional assessment of the needs of older people requiring care and their families, including carers.

More broadly, the Standard Format supports professionals in assessing carer needs alongside those of care recipients and guides them in planning responsive actions. In this sense, the practice is scalable, with scope for national and local adaptations. The head of the "Social Services - Older and

Disabled People" sector of the Union of Terre d'Argine' considers the Standard Format transferable to other settings and believes this is desirable as "*it is a good practice of social and health integration*" (ST).

The representative of the Home Care Support Desk adds that "having practices that work, such as the Standard Format, also attracts the attention of those who do not yet use them or do not know how to design and use them" (AM). She gives two examples of transferring not the tools themselves (which already exist at regional level) but the operators' experience in using them. Upon request, this experience was shared with the Union of Municipalities of the Reggio Emilia Plain (comprising Correggio, Campagnola Emilia, Rio Saliceto, Fabbrico, Rolo and San Martino in Rio, in the Province of Reggio Emilia) and with the Liguria Region (AM). The latter lacks specific regional legislation on carers but has implemented a regional fund providing monthly financial contributions to carers who assist family members with disabilities.

Reflecting on potential transferability, a social worker emphasises the importance of "adapting it to local realities, making its meaning and usefulness understood and making it a participatory tool", and avoiding it becoming "an additional burden on the work, or, in other words, yet just another form to fill-in" whose meaning and potential is not understood (EB).

STRENGTHS

Based on the analysed documentation, the strengths of the PAI Standard Format include:

- training courses for district operators (including health and social care professionals and staff from the Home Care support desks) with increased attention to carer role;
- involvement of social workers facilitating the identification and sharing of priorities and needs;
- coordination networks established after Regional Law 2/2014 to coordinate support policies, including representatives of associations, trade unions, ANCI-ER (i.e. the institutional body representing the municipalities of the Emilia-Romagna Region), Municipalities, Local Health Authorities and the Region supporting the smooth running and consolidation of the practice;
- introduction of an official tool for assessing carer needs and stress;
- user involvement enabling co-design of interventions;
- opportunities for discussion between operators, creating an important network between services and the Third sector, bringing carer issues to the fore. For example, an increased sign-posting by social workers to services offered by NGOs or condition specific organisations, such as peer-support groups or training opportunities.

The representative of the "Older and Disabled People" area of the Union of Terre d'Argine adds that the initiative's strength "is the ability to build a network, to work in an integrated manner with all stakeholders (services, local authorities, institutions, social and health services, voluntary associations, social cooperatives, etc.), and to share best practices and the best that each can offer" (ST).

WEAKNESSES/CHALLENGES

Based on the documentation analysed, the main weaknesses of the PAI Standard Format include:

- uneven implementation across the Emilia-Romagna Region;
- time gaps between regional decisions and local implementation, as introducing new tools is challenging for services often facing organisational pressures and lacking adequate preparation;
- the need to complete training for social workers and healthcare professionals in the UVM, covering both practical and relational aspects of welcoming carers, and stress identification;
- despite various initiatives, more opportunities for discussion among operators are needed to ensure a consistent approach to carer needs, and coordinated use of the Standard Format should be further developed across the Region;
- a gradual transition from paper to electronic archiving is needed to facilitate data analysis and shared information flows. Some regional health authorities have planned to include carer data sheets and Zarit scales in their management systems, but this process requires further consolidation;
- The fact that the current PAI template is lacking a focus on the resources of the carer, rather highlighting weaknesses and needs for support.

According to the representative of the "Older and Disabled People" area of the Union of Terre d'Argine, a main weakness is the fact that while there is now a structured process for making carers visible and assessing their needs, there is still a gap in the actions that can be implemented to support them because of funding restrictions: "*funds and financing are very limited and, because of this, it is not always possible to respond to the needs of different target groups within the population*". To address this, many budget resources are allocated "*to enhance services and provide creative responses to emerging needs*", using the Standard Format (ST).

The main challenge facing the "Social Services - Older and Disabled People" department, as reported by its representative, is to offer services that are "*more flexible and capable of responding to the new target groups*" (ST) they are dealing with, represented by:

- people with disabilities with behavioural disorders, as services were originally designed for mobility and cognitive disabilities;
- people with disabilities who are ageing and have greater care needs;
- partially self-sufficient older people whose family structures have changed, with increasing numbers living alone: "there is a lot of loneliness among seniors; these people need a life plan, to be developed also through the PAI, but they are alone and do not have the characteristics to move into a protected residential facility" (ST).

Faced with these challenges, the "Social Services - Older and Disabled People" department is not yet "*well prepared*", even though Terre d'Argine has always been "*a very virtuous area in providing responses to various needs, various targets and various requirements*" (ST). Nevertheless, efforts are underway to provide concrete answers, such as creating working groups "*integrated with families, associations, managers of various services, and social and health sector bodies*" (ST).

Among daily challenges, one social worker reports that "*the biggest difficulty we encounter when approaching families is getting them to shift their gaze and focus to their needs*". When services are offered to support them and allow carers time for themselves, "*they find it very difficult to do so*". This is especially pronounced in families with disabled members, where there is strong "*focus on the needs of the person being cared for*" (EB), whereas the department's approach is "*we want everyone to be well*". Family members are often so focused on caregiving that they cannot attend to their own health problems, either because they have no one else to entrust their family member to, or because they tend to think "*no one else is as good as me at doing these things, at providing care*". The challenge is therefore to "*break down a system, a way of thinking that has been created over the years*" (EB).

Another social worker notes that "carer guilt" is also observed in families with older care recipients, where carers consider their loved one's needs more important than their own: "*I have to take care of my family member and therefore I cannot think about my own wellbeing*". Service operators try to help carers understand they are the cornerstone of the PAI, because "*without them, the whole care system collapses*" (CB).

Making carers aware of their central role is crucial, yet service providers face difficulties in doing so. As one social worker notes, "*it is almost as if we already see the carer's needs. They don't see it, even though they bring their needs to us*". It is important to help carers understand that taking a break or time for themselves "*is necessary to protect the carers themselves and the entire service system*" and to avoid having to "*intervene in emergency situations*", when the ability to respond adequately drops dramatically (EB).

POTENTIAL IMPROVEMENTS

On improving the PAI Standard Format, the representative of the "Social Services - Older and Disabled People" sector emphasises the importance of lightening the burden faced by long-term care workers. These professionals "*have a very, very high emotional and physical care burden*". There is also high turnover and a shortage of professional educators, social and health workers (OSS) and nurses who, unlike in other European countries, "*are very poorly paid in Italy and in crisis*", despite "*the constant demand for mental stamina, always having to be very focused, emotionally available, welcoming and smiling*" (ST). The suggestion is that operators must "*work on themselves first and foremost, taking care of themselves before taking care of others*". This echoes earlier reflections: shifting focus from the person being cared for to those who provide care is important for both family carers and service operators.

From the perspective of professionals, a potential improvement might be more training on the use of the format, especially considering the high turnover of staff in local social services.

Regarding professionals involved in compiling the Standard Format, the service representative emphasised two useful tools: "*cross-disciplinary training, which is developed together with social and health services*" and "*supervision, which we also offer to single-profession and multi-profession social workers*" (ST). The need to promote "*economic recognition and develop a rationale for career prospects and professional improvement*" was also highlighted to support professions "*in crisis*". Without resolution, senior operators may abandon these roles, no longer considered viable. Unlike in healthcare, where nurses can become managers and coordinate professional units, this pathway does not exist in the social sector. The focus group participant's hope is that "*in the social sector, we can move in this direction, to provide career advancement opportunities for all these figures*" (ST).

CONCLUSIONS

Overall, the analysis of the Standard Format for Individualised Care Plan, developed by the "Social Services - Older and Disabled People" sector and the Home Care Support Desk of the Union of Terre d'Argine, is positive. The practice is particularly effective in recognising the rights of family carers. National legislation has also reduced the previous heterogeneity of tools for collecting data on informal carers' needs, enabling support projects for carers to be formulated alongside the PAI.

Some inadequacies remain in the forms used to collect carers' responses. To address this, "a regional working group, requested by the carers' Support desks in the regional territory and approved by the Region, has been set up" (ST). This integrated, cross-cutting group involves various stakeholders including social and health workers, family carers, associations and regional officials.

It is “responsible for reviewing the current drafts of the carer’s burden measuring forms for a subsequent submission for validation to the Region and, eventually, for local use” (ST).

Further experimental work is underway to integrate existing forms (which mostly address medical and health aspects) with forms capturing social dimensions, including the potential positive outcomes of caring. These are particularly important for young carers, but relevant to other groups too.

Focus group participants consider the practice sustainable in the long term, given its financing through the health system and national, regional and local public funds. It is also transferable to other Italian contexts, supported by synergies between interested organisations and operators in areas where the tool is already operational, such as the Union of Terre d’Argine.

Regarding the PAI Standard Format’s ability to promote care alliances/partnerships, participants emphasised the importance of signing a shared care plan with care recipients and their families, and building a “*mutual relationship of trust and respect*”. These elements provide the strongest foundation for collaboration between formal operators and informal carers, and for a tailored care pathway benefiting all parties (ST).

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4. Community House (Casa della Comunità)

ABSTRACT

This case study, conducted within the WELL CARE project, examines the Community House of Carpi (Local Health Authority of Modena, Emilia-Romagna) as an advanced implementation example of the national "Community House" model introduced by Ministerial Decree 77/2022. Community Houses serve as physical hubs for health and social-health services, designed to overcome service fragmentation and ensure multidisciplinary integration.

The Carpi structure, inaugurated in March 2024, operates in continuity with the previous regional "Houses of Health" (Case della Salute, previous name of Community Houses), launched in 2010. It brings together on-site services including a primary care unit (with General Practitioners - GPs), a Single Point of Access (PUA), a Territorial Operations Centre (COT), community nursing, an advice centre, and clinical psychology activities, with specific attention to family carers and adolescents.

A distinctive element of the structure is the emphasis on creating a support network that integrates public services, voluntary associations, and the local community. Activities such as the "Talking Bench" (Panchina Parlante) and training both promote exchange and care partnerships among professionals, citizens, and carers. This holistic care approach also extends 360° to the entire family unit, including carers, supporting their resilience.

At a regional level, the Emilia-Romagna Community Houses (140 active out of 187 planned by 2026) already showcased a positive impact causing a reduction of inappropriate Emergency Department visits and hospital admissions for conditions sensitive to outpatient care. The Carpi experience has also shown a reduction of inappropriate hospitalisations, especially after the activation of Territorial Operations Centres (COTs).

Despite positive results and professional enthusiasm, the scarcity of human resources compared to the actual needs, remains a critical issue. This problem limits the time dedicated to carers and citizens' network activities and support (such as training). Nonetheless, the Community House of Carpi, with its strong integration and staff motivation, still serves as a reference point and as a transferable model, confirming itself as a good practice in the national landscape.

INTRODUCTION

Name of the good practice: Community House of Carpi (Casa della Comunità di Carpi).

Country of implementation: Italy, Emilia-Romagna Region.

Implementation level: Local/Regional.

Leader organisation: Regional Health Service Emilia-Romagna – Local Health Authority of Modena (Servizio Sanitario Regionale Emilia-Romagna – Azienda Unità Sanitaria Locale di Modena).

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Website / online sources:
For information at the national level on Community Houses:

https://www.pnrr.salute.gov.it/portale/pnrrsalute/dettaglioContenutiPNRRSalute.jsp?lingua=italiano&id=5801&area=PNRR-Salute&menu=investimenti.

Community House of Carpi website: https://www.ausl.mo.it/luogo/casa-della-comunita-carpi/.

Date of data collection: WELL CARE focus group interview, October 2025. In addition, for realising the case study report, information retrieved from the references listed at the end of this document have been analysed, such as those included in Emilia-Romagna Regional Health Service/Agency documents (2024a; 2024b), as well as in other sources (e.g. AGENAS, 2024a; 2024b, 2025; Nobilio et al., 2019; Sturlese et al., 2019).

Description of the organisational structure of the practice:
The Community House of Carpi (Province of Modena) represents the local application of a national model which has been chosen by the WELL CARE project working group (including the Italian BNL) as a good practice to be explored through a case study analysis as, compared to other contexts, it can be considered a particularly advanced example among the other Community Houses operating in Italy and, therefore, able to highlight strengths and critical issues of its operation.

The content of this report is based on the analysis of documentation available online (listed in the "References" section) and the main findings of a WELL CARE project focus group conducted via videoconference on October 24, 2025, in which 5 key informants (belonging to public health and social services; see the Acknowledgments section for more details) from the Community House of

Carpi participated. The analysis is also based on information related to the Community House national model (as a contextual framework) (PNRR-Salute, 2025), as well as direct quotations from the focus group discussion, indicated by the initials of participants' names. The “Acknowledgments” section lists the names of the focus group participants and their professional roles.

Community Houses, introduced into the Italian system by Ministerial Decree (DM) of the Ministry of Health 77 of May 23, 2022 (Regulation defining models and standards for the development of local healthcare services within the National Health Service), represent an organisational model for population proximity care. The model is designed as a physical and easily identifiable location where citizens can access services for their health and socio-health care needs. It constitutes a meeting and integration point for complex primary care units, functional aggregations of General Practitioners, Community Hospitals, Territorial Operations Centres (COTs), and pharmacies.

DM 77/2022 defines in detail the requirements that all Community Houses must have at a national level:

- organisational standards (one Community House hub every 40,000-50,000 inhabitants)
- personnel standards for one Community House hub: seven-11 nurses, one social worker, five-eight support staff units (socio-health care and administrative).

In Community Houses, several kinds of health, social, and administrative professionals - physicians, nurses, midwives, health assistants, physiotherapists, social workers, secretaries, etc. - work in an integrated and multidisciplinary manner. Their objective is to plan and implement health and social integration interventions, together with the participation of the local community in its various forms: citizens' associations, patients, carers, volunteers.

The “hub and spoke” model identifies: a hub structure as the reference centre for more complex health services and care continuity; several spoke structures that represent smaller and more widespread primary care points, offering basic services, as detailed here below, and serving as contact points between citizens and the health system, connecting to hubs for more complex cases.

Services present in Community Houses:

- Mandatory in hub and spoke Community Houses

Primary care services delivered through multi-professional teams (General Practitioner, Paediatric Practitioner, Internal Ambulatory Specialists, Family or Community Nurse, etc.); Single Point of Access (PUA); Home care service; Ambulatory specialty services for high-prevalence pathologies;

Nursing services; Integrated booking system connected to Local Health Care Service Unified Booking Centre (CUP); Integration with Social Services; implementation of projects aimed to co-design services with users and to actively engage local communities; Connection of the spoke Community House with the reference hub Community House; Medical presence guaranteed 24 hours a day, seven days a week for the hubs and 12 hours a day, six days a week for the spokes; Nursing presence 12 hours a day, seven days a week, but strongly recommended 24 hours a day, seven days a week for hubs; 12 hours a day, six days a week for spokes;

- Mandatory in hub Community Houses

Basic diagnostic services; Continuity of care; Blood sampling point;

- Recommended in hub and spoke Community Houses

Services for mental health, pathological dependencies, child and adolescent neuropsychiatry; Sports medicine;

- Optional in hub and spoke Community Houses

Consultancy activities and activities aimed at minors; Public health interventions (including vaccinations for the 0-18 age group); Screening programs offered to specific at-risk population groups for early identification of diseases or their precursors, before symptoms manifest.

The National Recovery and Resilience Plan (PNRR), which is part of the Next Generation EU (NGEU) programme, namely the € 750 billion package agreed by the European Union in response to the pandemic crisis, has allocated investments of 2 billion euros for the activation of at least 1,038 renovated and technologically equipped Community Houses by mid-2026. In this context, the following information describes the Community House of Carpi as a good practice, as well as an advanced and innovative example compared to other Community Houses operating in Italy, being one of the first that were established, thus having incorporated a wider experience on the ground.

The Community House of Carpi is a hub structure inaugurated in 2024, although the organisation of their services began in 2021.

- The structure includes several services which, even if not exclusively directed to carers, are particularly relevant for this target group. Namely: A Territorial Operations Centre (COT), fundamental junction between the hospital and community-based services. More specifically, the COT is an organisational model that performs a coordination function for

taking on charge of the person with care needs and acts as a link between services and professionals involved in different care settings (territorial health and socio-health activities, hospital, ensuring continuity of care and thus supporting informal carers in transition phases. In case of fragile patients, it also liaises with the emergency-urgency network;

- A Single Point of Access (PUA), which constitutes the evolution of the social desk, and to which citizens turn when they need to contact socio-health services. This service is particularly relevant for carers as it represents the privileged channel for orienting themselves in the complex social-health system, obtaining information and access to specific services (home, economic, psychological and training support), simplifying procedures. PUAs represent an important socio-health integration node that works with the physically closest COT, so that they can develop very strong collaborations;
- Community nursing service which, together with other territorial services, addresses both healthy people and those with socio-health problems with their families. The objective is to promote health and to support chronic diseases' management. When addressed to carers, the service might include health education and practical support to manage home care, through home visits, monitoring of vital signs, assistance in managing medications, and integration with local services,
- Clinical psychology activities carried out by community psychologists reporting to the Carpi Health District. Specifically, services are directed to adult and young people, including carers, with emotional distress, anxiety, relationship difficulties or psychological disorders.
- A primary care unit, consisting of General Practitioners;
- An advice centre for pregnant women and related activities;

As reported by a former mayor of Carpi on the occasion of its inaugural ceremony, the Community House of Carpi "is easily accessible both by public transport and through the road system. It is also at a short distance from the beating heart of the historic centre. It is likely to become an essential reference point for the community" (Emilia-Romagna Regional Health Service, Local Health Authority of Modena, 2024a).

In addition to the above institutional services, other activities and respite care, supporting both family carers and the local community, are carried out by volunteer associations in coordination with the Community House of Carpi, such as the "Talking Bench" (Panchina Parlante), where, in a room made available for this purpose, volunteers, people, and service representatives meet, tell stories and compare experiences. Sharing moments with the community are also held, contributing to creating an extended support network. "*This is the strength of the Community House: the importance of creating a network*" (IS).

At the end of 2022, even before the opening of the Community House of Carpi, a participatory process with the local community, called the "Relationship Workshop" (Cantiere delle Relazioni), was undertaken. The process involved social and health services, the Municipalities, the Local Health

Authority and all the associations and voluntary organisations in the Carpi District (which includes the Municipalities of Campogalliano, Carpi, Novi di Modena and Soliera). In this context, informative and training events were implemented, both internally (involving the future Community House staff on the objectives to be pursued as well as the services and activities to be prepared and implemented), and externally (with territorial stakeholders). For this purpose, three synchronised working groups were established:

- a group representing the network nodes (i.e. condition-specific associations, carers' associations, pensionaries' trade unions, NGOs, etc.), where the population's needs were discussed;
- a youth group;
- a communication group, which involved the same stakeholders as above but with the specific task of co-designing with professionals the communication activities of the Community House.

As stated by a focus group participant: "we say that we worked with three legs: social, health and associations/volunteering. We are continuing to do so also with respect to the activities we have implemented in what we call the 'permeable and diffuse Community House': not only what is inside the structure, but all the activities and services interconnected with it" (CM).

START AND STATUS OF THE PRACTICE/INITIATIVE

WHEN DID IT START

Initiated in Italy by the Ministry of Health through the Recovery and Resilience Plan (PNRR) funding, responding to the need to integrate social and health services, Community Houses aim at overcoming service fragmentation and improving multidisciplinary collaboration and coordination. Community Houses should be physically close to citizens with care needs (increasing proximity) and able to provide a comprehensive evaluation of patients' physical, social, psychological and functional needs. They should also map communities' resources and potential. These aspects are particularly relevant in cases of complex conditions, such as disability or dependency, where family/informal carers are involved. A strong push for opening Community Houses came from the Covid-19 pandemic lockdown. During that time, it became clear that many Italian Regions lacked structures for patient care throughout the territory.

REASONS FOR STARTING

Specifically, the Community House is an ongoing initiative launched nationwide in 2022 and in the Emilia-Romagna Region in 2010 (as House of Health). In fact, since then, Emilia-Romagna has been

investing in the Houses of Health with the goal of making services easily accessible and close to citizens. The Covid-19 pandemic, together with PNRR funding, which allowed to further develop a regional network of territorial structures, including Community Houses (formerly called Houses of Health), provided a further impetus to strengthen regional healthcare. The scope was to place emphasis not only on proximity, but also on integration between health and social services, in coordination with the Third Sector and other associations. Currently, in Emilia-Romagna, there are 140 active Community Houses but, to facilitate access and usability of primary care to all residents, the goal is to reach 187 active structures by 2026. The Community House of Carpi was inaugurated in March 2024, and it's still in operation.

TARGET GROUP(S)

The Community House of Carpi (in line the Community Houses national model) caters for the general population.

Given that the persons with health and/or care needs are a main target group (as explained in the next section on "Care Recipients"), informal (family) carers (young carers, working-age carers, older carers, working carers) are also a target group. Health, socio-health and long-term care (LTC) professionals all work in the Community House, Social Health Operators (OSS), educators, social workers, nurses, health professionals (General Practitioners, specialists, midwives, physiotherapists), and administrative professionals (e.g. secretaries).

Regarding carer characteristics seeking assistance at the Community House, as highlighted by a focus group participant, they are predominantly "*older people, who may themselves be disabled and have little digital skills. Therefore, they are in strong distress. They would need to be accompanied/assisted themselves, also because they often provide care in complete absence of family support (they may have children, but they are busy with their daily lives or working therefore unable to provide effective support to the parent, who in turn feels 'abandoned' within the care system). These characteristics make carers' assistance very difficult because, apart from some support from the Third Sector, these people experience severe hardship at home. Our services are helping to ensure that they do not feel abandoned by the system because, by always being there for them, we provide important support, both psychologically and organisationally. We also put them in touch with the Third Sector*" (RL).

Within the Community House of Carpi, "there is also a palliative care clinic where carers bring people of all ages, including children with special needs (such as disabilities, learning difficulties or other needs) and from different cultures or backgrounds. Therefore, when meeting with carers, it is

important for a mediator to be present. Together with community nurses, we aim to increase carers' empowerment as much as possible, i.e. to preserve and support their autonomy" (IS).

Within the social and health integration area, there is a daily collaboration with the Territorial Operations Centre (COT) to accompany and support carers through a number of different projects "*such as accesses to services, protected discharges, home care services (which allow carers to take care of themselves). Another type of support for carers is financial, with projects funded by regional or national funds*" (BB).

Over the years, the nursing clinics of the Community House of Carpi have been transformed from simple spaces dedicated to healthcare services, mainly for frail patients, into real welcome and comprehensive care places. Today, as already described above in this section, the focus is no longer solely on the patient, but it extends to the whole family (including carers) and the community in which they live.

CARE RECIPIENTS

Community Houses are aimed at the general population of all ages with:

- physical disabilities (caused by frailty, accidents, illness, etc.);
- psychological/mental health problems (e.g. depression, anxiety, etc.);
- cognitive disorders (e.g. Alzheimer's, dementia, etc.).

At the Community House of Carpi "those receiving assistance are mainly highly frail patients with long-term care needs, who either come to the facility independently to ask for information about services they have heard about, or through external referrals (e.g. general practitioners, acquaintances or friends who have already used the service)" (RL), but also patients of all ages, including paediatric patients in palliative care.

Special attention groups also include people in need of care and the so-called "invisible" people. Young people in need of care are taken care of by community psychologists in collaboration with a participatory group of voluntary associations. The various activities aimed at them take place in the so-called "Youth Space" (Spazio Giovani), an area within the Community House where they can relax, socialise with their peers or study. Among other things, the Community House of Carpi is located in a strategic location, nearby city's high schools and next to the bus station. Students (as well as other residents) pass by every day, making facility's access extremely convenient.

The “invisibles” are those people not using the services, “not expressing needs (e.g. single-family households with people in need of care but without a carer) and for whom a series of activities have been implemented, including within clubs and meeting places, where people can report cases they know being 'invisible' to services, who could then be ‘connected’ in some way, thus emerging from invisibility and benefiting from the network of services offered within the Community House” (IS).

As for the people taken care of by the Community House of Carpi, according to one focus group participant (BB), they can be divided into a direct and an indirect target. Direct target are those people openly expressing a need or make a request directly at Community Houses. By contrast, the indirect target (e.g. family carers) doesn’t express a need directly to the Community House, but in other contexts/services. Eventually, they are also taken into care by the Community House services, described in the paragraph “Description of the organisational structure of the practice”. For example, family carers going through a difficult moment – e.g. during discharge from hospital of they loved ones – can benefit from post-discharge projects promoted by the District’s social and health integration area at the Community Centre, through a direct contact with the Territorial Operations Centre (COT).

OVERALL CHARACTERISTICS OF THE INITIATIVE/PRACTICE

AIMS

Community Houses, including the one in Carpi, are physical and easily identifiable locations where citizens can access healthcare and socio-health care assistance services. They serve as a meeting and integration point for complex primary care units, functional aggregations of General Practitioners, Community Hospitals, Territorial Operations Centres (COTs), and pharmacies.

The main objective of Community Houses is to strengthen territorial assistance but also to decongest/relieve hospitals and their Emergency Departments from non-urgent accesses, which can be managed by equipped territorial structures. This ensures continuity of care and real proximity healthcare always and without interruption, every day, weekdays and holidays, day and night.

Sub-objectives include:

- unified and integrated access to healthcare, socio-healthcare and social assistance for citizens, including those with LTC care needs, facilitated by the dedicated personnel working in the Community House;

- prevention and health promotion for citizens, through activities carried out by the Community House;
- taking charge of people with chronic problems and frailties;
- assessment of the person's needs (including patients and their families, including informal/family carers) and guidance to the most appropriate response service;
- response to the population's health demand and guarantee of continuity of care;
- activation of multidisciplinary care pathways involving integration between healthcare services, hospital and territorial services, and between health and social services for complex and LTC conditions.

Regarding innovation aspects, the following should be noted:

- Telemedicine systems can be integrated into Community House services to help assisted persons remain in their homes as long as possible. These models particularly benefit paediatric, adult, and older patients with chronic diseases, strengthening both territorial and home assistance. The effectiveness of this approach was recently demonstrated in an experiment by the "Local Health Authority" of Modena (AUSL), where the Carpi Community House is located (Emilia-Romagna Regional Health Service, Local Health Authority of Modena, 2024b);
- The reorganisation of territorial assistance brought by DM 77/2022 configures a "revolution" in the professional relationship with doctors: all professionals entering the National Health System from 2025 onwards, in addition to taking on charge of their patients, will also have to work with hourly services in Community Houses assigned by their "Local Health Authorities" (AUSL) (RIF day, 2025);
- As highlighted by a focus group participant, a further innovative element found in the Community House of Carpi is the "360° taking on charge" of the entire family unit (and in particular of those members who act as family carers besides care recipients) of the assisted person in collaboration with various Third Sector associations that make themselves available to support the family carer (i.e. condition specific organisations working in the field of stroke, dementia, Parkinson, sensorial disabilities etc. all provide support services for informal carers such as support groups, education, respite care, etc.). This is "*an absolutely innovative thing, much appreciated and which is offering us important results regarding the assistance provided to subjects with care needs*" (RL).

HOW DOES IT OPERATE

With reference to the professionals involved in providing various services, as of November 2025, the Community House of Carpi has:

- in the Territorial Operations Centre (COT): six "Local Health Authorities" (AUSL) nurses and two social workers from the Union of Terre d'Argine working in the Community House;

- in community nursing: one nurse dealing with organisational and coordination activities but not providing direct assistance, three community nurses who provide direct assistance at the Carpi location and at other locations within the Carpi Health District;
- in the PUA: four administrative employees from the social cooperative "Caleidos", who manage the Social Desk;
- various psychologists rotating through different activities, including those from the Counseling Centre (which houses the Youth Space and Adolescence Centre) and Community Psychology services. Additionally, Home Care services are provided both within the Community House as an outpatient palliative care clinic and throughout the Carpi District area.

MAIN OUTCOMES

Focus group participants from Carpi's Community House highlighted initiatives and tools that support the mental wellbeing and resilience of informal carers. For example, the Carer Care Load Measurement Sheet is used in home care, though still sporadically and at operators' discretion. This tool is becoming increasingly necessary and regional policy intends to make it mandatory. In practice, assessing family carer burden enables targeted relief interventions. As one participant explained: "*When the carer gives in, there's a domino effect; the assisted person loses home care conditions and must shift to institutional social or health settings. Family and carer resilience is extremely important, as this has both social and organisational care impacts*" (IS).

Moreover, as previously mentioned, the Community House offers psychological support services both for adults and young people, which are aimed to promote the mental wellbeing of patients.

Carpi's Community House increasingly focuses on family carer resilience. Though precise data isn't collected, one participant in the focus group reports that "*patients appreciate knowing we also care for their carers, having heard about this from others*" (IS). Since the COT became active, the service network's integrated responses have reduced inappropriate admissions and re-admissions. As one participant noted: "*Admissions aren't only for health reasons, sometimes families can no longer provide home care and resort to ambulances and hospitals*" (IS).

While comprehensive national evaluation results are not yet available, the Emilia-Romagna Regional Health and Social Care Agency has conducted an impact assessment of Community Houses (previously called "Houses of Health") in its territory (Emilia-Romagna Regional Health and Social Care Agency, 2020), as mandated by the Regional Social and Health Plan 2017-2019.

Consequently, an evaluation study was initiated to:

- assess the impact of Community Houses using regional administrative databases;

- measure citizens' perceived quality of Community House services.

The analysis referred to a cohort of patients aged 18 years and older, resident in the Emilia-Romagna Region for the entire year in the same municipality, cared for by the same General Practitioner for the entire year, and monitored in their contacts with the regional health system between 2009 and 2019. The analysis included the Health Centres open until December 31, 2018.

The main outcomes were that Community Health Centres had a significant impact on the reduction of inappropriate access to Emergency Room (-16.1%) and a significant impact, even if of smaller size, on hospital admissions for Ambulatory Care Sensitive Conditions (-2.4%), as well as on episodes of Home Care (+9.5%).

A study aimed at evaluating the impact of Houses of Health on selected results obtainable through regional administrative databases in the period 2009-2016 was previously published in a report (Dossier 266/2019) (Nobilio et al, 2019). The analysis included 64 Houses of Health located outside provincial capitals. The report documented significant reductions in both inappropriate Emergency Department accesses and hospital admissions for ambulatory care-sensitive conditions, along with increased integrated home care episodes. The analysis showed that co-locating family doctors' offices in Community Houses enhanced all three indicators.

A September 2018 regional survey (CaSa Qualità) on citizens' perceived service quality revealed high overall satisfaction, while identifying areas for improvement including accessibility, environmental characteristics, and organisational aspects (Sturlese et al., 2019).

A recent AGENAS (National Agency for Regional Health Services) report (AGENAS, 2025) documents the status of structures mandated by DM 77/2022, providing national and regional data on Community Houses, Territorial Operations Centres, and Community Hospitals as of June 30, 2025. The report reveals significant North-South disparities: of 660 active Community Houses, 53% are concentrated in three Northern regions: Lombardy (142), Emilia-Romagna (140), and Veneto (63). Only 28 facilities fully comply with DM 77/2022 standards, including all required services: Lombardy leads with 12, followed by Emilia-Romagna and Lazio with 8 each. In terms of outcomes for the direct target groups, this means a disparity in the access to these services by citizens across different regions.

Comparing the Community Houses launched with those planned, implementation rates exceed 60% in three Northern regions (Emilia-Romagna 75%, Lombardy 70%, Veneto 64%) and Marche (69%), while four Regions/Autonomous Provinces have no Community Houses and four have only two. Despite allocated funds, including PNRR funding, official regional data show implementation remains slow compared to the planned roadmap.

CARE PARTNERSHIPS

According to its general objectives, the practice promotes care alliances through improved care coordination. Additionally, several Community Houses offer informal carer training programs led by LTC professionals, creating valuable knowledge-sharing opportunities among these two groups.

The Community House activities and its network of community-based services for citizens and carers (supporting people of different ages, social backgrounds, and care needs, especially through training initiatives) highlights the ongoing collaborations in the area between professionals and carers, promoting an ongoing cultural development and creating concrete opportunities for collaboration and exchange between professionals and informal/family carers. These interactions support the formation and functioning of care alliances between the two groups, improving the quality of care provided to recipients and strengthening the resilience and mental wellbeing of both informal carers and professionals.

For example, Carpi's Community House hosts group meetings between carers and healthcare professionals -including geriatricians, community psychologists, and mental health specialists - to facilitate discussion and knowledge exchange about care activities. These meetings foster both a care alliance culture and concrete collaborations.

As one participant explained: "Educating carers on care techniques is fundamental to territorial assistance, both within the Community House and in-home care. We support families but cannot replace them; our motto is 'without carers, there's hardly home care'. Through skills training, carers feel supported while working alongside us to deliver care, enabling patients to maintain quality of life at home or within the community" (IS).

Carpi's Community House promotes care alliances or partnerships through various training events and collaboration with the nearby House of Volunteering, which hosts over 50 volunteer associations and facilitates meetings between operators, volunteers, and family carers in order to let them share opinions, experiences, knowledge, mainly concerning health and caregiving issues, etc.

Additionally, both venues organise citizen training on digital health tools, including electronic health records and GPs appointment apps developed with doctors that enable direct medical appointment booking and exchange of communication with the GP without calling the office. E-health tools have a practical impact on care partnership as they ensure an easier, quicker and prompter exchange and update of information between the informal carer and the care team, however – especially for older

carers – the lack of digital skills prevent them from benefiting of these tools. Additionally, various prevention and training initiatives are organised annually with the "Local Health Authority" of Modena (AUSL), including alcohol awareness (April), family carer month (May), Alzheimer's awareness (September), mental health and breast cancer prevention (October), and prostate health (November).

Another activity which contributes to share experiences and knowledge among operators, citizens and carers, is the "Living Library" or "Talking Bench". It is a bench renovated through a participatory workshop for the day against violence towards women attended by young people, volunteer associations, social services and Modena AUSL. Monthly intimate gatherings occur here where a "book" (a person sharing their professional or personal story) speaks to up to 10 listeners (e.g. citizens, LTC workers, informal carers, etc.). Among discussed topics, those related to caregiving are often addressed, thus contributing to develop a culture able to help to stress the importance to pursue care partnerships and their potential for the mental wellbeing of both informal care and LTC workers.

"Participants include citizens, school youth, volunteer association representatives, Community House health and social services staff, and the broader local community. We've frequently addressed carer themes, with people sharing their personal experiences, sometimes with family members present, or family members of those who've faced similar challenges, such as cases involving violence against women. This innovative initiative, which we consider quite significant, began a few months ago as a collaborative effort" (CM).

Another activity carried out by the Community House of Carpi, in collaboration with the social cooperative "Anziani e Non Solo", is the training of so-called special babysitters. Various professionals, including a home care nurse for paediatric palliative care, have trained participants who can then offer support and relief to parents of children with care needs, allowing them to go to the hairdresser, go shopping, or simply take a short break. Special babysitters capable of caring for these children are rarely found outside the family. "*This partnership, the network that was created, made it possible to provide training for these special babysitters, to support carers who are often very stressed, because they are parents of 'special' children with health problems requiring highly medicalised care gestures*" (IS).

Training activities are also organised with family assistants, including migrant care workers (the so called "badanti"), in collaboration with the Rehabilitation Medicine service and often with the participation of physiotherapists. These sessions focus on specific topics such as mobilisation, walking assistance, and feeding for the individuals cared for directly by the family assistants. These training activities contribute to more effective care partnerships, since the upskilling of migrant care

workers allows for improvement in their capacity to engage with formal care professionals and to be more proactive when discussing care practices.

In this regard, focus group participants emphasised that, while parent carers of foreign children with care needs receive particular attention to language use during training activities - including the presence of a linguistic-cultural mediator - this is less clear when training family assistants: "*I don't know how often there is a mediator, or someone who can 'translate' what we say into something truly understandable and helpful for the various family assistants. Perhaps there is really a need for more mediators; not only someone who translates the language, but also someone who can truly transform, based on culture, the content we want to convey. It is still difficult to find the right mediator for the right culture, because we have so many cultures to interact with, and this remains a challenge for*" (IS).

SUSTAINABILITY

Regarding resources, the main funding sources for Community Houses are European funds (PNRR for infrastructure) and national or local public funds (e.g., general tax revenues and social assistance funds). As previously noted, the PNRR, with the aim of reorganising care across the national territory, has invested 2 billion in Community Houses up to the milestone of June 2026.

In addition to being sustainable, the Community House model (thanks to the PNRR investments aimed at expanding this type of service nationwide) also has the potential to be transferable and scalable across a variety of local contexts. The implementation standards are outlined in the previously mentioned DM 77/2022. In addition, AGENAS (National Agency for Regional Health Services) published the "Guidelines for implementing the organisational model of Community Hub Houses" in April 2024 (AGENAS, 2024a), and the Conference of Regions and Autonomous Provinces released the "Guidelines for the hourly activities to be carried out by physicians in the unified primary care role within Community Houses" (Conference of Regions and Autonomous Provinces, 2025) in September 2025.

In addition to the PNRR funding mentioned above, it has to be highlighted that the Community House model integrates existing services and essentially does not create new ones, making it sustainable overtime through ordinary funding.

TRANSFERABILITY

Regarding the Carpi Community House and the replicability of the practice as an advanced model (both in organisational and operational standards and in terms of results) emphasis was placed on the efforts made by operators during the period when the concept of a network and Community House did not yet exist as more than a physical space, but also as a cultural place where the care

needs of the local community and family carers could be addressed and support opportunities created. In this context, significant work was done to promote a cultural paradigm shift through participatory working group meetings involving both citizens and service operators (i.e. physicians, nurses, social workers, etc.). This represented a transition from an initial phase, in which citizens simply requested more services and operators responded to care needs, to a subsequent phase marked by "*a revision of the perspective on the service offering of this type of initiative, characterised by a willingness to engage, take responsibility, and actively become part of the Community House network*" (IS).

Another element considered essential for the provision and potential transferability of all initiatives and activities implemented by the Community House of Carpi is the creation of a network: "*We need to start by connecting the existing network nodes in the territory, encouraging them to collaborate and creating conditions to build a shared response to care needs among services and associations already present. The work was precisely about getting to know each other, understanding what others do in their areas, and realizing that we can work together to provide a more complete response to citizens*" (CM).

Another strength of the Community House of Carpi is the creation of a support network connecting public services, the community, and volunteer associations: "*people know that when they enter that house, they can find not only solutions to their needs, but also opportunities offered through the network*" (IS).

The contribution that the Community House of Carpi experience can offer to the creation of additional networks and structures in other local contexts (especially those still at the beginning of their journey) should also be emphasised. As one focus group participant noted: "*We recently took part in a conference in South Tyrol, and sharing the experience of the Carpi Community House and of Emilia-Romagna in a place where they are just starting to create their Community House is a great help, because unlike us, they now have a few more reference points*" (IS).

STRENGTHS

It was emphasised that the proximity of services provided by the Community House of Carpi, along with the development of strong collaboration networks, "*makes integration much easier and allows us to provide concrete, almost instantaneous responses to the people we assist and, at the same time, to their carers*". Furthermore, according to operators, this also helps "*to recognise that it is right and absolutely essential for the person or the people caring for the assisted individual alongside us to receive support, both from us, from a health perspective, and in collaboration with the Third Sector, which is an integral part of the care provided*" (RM).

Another strength of the Community House of Carpi highlighted by focus group participants is the enthusiasm of those who truly believed in its creation, even when regulations outlined what needed to be done but not how to do it, and the initiative of those who, using their own creativity, organised and carried out various activities, meetings, and participatory groups. This reflected a constant commitment to reflect on how to implement the Community House and sustain its operations. As one participant noted: "*Enthusiasm was certainly a strength of the people involved. Then, flexibility (because the Community House, as you see it now, is different from how it was designed on paper, due to various logistical and organisational reasons) and we were not afraid to say, 'this is a dead end, so let's try another approach'. This is also a strength, because if we had followed certain directions rigidly, we probably wouldn't be talking about it in the same way today*" (IS). Another strength was the recognition of the tasks and activities of social workers within the new territorial health system. They are now seen as central to the multidisciplinary integration process pursued by operators and organisations, including the Community House of Carpi, across the regional territory.

Moreover, information and results sharing were recognised as a crucial element for ensuring alignment among all operators, translating in a more seamless care provision which better support people in need of LTC and their carers.

WEAKNESSES/CHALLENGES

With reference to the Community House of Carpi, a limitation highlighted by focus group participants is the scarcity of human resources and the limited time available relative to actual needs. In this regard, the need for more personnel was emphasised (clearly linked to financial resources despite the available funding) and consequently more time to provide network services to citizens and support to family carers, including through involvement in training and educational activities that can strengthen care alliances. Thus, the practice is contingent on securing continued funding.

Regarding weaknesses at the national level, as highlighted by the AGENAS Reports (AGENAS, 2024b; AGENAS, 2025), despite PNRR funding, there are delays, especially in the South, in implementing the reform outlined by DM 77/2022, and consequently in opening Community Houses nationwide, in line with the minimum target of 1,038 structures to be activated by June 2026. Another significant national challenge is the shortage of personnel, particularly medical and nursing staff, needed to meet citizens' demand for primary care and to provide all the services intended, including those within Community Houses.

The importance of recognising the sustainability limits of implemented projects was also highlighted, as well as the need to reorient efforts when necessary to avoid frustration and loss of energy. As one participant reflected: "*If I had to start over, I would certainly try to approach*

differently those moments when we realised we could not move forward, which caused great frustration because time and energy had been invested. Learning to manage these situations better (to say, 'okay, we've come this far, now let's try to do things differently') would have helped" (IS).

POTENTIAL IMPROVEMENTS

As one focus group participant noted, about Community House operators "The time they can dedicate to carers or citizens is less than what they could do… because these professionals can create networks and inspire people if they have a bit of energy for themselves, too. We are also starting to reach a certain age; we still have enthusiasm, but by the evening there's sometimes no energy left. Having more people could therefore be an area for improvement. One of many, because services and networks are made up of people and the day has only 24 hours. More staff would allow us to work more effectively and provide ample room for improvement" (IS).

Increasing human resources in this way would further enhance the range of services offered by the Community House, while also supporting the resilience and mental wellbeing of both operators (through reduced stress and workload) and informal carers (through lower care burden, improved quality of life, and more training opportunities), ultimately benefiting those receiving care.

Although some meetings were organised by the Community House of Carpi to present various projects (e.g. the activities of the Carer Desk of the Union of Terre d'Argine were introduced to the entire home nursing service team), it would have been useful to have more time and resources for a more direct involvement of individual operational units, so that the objectives, expected results, and impacts of the initiatives were fully understood. "*Looking back, it would have been useful to find more resources, this could have helped. Another thing that could have been done better, and that we tried to do, but time was tight, was to better present the key points of the projects we have carried out in recent years within the Union of Terre d'Argine. We tried to organise various meetings to explain the projects to all operators, but certainly, if we had had a little more time to do this also within individual operational units, it would have been even easier to understand the objectives we had set*" (SA).

The transformations introduced by DM 77/2022 and the PNRR have imposed a rapid pace and required strong adaptability. However, when change happens quickly, it requires clear and continuous communication to guide all operators through the innovation process. As one participant stated: "*We are in a phase of change, dur to the projects of Ministerial Decree 77/2022 and thanks to the PNRR. And so, when change is quite fast and dynamic, not all operators can understand where we are heading. Sharing this with everyone who contributes to our activities is therefore essential*" (SA).

Making objectives, strategies, and results visible is not only a communication issue but also a way to expand the collaboration network and involve new actors, keeping motivation high and preventing partners or volunteers from disengaging over time. As one participant noted: "*If we can work more on visibility, we can expand the network, make clear where we want to go, how we plan to get there, and try to involve as many people as possible. During long processes, some of the people who interact with us (like those in the volunteer sector) may drift away. We need more people who understand where we want to go and who can help carry out activities*" (IS).

CONCLUSIONS

Our analysis confirms that the experience at the Community House of Carpi has been positive and also focus group participants - which were among the founding members who contributed to its conception and implementation - considered this initiative as valuable. Most of the professionals working in the Community House of Carpi since the beginning have remained over time, signalling a strong sense of belonging and motivation. As one focus group participant observed: "*Working in this structure has certainly been positive and we all believe in it. Many of the people who are active now are the same ones who started with us. Unfortunately, some have retired (to our great regret) because they had essential emotional qualities and strong motivational abilities. Nonetheless, they still often participate in volunteering*" (SA).

Overall, within the broader process of reorganising and strengthening territorial care in Italy (driven by DM 77/2022 and PNRR investments) the experience of the Community House of Carpi described in this document confirms its role as a good practice within the national landscape.

This was possible because of the strong integration of services offered, synergies with the support and resource network spread throughout the local territory (including volunteering and associations), positive results achieved that were on par with other regional Community Houses (such as reduction of inappropriate Emergency Department accesses, hospital admissions, and high user satisfaction for services offered), and the various initiatives implemented to meet citizens' care needs. The importance of various actions, projects, and initiatives (such as training and support during patient discharge phases) and tools (like carer care burden measurement sheets) to support care burden, mental wellbeing, and resilience of informal carers, as well as operators, should also be reiterated, highlighting a progressive cultural elaboration and conditions for the development of care alliances.

Some critical issues and possible margins for improvement also emerged, which can be worked on to further strengthen the quality of services offered, organisational wellbeing, and the quality of care provided to citizens and carers. These services are already characterised by high standards,

thanks to service integration and the high skills and strong motivation of professionals who work and give life to the Community House of Carpi.

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5. Community Circles (Voorzorgcirkels)

ABSTRACT

The Netherlands is facing a rapidly ageing population, with the number of older adults expected to double by 2040. This demographic shift places increasing pressure on formal care services and informal carers, while traditional residential care facilities have largely disappeared, leaving many older adults living independently without adequate local support. In response, the concept of Community Circles (Voorzorgcirkels) was developed in the region Land van Cuijk (in the South-East of the Netherlands). The initiator of the Community Circles, Henk Geene, was asked in 2017 by the local division of Roman Catholic Older People's Organisations (Unie KBO) and the local Social Welfare Organisation to set up a project to explore what was needed for older people living at home for housing, care and wellbeing. For this purpose, a project structure was developed with partners such as a care provider, a housing cooperative, the village councils and the municipality. Based on interactive meetings with 2,000 older people, who gave 9,000 responses/suggestions, Geene developed the concept of the Community Circles as proactive, neighbourhood-based networks of 10-15 residents who provide practical and social support to one another before formal care needs arise. The concept was implemented soon after the Covid-19 pandemic in 2022 (Geene, 2025).

The community circles aim to enable older adults to live independently for longer, strengthen informal care networks, and foster social cohesion, while alleviating the burden on carers. Participation is voluntary but requires commitment, and members contribute according to their abilities, creating a low-threshold, inclusive environment. The methodology, as described by founder Henk Geene, involves three stages: initiating circles, developing their activities, and linking them to formal social and care structures. Three national coordinators, commissioned by the national umbrella organisation of care cooperatives Nederland Zorg voor Elkaar (NLZVE; literally meaning: Netherlands Cares for Each Other), and funded by health care insurers provide support through training, manuals, learning networks, and financial or organisational assistance.

Since their inception, hundreds of Community Circles have been established across the Netherlands. A rough estimate is that at present there are around 1,500 functioning. However, as these circles differ in form and are usually not formally recorded, it probably is many more of them. Local pilots report positive outcomes, including higher community engagement, better understanding of older adults' needs, and practical relief for informal carers. Participants also experience personal satisfaction from contributing to their neighbourhood. However, formalised care partnerships with formal providers remain limited. In the Netherlands, the circles are booming, because they require

limited additional funding and because there is a growing awareness among the population of the need to be supportive to each other.

Sustainability is supported through community ownership, low-cost structures, freely available manuals, training, learning networks, and NLZVE's knowledge platform. The methodology is designed for transferability, allowing adaptation to different local contexts while maintaining core principles. Further development is needed to strengthen connections with formal care and supportive tools for those who want to set up community circles.

INTRODUCTION

Name of the good practice: Community Circles (Voorzorgcirkels).

Country of implementation: the Netherlands.

Implementation level: National.

Leader organisation: Nederland Zorgt Voor Elkaar (NLZVE; Netherlands Cares for Each Other).

Contacts: Henk Geene, voorzorgcirkel@nlzve.nl.

Website: https://www.nlzve.nl/kennisbank_themas/voorzorgcirkels_kennisbank/default.aspx.

Date of data collection: WELL CARE case study interviews November and December 2025 and desk research.

Description of the organisational structure of the practice:
Community Circles are neighborhood-based networks of about 10 to 15 older residents - or households - who support one another in various practice-based ways. Members make clear agreements about being there for each other and discuss how they can offer help when needed. Participation is voluntary, but commitment is necessary. Community Circles are, in principle, formed proactively, that is, before urgent care needs arise (Geene, 2025; NLZVE, 2025; Voorzorgcirkels | NLZVE).

The term 'care' (in Dutch: zorg) in Community Circles (in Dutch: *voorzorgcirkels*, literally 'precaution circles') refers not to professional care, but to looking out for one another and offering practical

help and support, such as running errands, providing companionship, helping with technology, or assisting with minor household tasks.

The core belief is that everyone in the Circle can contribute meaningfully in their own way: “I once met an 80-year-old man who was in a wheelchair, heavily equipped with all sorts of medical devices. He could barely do anything himself. Yet, he had spent 30 years working in IT and was able to help healthy, active people with computers, smartphones, and other technology. There’s almost always something a person can contribute” (HG). Therefore, reciprocity is a core principle.

Community Circles were initially developed in one municipality in the Netherlands. Over the last five years, it has grown regionally from local pilots to some 1,500 circles nation-wide. (Note: Statistics are not available as Community Circles don’t require a formal registration. They are not always called Community Circles and they exist in many forms, depending on the choices the members make. The Circles are ‘owned’ by citizens themselves. Therefore, they themselves decide how they are functioning.) Presently, NLZVE is responsible for the dissemination of the innovation. They support (care) organisations, municipalities and citizen-initiators in establishing community circles by a website containing practice examples and information about how to set up a Community Circle, they can arrange local workshops and provide tools to support ways of working (for instance: how to explore what people can contribute).

The national umbrella organisation for long-term care providers (ActiZ) and health insurers (including VGZ/Coöperatie VGZ) support the community circles financially, through external communication (podcasts, websites, referring to the circles in their publicity etc.) and by sharing practical examples.

Benefits

In some neighborhoods, initiatives for older adults already exist, but they are often only accessible to a small group of assertive individuals who are comfortable asking for help (Podcast *Van Zorg naar Gewoon Leven*, 2025). For many people, asking for or accepting help can be difficult (NLZVE). This is where the Community Circle makes a difference: it lowers the barrier, making participation and engagement easier and more accessible for everyone.

Community Circles provide social support and enhance people’s self-reliance within their own environment. Although these circles are informal by nature, care economists and participants emphasise that they serve as an important alternative to professional care—not as a replacement, but as a valuable supplement (Actiz, 2025). For instance, those who receive help from a neighbour, family member, or volunteer often require formal care less frequently. At the same time, the circles support people to better manage their own lives and strengthen collective self-reliance within the community. Through this network, issues such as loneliness, overburdening, or neglect can be identified and addressed early, while participants receive support and maintain their independence.

START AND STATUS OF THE PRACTICE/INITIATIVE

WHEN DID IT START

Henk Geene is the developer and initiator of the Community Circles. He was approached by the municipality of Land van Cuijk (South East of the Netherlands, 90,000 inhabitants) with the request to set up a project for older adults living at home, focusing on housing and care. He began by organising sessions for the community. Each session followed the same structure: before the break, the societal challenges surrounding ageing and care for older people in the Netherlands were discussed, with the goal to raise awareness. After the break, participants engaged with one of six cases and were asked to write down how they would respond if they found themselves in that specific situation. The cases ranged from a low care need to high care need (i.e., near-complete dependency). The sessions were a major success: 20 meetings were held, attracting around 2,000 older adults. These were mainly vital, older people (60+) living independently at home – who are also the main target group of the Community Circles.

When Henk reviewed the responses to the cases, he noticed that many older adults indicated that they preferred support from their immediate surroundings - people living in their own street, neighborhood, or village – rather than relying primarily on their children. Based on this input, Henk felt the need to develop some sorts of 'neighborhood circle.' Furthermore, the participants indicated that they liked the idea of responding proactively, even before care needs arise. Based on these two dominant themes (the preference for support from the immediate environment and the idea of a proactive response), what was led to the development of *Voorzorgcirkels*.

The first Community Circles emerged mainly in apartment buildings where many older people live and neighborhoods where residents took the initiative themselves. These Circles often started small: a handful of neighbors having coffee together, making agreements about how they could support one another, or helping with everyday tasks such as groceries, small repairs, or transportation. As expressed during the interview with Henk Geene: "*The people who join now do so because they feel: we have to look out for each other. Partly because the care system is overstretched—there's too little staff, costs are rising, and population ageing is enormous. But also because many of us simply believe in taking care of one another. That's what being a community means" (HG).*

Through a process of trial and error, and after helping to develop roughly 10 Community Circles, the outlines and principles of today's Community Circles in the Netherlands gradually took shape.

The key elements of Community Circles, as described by Henk Geene (2021) in his book, are:

1. They are developed for reasons of precaution: to prepare for ageing and to take measures on beforehand, in case needs for support emerge in a later stage;
2. Healthy vital older people help older people in need of support and care: there should be a balance between both categories;
3. Reciprocity is key: you are helping now, and you will be helped yourself at a later stage:
4. An inventory is made of the demand for assistance and the assistance offered;
5. There is someone with a designated task to connect needs and supply;
6. The circle consists of eigh-nine to 12-13 people;
7. The circle reassures people that assistance will be available if needed;
8. Participation is voluntary, but not without obligations;
9. Members of a circle live at walking or biking distance;
10. Circles take off work of the hands of professional organisations;
11. Circles contribute to meeting other people and thereby to less loneliness.

While the idea of Community Circles has received many positive responses, some resistance was encountered. Although this resistance has decreased over time, it still occurs to this day (HG) (Podcast Nieuwe Blik op Zorg, 2024). Some older people simply say: "I'm healthy now, I'll deal with things when the time comes". These people were not inclined to prepare for a future situation of care dependency. They believed the Dutch government would look after them if needed, and, for instance perceived: "*We worked hard and built this country, the state should take care of us*" (HG).

PRESENT SITUATION

In 2023, Henk Geene partnered with Nederland Zorgt Voor Elkaar (NLZVE) to support the scaling up and further development of the Community Circles in the Netherlands. On their website, NLZVE writes that the start of a Community Circle involves 'trial and error.' They perceive that encouragement and guidance can make a difference, which is why they offer support. More specifically, three project leaders were appointed at NLZVE who are responsible for the continued growth and refinement of the Community Circles in the Netherlands.

Health insurers VGZ and Zilveren Kruis provide financial support for the Community Circles. Health insurers do not necessarily consider the Community Circles to be *the* solution to all systemic issues in healthcare, but they do help reduce the pressure on the system. Moreover, they advocate for a more connected and caring society (Podcast Nieuwe Blik op Zorg, 2024).

Since 2024, the Community Circles have appeared regularly in national media, received significant attention at national conferences, and have been the subject of several Dutch podcasts (e.g., *Nieuwe blik op zorg*). There is also concrete interest from countries in the Noridc-Baltic region (Denmark, Sweden, Finland, and Lithuania). Circles will be implemented and evaluated in these countries as part of the SustainCare project (2025-2028).

REASONS FOR STARTING

The Community Circles emerged against the backdrop of a rapidly ageing society, where the need for care is rising quickly. In 2020, the Netherlands was already facing a growing population of older adults; by 2040, this number will have doubled. This means a sharp increase in care needs, while there is a shortage of professional carers (especially in long-term care services). Furthermore, informal carers are often overburdened.

At the same time, the care landscape has changed significantly. Traditional residential facilities for assisted living - once a key pillar in supporting older adults - have almost entirely disappeared. Most have been converted into nursing homes, leaving a gap in accessible, lower-level support close to home. As a result, older adults now live independently for longer, but often without the infrastructure needed to do so safely and comfortably. For people with dementia, these risks are even greater: when their primary carer can no longer provide support, an acute situation often arises, because there is usually no social network ready to step in.

This development made it clear that a new way of living together was needed: one in which people do not wait to seek help until something goes wrong, but instead surround themselves in time with a network that can provide safety, proximity, and practical support. Against this backdrop the Community Circles were developed.

TARGET GROUP(S)

Although Community Circles welcome participants “from young to old,” they tend to concentrate on adults aged 60 and above, as having a reliable support network becomes increasingly important with age (NLZVE, 2025). Beginning participation around age 60 considered as ideal (but also younger people can join, provided they feel affiliated to the aims and formula of the circles): in the early years, individuals may primarily contribute support to others, while later in life they may rely more on the network themselves. That being said, in some municipalities or neighborhoods, active participation from adults aged 30 and above is being pursued (MV). Community Circles are, in principle, open to all citizens in a given neighborhood who wish to become a member of a Circle.

Secondly, the community circles focus on local residents and volunteers who actively participate and offer support. They also aim to connect welfare and care organisations as well as municipalities to the circles so they can help facilitate and sustain them. Formal long-term care organisations are not replaced; rather, they may collaborate with a Circle - for example, when a social support need is identified that members of a Circle can address.

CARE RECIPIENTS

As mentioned earlier, Community Circles focus on the phase *before* people require professional care (hence the term *"voorzorg"* - "before care" or 'precaution'). In practical terms, this means that members do not yet have a formal or professional care need. Instead, people might have more practical needs, like someone to drive them to the hospital or assist with grocery shopping. They might also have social needs and seek companionship. During the interview, Henk Geene emphasised that it is important to start with relatively simple tasks, and for initiators to avoid introducing physical or medical care tasks too early. People tend to withdraw quickly if these kinds of activities are mentioned at the outset. However, Henk believes that given the current shortages of care professionals and the growing ageing population, in the future, members of Community Circles may perform basic nursing tasks, such as putting on compression stockings or assisting with drippling eyes.

Moreover, on a small scale, some Community Circles have already begun carrying out minor care-related actions: "I now feel comfortable talking about helping each other with compression stockings—putting them on, for example. And I notice that people don't shy away from that. But I won't go further than that" (HG).

Mirthe Verberkt, a social worker in a welfare organisation in the region Land van Cuijk, was more cautious during the interview. She stressed that it is important to note that performing care tasks cannot be imposed on any Community Circle. Each Circle is autonomous, and members collectively decide which tasks they are and are not willing to undertake.

VISION

Looking to the near future, Henk Geene foresees that professional care providers may also start referring people to a Community Circle. During the interview, he gave the example of general practitioners, who could refer individuals experiencing loneliness or informal carers who are overburdened to a Community Circle for (practical) help and support. He also mentioned that Community Circles could play a role when someone is discharged from the hospital. Today, if a patient is released after surgery but lacks a supportive home network, they are often referred to a care hotel—placing additional pressure on the professional care system. Henk expects that Community Circles may increasingly help fill this gap. While Mirthe Verberkt acknowledges that professional care providers may refer individuals to a Community Circle, she emphasised that the ultimate decision to initiate a Circle lies with the local community itself, including determining which tasks its members are willing to take on. In other words, the development of a Circle cannot be imposed on or expected of a community.

OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE

AIMS

- Enabling older people to live independently in their own home for as long as possible: enhancing self-reliance;
- Strengthening informal support and community networks to postpone the need for formal care;
- Increasing community cohesion and connectedness, encouraging mutual support, and reducing loneliness.

HOW DOES IT OPERATE

In recent years, many Community Circles have been developed from the ground up, initiated by committed local residents. Increasingly, municipalities and professional care and welfare organisations also show increased interest in the Community Circles and are making plans to set these up.

In his book, Henk Geene outlines how Community Circles are typically set up. A Community Circle typically begins with a starter meeting, where interested residents come together to receive information. People who live close to one another - ideally within walking distance - are intentionally seated together so that, if they feel enthusiastic, they can immediately decide during the meeting to form a Community Circle. These starter meetings can be organised and led by motivated individuals, on a small scale, or the initiative could be taken by, for instance, a welfare organisation.

Adding to this, Mirthe Verberkt explained during the interview that they as a local Welfare organisation aim to motivate people to come to the starter meeting, by teaming up with three local residents who are enthusiastic about the development of a Community Circle, and who are asked to personally visit others with an invitation to take part in this first meeting.

The second step, as outlined by Henk Geene in his book, is for participants to discuss what kind of support they can offer and what kind of support they may need themselves (e.g., groceries, transportation, companionship, small household tasks or outdoor chores). More specifically, people typically fill in what type of help they would like to receive and what type of help they can offer. Two 'connectors' are then selected—members who monitor incoming support requests, keep an overview of who can offer which type of help, and make the necessary matches (Podcast *Van Zorg Naar Gewoon Leven*, 2025). These 'connectors' are from the local community. Sometimes, they

receive some training but this is not common and also not required. They often select themselves, often because they strongly support the idea of Community Circles, or are proposed by local social workers or lay people who take up the initiative.

The Community Circles function in an informal manner, meaning that there is no 'strict' evaluation happening as to whether support is offered at all times (to give an example: the connectors will not 'check' whether the lawn of a member who requested help with this, is actually mowed by the member who offered to take on this task). This informal approach is intentional and aligns with the underlying values of the Community Circles, which emphasise autonomy, reciprocity, and community ownership rather than oversight or control. By avoiding rigid monitoring mechanisms, the Circles aim to foster a supportive environment in which members feel empowered to offer and request help without fear of judgment or administrative burden. Any issues or unmet expectations are expected to be addressed through open communication among members, or, if necessary, with the support of a connector acting as a facilitator rather than an enforcer.

The time frame for a Community Circle to be developed may differ, ranging from a few weeks (after the starting meeting) to a few months. It very much depends on already existing connections between people or whether circles are set up amongst people who hardly (or even not) know each other.

MAIN OUTCOMES

Research studies into the outcomes of the Community Circles are presently lacking, meaning that systematic, empirical evidence on their effectiveness is not yet available. That being said, individuals involved in these Circles frequently report positive experiences, including increased community engagement, stronger social connections, and practical relief for informal carers who benefit from shared responsibilities and mutual support (NLZVE, 2025). For instance, a member of a Community Circle may offer to take the client on a walk, giving the informal carer some alone-time.

Moreover, both in the interview with Henk Geene and in the podcast *Van Zorg Naar Gewoon Leven*, it was emphasised that many participants derive a sense of purpose and personal satisfaction from helping others and contributing to their local community. This intrinsic motivation appears to play an important role in sustaining participation and reinforcing social cohesion within the Circles. While these observations are primarily anecdotal, they suggest that Community Circles may have meaningful social value beyond direct practical assistance, pointing to potential benefits for individual wellbeing and community resilience.

CARE PARTNERSHIPS

True *care partnerships* - in which members of a Community Circle work together with staff from professional care or welfare organisations - are still limited in practice: "*Formally, we're not yet at the point where clear pathways exist between informal and formal care. Everything we have developed so far is still part of the preliminary phase. It all takes place before the formal care trajectory begins*" (HG).

At the same time, the first steps *can* be taken toward building such connections—between Community Circles and professional care providers (particularly home-care organisations), as well as with general practitioners and hospitals. More specifically, this could work in relation to home care: "*It's no longer easy to receive a home-care entitlement. If the situation isn't urgent or severe, home care might say: 'Listen, madame, you will receive support from us, but we too are facing shortages. We cannot do everything ourselves. We'll look at what you can do independently, but also at what people around you might be able to help with. Together, we'll build a network with you, and from there our home-care support will begin.' From such an urgent situation, you can more easily encourage someone - and their environment - to see that things aren't going well. That can be an opportunity to establish or involve a Community Circle at home for particular tasks or support. In this way, you can start building a bridge between Community Circles on one hand and other care providers on the other*" (HG).

In several sites in the Netherlands, small-scale initiatives have begun to link Community Circles with professional care providers. Mirthe Verberkt described how such collaboration can work in practice: *"We have occasionally seen that the connectors - those who match supply and demand within a circle - also take on a signaling role. For example, when someone hasn't tended their garden for a long time or hasn't been seen outside for weeks, they may ask the district nursing service to briefly check in to see whether there is more going on, or whether additional support is needed. A Community Circle is not a replacement for professional care, but it can be a valuable addition. It's wonderful if someone receives their medication every day at 11 a.m., but if they then spend the rest of the day alone at home, they could really benefit from something as simple as having coffee with someone once a week. So, we also try to coordinate with district nursing services—asking whether there is anything else needed"* (MV).

SUSTAINABILITY

Sustainability is strengthened through community ownership - local residents themselves acting as the driving force - as well as a low-cost set-up, the availability of freely usable manuals and step-by-step guides, training opportunities, organised and provided by the national coordinators and NLZVE's role as a knowledge platform for continued development. National partners (including healthcare insurer VGZ as well as NLZVE) support scaling efforts; however, securing long-term

funding and structural embedding within municipalities and organisations remains an ongoing challenge.

Collaboration with local welfare organisations, senior citizen associations (such as the local department of the Roman Catholic older people's organisation, KBO), municipalities, and health insurers supports the initial set-up, knowledge exchange, and in some cases funding or organisational capacity. NLZVE also facilitates connections with relevant local partners.

TRANSFERABILITY

There is an extensive step-by-step methodology available that can be followed to set up a Community Circle. This methodology is extensively described in the book by its founder, Henk Geene (Geene, 2025, p. 64). It outlines, among other things, the three stages in the development of *community circles*:

1. Initiating community circles: in principle, everyone can start a circle, citizens, local councouncils of citizens, volunteers' organisations, professional organisations, housing cooreratives as well as municipalities. The process differs, depending on how people live: independently in neighbourhoods, in apartment flats, rural or urban. How more nearby, the easier it is to set up circles.
2. Developing community circles; usually it requires more meetings to set up a circle. Issues need to be addressed such as: who takes the lead, what should be the program of the first meetings, to make an inventory of 'supply' and 'demand' of potential members. Supportive tools are available (as mentioned before), but in the end, people themselves decide how they start.
3. Linking community circles to the existing social support and care structures. After these issues are arranged and a circle is initiated, one may organise links to professional care, welfare and housing organisations, as well as volunteers' organisations. But again, members of the circles and organisations themselves decide in a dialogue. Therefore, processes, outcomes and structures differ to a large extent.

For the adoption of community circles in regions in the Netherlands where no circles exist, several phases can be distinguished (Geene, 2025, p. 56):

- The first phase centers on *raising awareness*: helping older people recognise that they will be increasingly reliant on themselves and that it makes sense to look after one another by active, fit older people supporting more vulnerable people;
- The second phase involves *gathering experiences and needs* from older residents, as well as identifying the opportunities and bottlenecks they encounter in the areas of Housing, Care, and Wellbeing;
- The third phase focuses on *implementing the projects* and develop connections to organisations for Housing, Care, and Wellfare.

Although the core principles of the *Voorzorgcircles* are essentially the same, regional differences in approach can be observed that deviate slightly from the model as originally developed by Henk Geene. For example, Mirthe Verberkt indicated that in the neighborhoods where she works, less emphasis is placed on creating a sense of urgency through negative framing, and more on highlighting the value of doing things for one another. As she explained: "*That's what we always say as well: don't tick all the boxes. What do you actually enjoy doing for someone else? Is it cooking for someone, walking a dog, babysitting a child once in a while? You name it. Those things give people a positive feeling. Instead of saying, 'You all need to look out for each other more, because the system can't cope anymore.' That may be true, but starting from that point of view can be quite difficult in practice"* (MV).

The methodology is explicitly designed to be transferable. NLZVE has published materials (scripts, invitations, visual guides) and there are concrete examples of local implementations in various municipalities, indicating strong transferability. While the approach requires local adaptation (culture, networks), the formula appears to be relatively easy to reproduce, as can be seen by the mushrooming development of community circles in the Netherlands (Van Roosmalen, 2026).

STRENGTHS

The strength of a Community Circle, according to interview respondents (HG and MV) lies in its accessibility and the principle that everyone - young or old - has something meaningful to contribute, as the concept is low-threshold and inclusive, organised locally within the community, strengthens social cohesion and informal care structures, operates at relatively low cost with national support, offering practical resources such as a handbook, leaflets, and a step-by-step guide, and is positively valued by municipalities and health care insurers (ActiZ, 2024).

Geene notes in his book that the circle can be seen as a living organism. It is not a static entity: members leave, new members join, and these new participants place different emphases. In addition, connections can be made with various social and professional structures, such as home-care services or welfare organisations. The community circle maintains an open relationship with society, and its members determine how they position themselves in relation to their immediate social environment. The *couleur locale* will shape each individual community circle (translated directly from Geene, 2025, p. 92).

WEAKNESSES/CHALLENGES

During the interview, Henk Geene reflected on some of the challenges experienced: "The Circle itself is very simple, but getting to the point where a Circle can be established is difficult. And that

difficulty lies here: seventy years ago, we had naoberschap ['neighborliness']—neighbors naturally looking out for one another. Then came a period of individualism, when life went well for most people and we needed each other less. And now we need to shift back toward collectivity. Among older adults, especially the baby boomers, this requires a reset of mindset. They need to move from an individual orientation to a collective one. And that transition is challenging" (HG).

Furthermore, as outlined in the subsection *Care partnerships*, the connections between Community Circles and professional care providers are still limited in this stage of the implementation of the concept. During the interview, it was emphasised that Community Circles are autonomous and decide for themselves which tasks they are and are not willing to take on. It therefore remains uncertain to what extent members of a particular Circle will actually collaborate with professional care providers. Moreover, care is not the first driver for the circles: it is more giving attention to each other, providing practical help and, thereby, developing meaningful relationships that contribute to the wellbeing of all involved.

Another challenge concerns the lack of transitional funding (Geene, 2025, p. 32). The government has not yet created sufficient structural conditions to facilitate the transition process towards a society in which participation of citizens comes first instead of relying on professional care and support. One such condition is the provision of a transitional budget for partners involved in the "pre-phase" of support—stimulating active older citizens who assist vulnerable neighbours or other members of society, either through community circles, care cooperatives, volunteers' organisations or other forms of citizen participation. This funding is essential for successfully managing the societal changes required, according to Geene.

CONCLUSIONS

Community Circles represent an innovative approach to supporting vital, older adults, who often do not have a LTC need yet, in their own neighborhoods, with the aim of enhancing self-reliance, fostering social cohesion, and providing practical informal support before formal care becomes necessary. Over the past four to five years, the initiative has expanded from small local pilots to approximately 1500 Circles nationwide, demonstrating that (older) adults are willing and able to contribute meaningfully to their communities. The core principle - that everyone can participate and contribute in some way, regardless of their personal limitations - ensures accessibility and inclusivity. Local organisation, low-cost set-up, and the availability of practical resources offered by NLZVE, such as handbooks, visual guides, and step-by-step manuals, further support scalability and sustainability. Regional pilots and case reports indicate that Community Circles increase community engagement, provide better insight into older adults' needs, and offer practical relief for informal carers. Participants report high satisfaction from contributing to their neighborhood and helping others, highlighting the social and emotional value of the initiative. Finally, participants report

stronger social connections and they receive practical or social support, which potentially makes it possible for them to live at home longer.

Community Circles operate proactively, forming networks before urgent care needs arise. This early engagement allows participants to maintain independence, strengthen collective self-reliance, and identify or address issues such as loneliness, overburdening, or neglect at an early stage. Practical tasks typically start with simple support, such as running errands, offering companionship, or helping with minor household tasks. The autonomy of each Circle ensures that members decide collectively which types of support they are willing to provide, maintaining a balance between the needs of more and less able members. This flexibility enables Community Circles to function as a "living organism," adapting to changing membership, local context, and community dynamics, while maintaining open connections to formal care and welfare structures as appropriate.

Despite these strengths, several challenges remain. Collaboration between Community Circles and professional care providers is still limited. The voluntary and autonomous nature of the Circles implies that members may or may not be willing to take on tasks that overlap with professional care, in particular, when it comes to personal care. leaving the potential for formal collaboration uncertain. Finally, Structural support from government, municipalities, and health care insurers is not fully in place.

Establishing a Community Circle also requires a cultural shift from individualism to collective responsibility, particularly among older adults accustomed to self-reliance. While pilots have shown that guidance and encouragement help overcome initial resistance, scaling remains a gradual process. Furthermore, monitoring and evaluation are currently conducted regionally, and extensive research into the outcomes of Community Circles is presently lacking.

In conclusion, Community Circles provide a promising model for neighbourhood-based support of older adults, combining proactive engagement, community ownership, inclusivity, and flexibility. They have the potential to strengthen informal support networks, increase social cohesion, and offer practical help, complementing rather than replacing formal care. To fully realise their potential, further work is needed to expand structural support, formalise partnerships with professional care, and secure transitional funding.

ACKNOWLEDGEMENTS

Two interviews were conducted:

- Henk Geene (initiator of the Community Circles, author of the book that outlines the methodology. He has a Master in Psychology. Henk started with the initiative in his early seventies after a professional career in the disability sector)
- Mirthe Verberkt (Social worker and project leader at Sociom, a Welfare organisation that is involved in the establishment and scaling up of Community Circles in three regions in the South-Eastern part of the Netherlands)

REFERENCES

The items below link to resources that are available online and contain more information about the background and functioning of community circles (all in Dutch).

Book by Henk Geene, that outlines the methodology of the Community Circles: Geene, H. (2025) Voorzorgcirkels als antwoord op Vergrijzing. Barneveld: Boekenbent (4th edition).

Knowledge base from Netherlands Cares for Each Other: NLZVE Kennisbank

Article by ActiZ: Voorzorgcirkels groeiende trend in zorgpreventie

Presentation by Henk Geene

Article in popular Dutch press:
https://www.rtl.nl/nieuws/binnenland/artikel/5545483/voorzorgcirkels-buren-hulp-toename-netwerkcirkel

Article by Actiz – association of healthcare providers in the Netherlands:
https://www.actiz.nl/actueel/voorzorgcirkels-groeiende-trend-zorgpreventie

Podcast Van Zorg naar Gewoon Leven – episode Community Circles:
https://vanzorgnaargewoonleven.nl/podcast/

Podcast Nieuwe Blik op Zorg – episode Community Circles:
https://www.cooperatievgz.nl/cooperatie-vgz/nieuws-en-media/podcast

6. Colourful Relief (Kleurrijk Ontzorgen)

ABSTRACT

Colourful Relief (Kleurrijk Ontzorgen) is an ongoing program developed by Cordaan (a large long-term care provider organisation) to strengthen the home situations of adults with learning disabilities who live with their families in Amsterdam. The initiative was initiated following concerns raised at Cordaan by Day Centre staff about the wellbeing of both clients and their relatives who continued to provide care at home, with staff often facing strained relationships with these families due to low levels of trust and suboptimal communication. Many of the families - the vast majority of which has a migration background - faced various barriers in their interactions with the formal care system, including unfamiliarity with the care system, low trust in formal care services, past negative experiences, and a lack of suitable services for adults with high support needs.

Colourful Relief addresses these issues by offering a range of outreach and preventative supports, including an ambulatory team providing home-based assistance in various domains (e.g.,

administrative, practical and behavioral support), an intercultural consultant working to improve trust and communication, extended Day Centre hours and overnight respite care, and workshops aimed at strengthening staff's intercultural competence. These activities aim to reduce the risk of crisis situations at home, support informal carers' wellbeing, and foster constructive partnerships between families and LTC workers at Cordaan.

Qualitative evaluation findings demonstrate improved communication, increased trust in care providers, greater uptake of respite services and enhanced self-efficacy among staff. Families report feeling more recognised and better supported, while staff describe increased competence and confidence in working with diverse households. Preliminary quantitative evidence also suggests a lower incidence of emergency admissions among this group compared to similar providers.

While the program has become embedded within Cordaan, long-term sustainability depends on securing structural funding for the program's activities beyond the current mix of regular and temporary sources. Despite this uncertainty, Colourful Relief illustrates a transferable approach to strengthening care partnerships and supporting informal carers through preventative, relationship-centred and diversity-sensitive work.

INTRODUCTION

Name of the good practice: Colourful Relief (Kleurrijk Ontzorgen).

Country of implementation: the Netherlands (more specifically: Amsterdam).

Implementation level: Local.

Leader organisation: Cordaan (one of the largest LTC providers in the Netherlands, based in Amsterdam).

Contacts: Fenne Verhoeven (project lead and diversity experts), kleurrijkontzorgen@cordaan.nl or through Ludo Glimmerveen (researcher), L.M.Glimmerveen@vu.nl.

Website: https://www.cordaan.nl/verstandelijke-beperking/kleurrijk-ontzorgen/.

Date of data collection: This report is based on a secondary data analysis of earlier qualitative interview data collected by Ludo Glimmerveen in 2021 as well as qualitative interview data collected by Carline Wesdorp and Ludo Glimmerveen in 2025 (see Glimmerveen & Voss (2024) for an earlier analysis of the 2021 data). This template was filled in in November 2025, mainly drawing on the data collected in 2025.

Description of the organisational structure of the practice:
Colourful Relief is a program that was initiated and is executed by the Amsterdam-based long-term care provider Cordaan; one of the largest Dutch provider organisations. Cordaan provides care and support for older people, people with disabilities, youth as well as people with mental health support needs. This program falls under the division 'Wonen, Werk en Dagbesteding' (English: 'Housing, Work and Day Services') of the Disability and Mental Health Care branch of Cordaan. The program is led by a project manager (who works as a diversity expert at Cordaan) and supported by a policy advisor also employed at Cordaan. The various services that have been developed under the program have their own manager, who report to the director of Housing, Work and Day Services.

START AND STATUS OF THE PRACTICE/INITIATIVE

WHEN DID IT START

The first activities that can be considered the start of what is now known as Colourful Relief commenced in 2018. These initial activities were mainly geared towards exploring the support needs of the target group - i.e., families who care for an adult relative with learning disabilities at home, often with a migrant background - in their home situation; needs that were until then relatively unknown to the organisation and its staff.

The initiative is still ongoing. So far, the program is supported through a largely temporary stream of funding (mainly through the Dutch national Long-Term Care Act, but also including Cordaan's own resources) to experiment with the approach developed under the program. Cordaan is currently negotiating with funding and regulatory agencies to secure structural funding for these activities.

REASONS FOR STARTING

Activities started after care staff at Cordaan's Day Centers became increasingly worried about the home situation of some of their adult clients with learning disabilities who lived with their family in the community (i.e., not in residential care facilities). Staff members were occasionally worried about the wellbeing of household members who cared for their relative with a disability, suspecting high burden and fragile support systems at home which could also put the wellbeing of their clients

at risk. At the same time, the quality of the relationship that staff members had with these clients' relatives was often suboptimal (characterised by low trust and limited and/or strained communication). So, in spite of their worries, care staff often did not have a clear sense of what the home situation looked like, nor did they feel capacitated to relate to this situation in a supportive way (and supporting relatives was also not part of the formal scope of their work). Based on these signals, the then-director at Cordaan commissioned a team (initially consisting of a project lead, policy advisor and an intercultural consultant) that would investigate what these home situations looked like, what support needs these families had, and how Cordaan could organise such support to relief these families and strengthen their resilience.

TARGET GROUP(S)

The primary target group of Colourful Relief consists of the family members of Cordaan clients with learning disabilities. In particular, it concerns family members - mainly parents and siblings - that actively choose to continue to care for their relative in their own home, also after this relative has reached adulthood (18+) and developed care and support needs that may put considerable pressure on these family carers. In many situations, their relative with a disability would qualify for moving to a residential care setting. And in many cases, the relationship between these families and the formal care system was characterised by relatively low trust - often rooted in a history of negative experiences with the care system and lacking supports that aligned with these families' needs and preferences - and suboptimal communication.

Around 80% of the families that are supported through the program have a migration background (i.e., with parents being first or second generation migrants). Looking at statistics for Amsterdam, there are substantial differences in the choices that families with or without a migration background make in either caring for their adult child at home or in a residential care facility (Glimmerveen & Voss, 2024). Families with a migration background seem far more likely to care for their relative at home, also when these relatives qualify for living in a residential care setting. To make this more concrete: 47% of people living in a residential care setting (n=1,415) had a migration background, compared to 76% of those living with family (n=1,014). A particularly large differences can be found among people from Moroccan descent: 83% of this group lives with family, compared to only 24% of the people without a migration background (Van Wijk et al., 2022, p.21).

Several issues seem to contribute to these families' choice to continue to care for their adult relative at home:

- *Cultural or religious norms* may contribute to the desire among families (and mostly: parents) to remain the primary carer for their relative. At the same time, our interviews also showed how this imperative was sometimes misinterpreted by care staff, who would sometimes think that families 'did not want support' and that they want to do everything by themselves as much as possible. This sometimes appeared to be a false assumption: 'they might not want their child to move to a residential setting […] but they do want support for their child' (intercultural consultant);

- *Being unfamiliar with the formal care system:* Especially among parents who are first generation migrants, unfamiliarity with formal support services can be a barrier for exploring possibilities for using formal support services at home. It could also contribute to not considering residential care as a desirable option, for example in a case where parents 'think that all care staff at a residential facility would leave to go home at six' and leave their children unattended.

At the same time, other reasons for the 'distance' that families experienced towards formal care services are rooted in the formal care system itself (discussed in more detail by Glimmerveen & Voss (2024) and Ben Sajet Centrum (2021):

- *Formal services were not geared to this target group:* In the majority of cases in the Netherlands, people with learning disabilities and 24-hour care and support needs move to a residential care setting before they reach adulthood. As a result, many support services are geared to children and youth with disabilities but cease to be available for people that are 18 years or older. Even family members that were well-acquainted with the Dutch care system were often unsuccessful in finding formal support services that would match the relatively intense support needs of their relative;

- *Mistrust was often reinforced after negative interactions with the care system:* Family members reported instances in which they felt that their needs, concerns or preferences were not recognized or taken seriously by care professionals. Experiences with being discriminated against (both within and beyond the care system) were mentioned to fuel mistrust of professionals and 'institutions. Moreover, families sometimes feel 'pushed' to adhere to the norm of moving their relative to a residential setting. Some family members were reported to fear that their relative would be 'taken away from them' if professionals felt that the family could not properly care for them. This could act as a barrier for informal carers to openly discuss issues of burden or other vulnerabilities with LTC workers.

Contributing to the urgency of improving the supports for these families is the fact many of the parents targeted by Colourful Relief are ageing. An analysis by Cordaan showed that in 2023 28% of the primary family carers are 60 years old or older (in a total population of 570 clients). In 10 years, this percentage is expected to rise to 77% – a development that is likely to increase the number of home situations with progressively fragile informal support systems.

CARE RECIPIENTS

The care recipients assisted by the program's primary target group are adults (18+) with mild to severe learning disabilities - and regularly multiple disabilities - who live with their family members (often: parents and/or siblings). Most of these care recipients have been assigned a care indication of VG4 or higher, which in the Dutch system indicates that the person has moderate to high care and support needs, a need for at least regular supervision and assistance, and often qualifying for living in a residential care setting with 24-hour support. While the group of care recipients is characterised by considerable diversity, these adults function at a younger developmental age (ranging from early childhood to young teens), communicate in a variety of ways (from fluent speech to assisted, non-verbal or sensory-based communication) and often benefit from a clear structure and guidance within their daily activities. The group that is served through Colourful Relief are generally clients at one of Cordaan's twelve Day Centers or supported workplaces (i.e., inclusive work environments that provide people with learning disabilities tailored guidance, structure and opportunities to develop skills while participating meaningfully in everyday work), and live in or close to Amsterdam.

OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE

AIMS

The main aim of the program is to support the home situations of clients so that these clients can continue to live at home if possible and live a fuller life, while sustaining or improving the wellbeing of family carers. This main is pursued by developing and offering a range of outreach services and preventative interventions that reduce the risk of emerging crisis situations in the home situation. As a result of these activities, Colourful Relief tries to:

- Fill the service gap that was experienced by the target group (i.e., to develop and offer services that align with the relatives' often-high support needs of clients within the home situation; enabling family members to continue their caring role while respecting their particular situation and preferences);

- Improving the relationship, fostering trust and strengthening mutual recognition and support between Cordaan care staff and clients' family members.

HOW DOES IT OPERATE

Under the Colourful Relief program, a number of additional services have been developed in pursuit of these main goals:

- An ambulatory team (5.5 fte; with a combined average case load of 50 families) that can provide support to households that care for an adult relative with a learning disability. Team members have a variety of educational backgrounds, mainly including vocational training in social work and social care. Support is provided in the home and can focus on various domains, including:
  - Supporting with administrative work around care and support;
  - Supporting household members in dealing with challenging behaviors by their relative with a disability;
  - Helping both families and client to adjust to enrolment at the Day Centers;
  - Doing activities (e.g., going outside, playing a game) with the person with a disability, offering respite to family members;
  - Helping families with establishing more structure in everyday activities;
  - Providing families with support to maintain or strengthen social connections;
  - Helping families to explore possibilities for residential care if needed and desired.

- Availability of an intercultural consultant that both staff and households can call upon in relation to individual cases to explore how a household can be better supported. Between 2020 and 2025, two different people held this position. Both had a migrant background themselves; one being trained as an educational psychologist, while the other had not received formal training as a care professional but held 25+ years of experience in various position at Cordaan including at the Client Intake and Service Office. The intercultural consultant can contribute by either investing in the relationship with relatives (e.g., by doing home visits or meeting them at Cordaan locations) or by supporting staff members in their interactions with relatives. Often, the consultant is called upon by colleagues from the Cordaan Day Centers or supported workplaces in situations where they are unable to establish constructive relations and communication with families. The intercultural consultant has more time and flexibility available than other staff to invest in this relationship, taking additional time to establish rapport and explore the situation and needs. Between 2022 and June 2024, the intercultural consulted directly or indirectly supported 180 families.

- Extended opening hours for the Day Centers (longer weekdays + weekends) and overnight respite care for relieving the pressure on households. Every weekend, Cordaan's overnight facility can receive 11 clients who live with their family to give family carers an extra break. Once every month, clients can visit one of the Day Centers on Saturdays (normally these are only open Monday to Friday).

- Workshops for Cordaan care staff to strengthen their intercultural competence. Throughout the organisation, Colourful Relief's project lead and intercultural consultant organise workshops for various care teams, supporting them to reflect on – among other things – how their own cultural frame of reference influences them in their interactions with family members. The workshops help them develop behavioral repertoires for these interactions in order to establish more constructive relationships. Between 2022 and June 2024, 30 of such workshops were organised.

In terms of resources: initial costs for developing these services were carried by Cordaan itself. Attracting sustainable funding has been an issue that was explored with funding agencies from the onset on the program. Some components of the program are now funded through regular public long-term care funding, while other parts are covered by temporary 'experimental' funding that was made available by regulatory and funding agencies. With this latter funding ending soon, Cordaan and these regulatory and funding agencies are exploring possibilities and conditions under which this temporary funding may be made structural.

The annual budget for the whole program has been around 450,000-500,000 euro.

MAIN OUTCOMES

Analysis of the interviews with care staff and family members highlighted positive outcomes in several domains. These included:

- Improved relationships and more (positive) communication between relatives and care staff. Family members shared that they appreciated the communication and support they experienced from both the intercultural consultant and the ambulatory team. This did not only improve their relationship with these specific professionals, but it also contributed to the quality of communication and relationships with other staff at Cordaan:

- Sister of client: “Our communication with Cordaan has changed because of this. […] I also speak to care staff differently. I also check how they are doing, and engage in small talk, to strengthen the bond with staff. […] I also notice this with the overnight respite care: we keep in touch a lot more, there is a much lower threshold. When something is up, I just call them”;

- Sister of client: “There is not only contact when something needs to be discussed, by us or by Cordaan. There is more than that. Not just about administrative or informative issues. My mother also feels a lot more involved and in control with the care for [client] at Cordaan. […] She feels less barriers and picks up the phone now when there is something she wants to discuss”.

- Increased trust in formal care and feeling recognised by care staff. Family members appreciated the increased sense of recognition for their situation and (cultural or religious) preferences, particularly in their contact with the intercultural consultant:

  - Sister of client: “She was much more aware of how this works in our culture. Or where my reasoning comes from, you know? I think that she works with a much more culturally-sensitive approach”.

- Uptake of additional respite care services has strengthened wellbeing of family carers. The work by the intercultural consultant and the ambulatory teams seems to have lowered the threshold for some families to use additional respite care services. Particularly siblings shared how this had relieved the pressure on their parents:

  - Sister of client: “My mother thinks it [overnight respite care] is hard, because she needs to hand over the care to other people. Especially when spending the night. […] But I know that she secretly thinks it is really nice, even if she won’t admit to it. Because she starts to doing things again [that she has not done for a while]. During the weekend, she visits her brother again, which she would not do otherwise because she would need to make arrangements [about the care] for my brother with us [siblings]. But you noticed a barrier there because we all have our own lives. […] So now she goes out more, and I am really happy about that.

  - Mother of client: “It took me a long while, until at some point I was under a lot of pressure, and I had to admit that this overnight respite care was actually quite nice.

[…] I was pretty burned out then; I really did need help and support. And I am really happy that I was able to get it in a way that matched what I needed".

- Improved intercultural competence among care staff. Staff members at the various Day Centers and supported workplaces reported to be happy with availability of the intercultural consultant, who has contributed to improving their relationships with those families who previously felt 'distant'. At the same time, several staff members shared how they also feel more competent themselves in establishing constructive relationships with families. They noted feeling less barriers to 'just approach' people and get in touch with them. And that they felt more aware of their own cultural baggage – and that having this baggage was okay, but also important to be aware of. A staff member at a Day Center shared how she learned that 'having a different background' should in itself not be seen as an explanation for anything, and that she puts more effort in finding out 'with whom she was sitting at the table'.

Part of the analysis described above has published in a number of Dutch-language articles and reports that can be found here (Glimmerveen & Voss, 2024; Van Wijck et al., 2022).

On a quantitative note, Cordaan and the regional LTC funding agency did a joint internal evaluation in which they compared to the incidence of emergency admissions among Cordaan clients in the context of the program with another comparable LTC provider that operates in a similar environment. This analysis shows a substantially lower incidence of such emergency admissions at Cordaan (6.4% compared to 13.5%). While the figures that are mentioned in the evaluation report do not show how the characteristics of these two populations compare, the figures at least suggest positive outcomes in terms of strengthening the support systems at home.

CARE PARTNERSHIPS

Promoting care partnerships among LTC workers and informal carers is a key objective of Colourful Relief. The qualitative data that has been gathered - as discussed above - indeed suggest that the program's activities seem to foster supportive relationships and mutual recognition among these target groups. We see several ways in which the program contributes to care partnerships:

- It contributes to sharing care by offering services and support in the home environment (including but not limited to respite care) that are geared to enabling informal carers to sustain their caregiving role while also sustaining or strengthening their own wellbeing;

- It explicitly invests in more trusting relationships between care staff and family members, making sure that families feel more *recognised* in their needs and preferences, while also contributing to family members' recognition for the situation of LTC staff. Overall, this contributes to more constructive and mutually supportive relationships;

- Colourful Relief contributes to the sharing expertise between both target groups. I.e., family carers are approached and recognized as experts in the care for their relative, whereas care staff also share their behavioral expertise by supporting family carers and building their capacities in dealing with challenging behaviors of their relative.

SUSTAINABILITY

Sustainability has been a key issue from the early development phases of the program. The progress, achievements and challenges within the program have from the onset been discussed extensively with the responsible regulatory and funding agencies, including the Dutch Ministry of Health. While some activities are by now funded under the regular LTC funding system, other activities still rely on temporary funding. Particularly for the ambulatory services that are developed within the program, it is still to be decided whether structural funding will be available from 2027 onwards.

Also, in relation to sustainability, much effort has gone into raising awareness within the internal organisation of Cordaan around the importance of the program's activities. Traditionally, the vast majority of services is directed at persons with disabilities themselves, with limited direct support available for the informal support system that cares for these persons at home. The program has therefor - within and beyond Cordaan - done much advocacy work to highlight the importance of investing in relationships with and support for family carers. As a result, Colourful Relief has become an established part of the organisation's activities – although the continuation of activities is still contingent on the availability of structural funding, which is currently being negotiated between Cordaan and the various regulatory and funding agencies.

TRANSFERABILITY

On the one hand, the context of the program is fairly specific, i.e., based in a highly urban setting and with a target group of which the vast majority has a migration background. At the same time, involved staff members believe that the services and approach that have been developed are equally valuable for families without a migration background. Moreover, while studying the program we [the researchers] came across other promising practices that were based in a different setting and for target groups with different demographics, but which relied on similar mechanisms (such as this 'Copilot' practice in which extra support is provided to families caring for a minor with learning disabilities) that seemed to deliver the sought-after results (i.e., improved support for

relatives' wellbeing and improved quality of the relationship between relatives and formal LTC providers). That said, the approach developed under the Colourful Relief program will be particularly relevant and transferable to other regions with a considerable population with a migrant background and with relatively high numbers of families choosing to care for their relative with an intellectual disability also after they reach adulthood.

STRENGTHS

The various interviews have pointed to the following strengths of Colourful Relief and its activities:

- Informal carers have been included as a key target group for support services, instead of 'merely' being the relatives of people to whom care and support are primarily directed;

- Household members have been explicitly positioned as experts for their knowledge about their relative with a disability, which has provided a basis for establishing care partnership dynamics characterised by mutual recognition and improved trust;

- The program provides the space for care staff to take smaller steps in exploring the situation and support needs in the home situation (instead of always having to be pronouncedly 'goal-directed'). This also results in more time to build relationships. Being able to spend more time doing such 'relational work' helps to foster more open communication in which family members feel safer to discuss vulnerabilities. This eventually contributes to a clearer picture of how families can best be supported to sustain their wellbeing and caregiving, but also to an increased willingness of family members to consider additional support;

- The focus on building intercultural and diversity-sensitive competences of care staff has, first, been appreciated by family members who report to feel more recognized for their specific (culturally or religiously inspired) preferences. Second, it has also led to increased feelings of self-efficacy among staff members in approaching and collaborating with family members that may have different cultural backgrounds then themselves. The program has also made care staff more aware of their own (often implicit) cultural frames of reference shaping their caring norms and how they approach families;

- The intercultural consultant and ambulatory team's flexibility to align with and respond to the specific situations and needs of the households that are supported has been a key factor in strengthening support in the home situation and fostering care partnership relationships. The ability to immediately respond to the 'small needs' that can fairly easily be addressed

(even if they may fall outside their formal jurisdiction) has shown to be important for two reasons. First of all, families receive very practical support if professionals are able to 'fix' small-but-concrete issues that they face in their everyday lives (e.g., helping with translating a letter; getting in touch with the housing corporation; helping with ordering a new mattress; etc.). But in addition to such practical support, addressing these 'small needs' is also of symbolic significance. It shows families that they actually benefit from these LTC workers' involvement. It enabled the latter to showcase their value and trustworthiness. This was particularly relevant in settings that– as with many of the families served by the program – are characterized by relatively low trust in professionals and 'institutions';

- Looking at the aforementioned evaluation results, evidence seems to suggest that the activities of the program help to reduce emergency admissions within this target group. This highlights the program's potential for preventing the human suffering as well as the considerable public spending that is inherent to such emergency admissions;

- When looking at the development and implementation of Colourful Relief from an organisational perspective, it has been key that Cordaan's leadership explicitly supported the program. Particularly as there were initially no external funds available for these new activities, it was key that the organisation freed up staff time and resources to develop and experiment with these additional support services. The fact that Cordaan is a large provider organisation also made it possible for them to make such initial investments – something which may have been much harder for smaller organisations.

WEAKNESSES/CHALLENGES

Whereas all stakeholders - including the Cordaan leadership and responsible funding and regulatory agencies - seem convinced about the added value of the approach and activities developed within Colourful Relief, there is still some hesitance in making structural funding available for its activities. This mainly has to do with the fear of expanding eligibility criteria for support in the home situation and the increased costs this would bring to the public care system. While some have argued that the support provided under the program resembles case management services that are also offered in the care for older people, others have highlighted that the timespan of care trajectories is different here. Support for families caring for a relative with a disability may be lifelong, whereas in the care for older people it is often confined to the last phases of life. If this ambulatory support for families would become structurally available and publicly funded, some fear the financial pressure this will bring to the care system. Although others emphasise the preventative nature of such investments - reducing costs elsewhere - this fear has made regulators more hesitant to make structural funding available.

The stretching of boundaries of this scope of support for these families has become an issue in a different way. The flexibility that characterises the approach developed under Colourful Relief sometimes means that LTC workers engage in activities that others do not see as the 'core focus' of professional, publicly funded services. Especially in the context of staffing shortages, some people in the organisation have called for being clearer and stricter about what constitutes the domain and boundaries of the role of professional care. For example, it has been questioned whether 'playing games' or 'going on a walk' with clients - or other activities engaged in to establish rapport or bring respite to family members - should be part of LTC workers' scope in a time where staff shortages are increasing. Others have countered that it is exactly such activities that may be necessary to improve the relationship with families, get to know their situation, and tailor the support to their particular needs.

Colourful Relief has encountered several other challenges over the past years. These include:

- Staff continuity. For a variety of reasons, it has been a challenge maintain staff continuity within the different activities under the program. Such reasons include overall shortages on the labour market, but also changes in management and insecurity among staff about the limited funding horizon for the program's activities. This led some staff members to accept a more stable position elsewhere. While a lack of continuity in staff would be challenging anywhere, it presents some specific challenges in the context of this program. With its reliance on relationship-building with families – particularly in contexts of relatively low trust – changes in staff make it harder to invest in constructive long-term relations between LTC workers and informal carers. Moreover, in cases where staff shortages and changes temporarily compromised the quality of services (e.g., if respite care services where not operating at full capacity), this could sometimes validate the limited trust of families that were already hesitant to use such services;

- Demand is increasing faster that the program's capacity. Partly linked to the issue of staff continuity: the demand for Colourful Relief's services grew faster that the program's capacity. While this can also be considered a success of the program – the developed services are in high demand among families that previously lacked tailored support – it has been an organisational challenge that the program's leadership and staff are navigating;

- Balancing between interests of the family and colleagues: While the work of the intercultural consultant and the ambulatory team often acts as a 'bridge' between the families and staff working at the Day Centers or supported workplaces, this in-between position could also be challenging. It could lead to coordination challenges (discussed below), but also to staff members contesting the position of these 'new professionals' that clients' support structure.

In the words of a Day Center employee: 'what does she bring that I can't already do myself?' In some cases, the intercultural consultant shared that she sometimes wondered whether – in case meetings with family and staff members – she 'chose sides with the family' more than she should have;

- Structural funding: As mentioned before, securing structural funding has been an ongoing challenge, and is still being negotiated among Cordaan and the relevant funding and regulatory agencies.

POTENTIAL IMPROVEMENTS

One organisational issue that may still be improved is the alignment between the role of, on the one hand, the intercultural consultant and the ambulatory team and, on the other hand, the staff at the Day Centers and supported workplaces. For example, at the Day Centers one staff member is assigned to each client as their care coordinator. Part of this role is to coordinate care and support with the clients' family members. When the intercultural consultant or the ambulatory team becomes involved with this same client, is has not always been clear to those involved (including family members) who would take on a leading role in coordinating care. Moreover, staff members at the Day Centers would not always have a clear idea of what the work of intercultural consultant and the ambulatory team exactly looked like. Lack of communication or coordination between colleagues could sometimes also lead to confusion or frustration among family members, which is particularly significant in situations where trust is already limited or fragile. Ensuring clearer communication and information exchange among colleagues therefor has the potential to further improve the practices developed under Colourful Relief.

CONCLUSIONS

The development and implementation of Colourful Relief demonstrate how a long-term care organisation can meaningfully strengthen the support systems of families caring for an adult relative with a learning disability at home. The program supports LTC workers in building more constructive and trusting relationships with relatives who had often felt distant from, or even mistrustful of, the formal care system. By creating space for outreach, relational work and a more nuanced understanding of each family's situation, the program has helped both groups navigate their relationship and strengthen carers' mutual recognition, while also providing addition support and respite services that were previously unavailable to families.

For families, a key contribution of the program lies in the fact that they are explicitly recognized as experts, but also as a group that may need support in their own right. Where many parents and siblings had felt unseen, unsupported or misunderstood, the program offers practical and emotional

support and an approach that affirms their expertise in caring for their relative. The availability of the intercultural consultant and the ambulatory team has lowered thresholds for communication and made new forms of support accessible. This, in turn, seemed to have alleviated pressure on informal carers, many of whom are ageing and at risk of caregiving fatigue. The qualitative accounts (Glimmerveen & Voss, 2024) show how these interventions have shown to improve wellbeing, expand possibilities for respite and help families feel safer to discuss vulnerabilities with care staff that would otherwise remain unspoken.

The approach developed in the program seems to contrast the currently dominant paradigm in the Netherlands that - in times of workforce shortages - promotes a task shift away from paid LTC workers to informal carers. Instead, Colourful Relief encourages a step forward: an outreaching approach with room to explore home situations gradually, to take time to build rapport, and to acknowledge the cultural frames of reference that shape interactions. Staff members report feeling more competent and confident in engaging with families who may have different backgrounds or expectations, and more able to rely on the support of the intercultural consultant when communication proves difficult. Initial evidence from an internal evaluation by Cordaan and the care funding agency suggests that this approach seems to prevent crisis escalation, reduce emergency admissions and - as confirmed in our own data collection - promote smoother collaboration. The program therefore not only supports families directly but also creates an environment in which staff feel empowered to work relationally.

The role of organisational and managerial support has been crucial in enabling this development. Cordaan's leadership made resources available at a stage when no structural external funding existed. This early commitment allowed the team to experiment, learn and iteratively build these new support practices. Leadership support has also been instrumental in raising awareness within the organisation that caring for adults with learning disabilities cannot be confined to the person receiving services alone; the wellbeing and capacity of their family is integral to sustaining care at home.

However, the limits of such managerial support are also evident – especially as long-term funding for these activities has remained uncertain. This uncertainty has also led to critical questions on whether some of the activities should indeed be pursued by the organisation, or whether they lie beyond the role of professional long-term care. While regulators and funding agencies recognise the program's substantive value, hesitations remain due to concerns about expanding entitlements and the associated financial implications. This tension highlights a broader issue in the long-term care system: preventative, relationship-centred and outreach-oriented work can be widely supported in principle yet remain difficult to embed structurally when funding mechanisms prioritise more narrowly defined, individualised care.

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Van Wijck, F., Kremer, M., The, A., & Glimmerveen, L. (Eds.) (2022). *Leven en zorgen in de grote stad* ['Living and caring in the big city']. Amsterdam: Ben Sajet Centrum.

More information about the program can be found on the following websites:

- https://www.kennispleingehandicaptensector.nl/tips-tools/tools/kleurrijk-ontzorgen-bij-cordaan;
- https://www.cordaan.nl/verstandelijke-beperking/kleurrijk-ontzorgen/.

NB. The insights shared in this document have partly been described in the sources listed above, but they will be discussed in more detail in a Dutch-language publication authored by Ludo Glimmerveen and Carline Wesdorp that is scheduled for Spring 2026.

7. Family Carers Training (Usposabljanje za družinske in druge neformalne oskrbovalce)

ABSTRACT

This report presents the selected good practice the 'Family Carers Training' a long-running practice developed and delivered by the Anton Trstenjak Institute (ATI), together with over 40 Slovenian municipalities and local partners such as health professionals (community nurses or physiotherapists), local municipal administration. Since October 2001 the practice has continued without interruption, gradually moving from early cycles embedded in residential care to a community-anchored program implemented across more than 40 municipalities from various regions of Slovenia and adapted to local needs. What started as a response to very human problems, such as guilt and relational strain when a relative moves into care, burnout among employees, and the under-recognition of unpaid family care, has matured into a clear method. The training consists of 10 consecutive meetings led by an ATI facilitator and topic-specific local professionals, followed by the founding of a peer 'group of relatives' supported for at least a year and after that often led by newly trained participants themselves. Financing has combined national developmental support and municipal co-funding, with typical total costs for a full cycle (including literature, trainers' time and travel, and a year of group support with leader training) running in the range of six to seven thousand euros. In several municipalities the local government covers a very high share of that cost.

Outcomes are assessed through questionnaires completed by participants at the end of the training and are visible at several levels. At the individual level, carers are reported to consistently describe gains in competence, confidence, and self-care, a clearer view of services and rights, and relief from isolation thanks to the peer dynamic. At the family and care recipient level, participants report more respectful everyday interactions and better problem-solving, especially around dementia and mobility. At the community level, the practice seeds social capital: alumni frequently volunteer, some formalise their skills and move into paid care roles, and the groups of relatives become small hubs that municipal actors can partner with. The model's strengths are its human scale, as the practice involves a large number of people from different locations and municipalities' responsiveness (for example, one meeting is reserved for the cohort's most pressing topic), and deliberate cross-sector collaboration between a non-profit organisation, medical professionals, and municipal representatives. Its vulnerabilities are the capacity needed to staff such a comprehensive course, uneven municipal willingness or ability to co-fund, and the uncertainty introduced by evolving long-term care legislation. The report closes with practical recommendations to stabilise

financing, recognise competencies, strengthen measurement, and continue building partnerships so that the practice's human value is matched by durable system support.

INTRODUCTION

Name of the good practice: Family Carers Training/ Usposabljanje za družinske in druge neformalne oskrbovalce.

Country of implementation: Slovenia.

Implementation level: Local urban, local rural.

Leader organisation: Anton Trstenjak Institute Ljubljana/Inštitut Antona Trstenjaka Ljubljana.

Contacts: Ajda Cvelbar Kern, Training leader employed at the ATI; ajda.cvelbar@iat.si.

Website: https://www.inst-antonatrstenjaka.si/sozitje/projekti/39.html.

Date of data collection: WELL CARE project focus group interview, October 2025. The focus group included 4 participants: Anka Debeljak (local training organiser and participant, nurse at Ribnica Health Center), Marjeta Sternad Kuharič (head of the of the municipal administration – course commissioner), Ksenija Ramovš (one of the co-founders of the training, ATI), Ajda Cvelbar Kern (training leader, ATI) in addition to the data from the focus groups data from (Institut Antona Trstenjaka, n.d.) and (Ramovš, 2006) (Ramovš, 2007).

Description of the organisational structure of the practice:
The practice 'Family Carers Training' began in October 2001, when the first cycle was delivered at the Franc Salamon Retirement Home in Trbovlje. That first edition arose almost by chance, out of conversations between the home's management and IAT about pressing relational needs among staff and relatives. From the outset, the developmental team of facilitators that consisted of Ksenija Ramovš (ATI) and some employees from the retirement home of Trbovlje saw how guilt after a move of the older family member into a home for older people could distort family relationships, and how population ageing was increasing the number of people needing long-term care. As the case study focus group informants observed, most care still happens at home, delivered by family members and other informal carers such as friends and neighbors who, at that time in Slovenia, when the idea of this good practice was being formed, were largely unsupported in any systematic way. The

training seeks to address this by offering concrete knowledge, a space for mutual support, and relief through shared problem-solving.

During the early years, the program was hosted by several homes for older people for both formal carers and relatives of older people in Trbovlje, a municipality in central Slovenia, Vrhnika, a municipality in central Slovenia. and Logatec, a municipality in southwestern Slovenia. Before, research in Komenda (a municipality in northern-central Slovenia) where the empirical part presents data on the care needs of residents aged 60+ in Komenda, from the 2005 study Quality Ageing and Intergenerational Cohesion (Ramovš, 2006), confirmed the lack of comprehensive support for informal carers and motivated a shift into using this practice in municipalities. From 2005 onward, IAT and local authorities co-developed community-based cycles, piloted and evaluated them, and then scaled across Slovenia, with some dissemination done in Croatia. The core logic, of community-based cycles is to identify needs of the people in the community, test in practice, evaluate and refine. The program has been implemented continuously from its inception to the present.

Finance and policy have shaped how the practice could grow. For roughly fifteen years the program has been partially co-financed nationally by the ministry, while "*co-financing by municipalities is essential '…' Ideally, at least 80% should be paid by the municipalities*" (KR). As a representative of one of the municipalities puts it: "*we had 90% participation from the municipal budget, and 10% from the ministry*" (MSK). The typical total of the training comes to around six to seven thousand, including "*10 meetings and one year of support for the family group alongside leader training, travel, and literature"* (KR). Thus, the financial support of the practice depends on political will and budget cycles.

START AND STATUS OF THE PRACTICE/INITIATIVE

WHEN DID IT START

The practice began in October 2001 at the Franc Salamon Home for Older People in the municipality of Trbovlje. It arose from the intersecting needs of formal carers and relatives of older people, and the social pressures of population ageing. In the words of the program leader Ksenija Ramovš (holds a master's degree in sociology, a qualified social worker and a co-founder and long-time director of the Anton Trstenjak Institute) with a team of another 3 facilitators and employees from the collaborating Institution. The early drivers were "*the need of employees and relatives for relational care which is central to family caregiving, as it ensures that older adults feel valued and understood, not just looked after. '…' and employee burnout*" set against the "*increased risk of an aging population, more people in need of long-term care, and pressure on the care system*" (KR). Those words frame why a training model was necessary and why it had to be practical, relational, and embedded in real services.

The first cycles of the good practice took place in and around nursing homes for older people, where relatives of older people and staff could meet in a structured but humane setting. Facilitators quickly learned that perspective-taking tools could unlock empathy and concrete change. Ksenija recalls: "*we put the relatives in wheelchairs and fed them '…' to give them (carers) a little sense of what it's like to be on the other side*" (KR). With the example she points to the pedagogy of giving people direct experiences, inviting reflection, and then connecting lessons to daily routines. Participants also discovered that communication and small environmental adjustments often mattered as much as technical skill when it comes to caregiving.

REASONS FOR STARTING

By 2005, after a quantitative study in Komenda that was conducted in 2005 among approximately 280 residents aged 60 and over in the Municipality of Komenda (3). Data were collected using a structured questionnaire examining functional abilities, living conditions, social networks, and needs for care and support. It identified a lack of comprehensive support for informal carers, the Family Carers training developmental team consisting of 4 facilitators with complementing skills and the collaborating institution professionals began to move the practice into municipalities, by beginning to develop and implement training courses in local communities. This shift made sense, as most care takes place at home, and carers face questions about mobility, medications, intimacy, grief, and the right way to ask for help. Municipal settings allowed local physiotherapists, district nurses, pharmacists, social work staff, and dementia associations to take part directly, so the experts matched the services and needs in the community.

Since the creation of the good practice onwards, the practice has been continuous: "*The practice has been implemented continuously since its inception*" (KR). While content has evolved, like adding dementia-specific sessions, experimenting with virtual-reality demonstrations, or addressing new administrative pathways, the spine of 10 consecutive meetings has remained stable. That stability is a feature, because it gives both facilitators who regularly change depending on the topic covered and participants a reliable rhythm that supports trust-building and gradually deepening discussions between both parties.

Crucially, the practice is not only 10 meetings long. It also follows with the participants' creation of a peer group of relatives, often led by two trained leaders from the cohort who volunteer for this role and come from various backgrounds and are supported professionally for a year via co-leading their group and topic selection in their monthly meetings. This ensures that learning does not get lost after the certificates are handed out. The group becomes a place to return to with new challenges, a micro-network that makes the local system feel navigable.

TARGET GROUP(S)

The principal audience is clearly defined by the lead practitioner: “family and other informal carers, that is, people who care for family members or older people in their home environment without formal payment or as part of an informal network” (KR). This focus acknowledges the reality of how care is organised in most communities: families carry a major share, and friends or neighbours often step in during crises or as part of everyday neighbourliness. The course is therefore built to meet people where they are, whether they are deep into caregiving or preparing for what is likely to come.

Over 20 years and at least two trainings a year with up to 25 participants the training facilitators observed a consistent composition of participants. They estimate that more than 70% of training users are informal carers, 20% are not yet carers and at least 10% are formal carers. Predominantly women (spouses or daughters) of various economic backgrounds. These figures are presented as grounded approximations derived from registration data which is given by the participants as they enrol in the training (are they carers at the moment, are they formal or informal carers) and facilitation notes that facilitators take during the sessions across cycles rather than as a single cross-sectional survey, which makes sense given how the practice operates over time and across different municipalities.

Facilitators describe that there is also the presence of formal carers in some cohorts. They add that it is a great added value, especially if someone who attends these trainings is also a formal carer, because the exchange of knowledge takes place all the time between formal and informal carers. Having a district nurse, physiotherapist, or care assistant in the same room as, for example, a daughter caring for her mother helps both sides. The family member is also able to hear how services work from the people who deliver them, and on the other hand, the professional hears what daily life looks like outside the structured hours of a shift from an informal carers’ perspective.

Ajda Cvelbar Kern (the training leader) and Ksenija Ramovš (the training co-founder) say that because local systems differ, stakeholders, such as doctors, physiotherapists, nurses, etc., are woven into delivery: “*If possible, we always invite a physiotherapist and a district nurse from the local area ‘…’ because they have the most insight into their environment and know the people who come*” (KR). Associations also join when relevant. For example, relatives once invited a pharmacist from the local pharmacy, and dementia-focused sessions have included opportunities to see what a day in the life of a person with dementia is like using VR goggles. These integrations make the training a miniature version of the local care ecosystem, which is exactly what carers need to navigate afterward in their own homes.

Beyond demographics, the target group shares certain emotional and practical realities. People arrive with a mix of love, fatigue, worry, and guilt. Many "*are not passive listeners but actively approach the topic '…' with their own situation*" (AD) which the method intentionally welcomes. The course becomes a safe place to say out loud what is otherwise hard to say: that help is needed, that boundaries are necessary, and that, as Ajda says, "*there is nothing wrong with that. That they don't have to do everything themselves '…' it is normal to be tired, and '…' we need to find ways to help ourselves*" (ACK).

Framed this way, the target group is broader than a narrow statutory definition, as it includes current carers, people anticipating care, and a small but important contingent of professionals and volunteers.

Breadth is seen as a strength because it mirrors the mixed, real-world teams that help to keep older people at home. It also ensures that the cohort's questions are varied and concrete, which in turn sharpens the relevance of each session.

CARE RECIPIENTS

Through the carers, the practice ultimately serves people who are infirm, chronically ill, or disabled and who live at home: "*people who are infirm, chronically ill, or disabled, who live at home and need help*" including "*younger people who need help*" (KR). Indirect information gathered during training suggests that among informal carers in Slovenia, approximately 90% are family carers, (10% are friend and neighbours) of which more than 5% are carers of younger family members (under 45 years of age) and about 10% are other informal carers (neighbours, friends who do not live in the same household, etc.). These proportions do not come from one-off measurement but recur across cohorts as participant carers describe whom they support.

The conditions that bring people to seek support are diverse but familiar in ageing societies: dementia, post-stroke sequelae, physical disability, incontinence, hip fractures, end-of-life accompaniment, and the family relationship strains that follow major health events. In practice, the content of the 10 meetings adapts to these realities. If a cohort is full of carers supporting people after stroke, the open session may focus on mobility and speech strategies. If dementia dominates, the group may choose communication, daily routines, and understanding distress.

What matters most is that the training links the recipient's needs to concrete, local actions the carer can take.

OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE

AIMS

The aim is to empower and leave informal carers with better competence, confidence, and wellbeing so that their care remains humane and sustainable. Ksenija (practice cofounder) describes the intent: "*This is the basic purpose of training, not just training, but that people actually get something out of it*" (KR). The sessions are designed to blend practical skills, communication, self-care, navigation of services, and peer connection. The culture is participatory, captured in the mantra: "*the method 'all teachers are students*," so participants "*are not passive listeners, but actively approach the topic '…' with their own situation*" (ACK). That culture legitimises the messiness of real life and allows difficult topics, such as continence care, boundary-setting with siblings, grief, to surface without shame. Because the audience is mixed, specific objectives are expressed in accessible terms: safer mobility and transfers; better understanding of aids and home adaptations; clearer ways to ask for and use home nursing and home help; and the confidence to speak with professionals and relatives about sharing responsibilities.

HOW DOES IT OPERATE

A standard cycle consists of 10 consecutive weekly meetings, each lasting long enough for content and group (up to 25 people) work to co-exist. Ksenija says that "*As a rule, two experts participate in 10 consecutive meetings*" (KR), typically an ATI facilitator and a local professional whose expertise matches the topic of the day. The design reserves space for responsiveness: "*Eight to nine topics are structured in advance '…' One is deliberately undefined, and then during the course, the content is defined*" (KR). That co-design moment allows the cohort to place its thumb on the scale, ensuring that the most pressing need receives attention. Information material is prepared by ATI, such as posters and flyers. Participants are recruited locally through the municipality's information channels and social networks, as well as through organisations working in the field of ageing within the municipality, particularly retirement associations. Announcements in churches have also proven effective. Typically, there would be 2 or 3 trainings a year each in a different municipality.

METHODS AND PEDAGOGY

The pedagogy aims to turn listening into doing. Facilitators bring equipment into the room where possible and, when appropriate, role-play situations. They do so also with the help of modern technology, such as VR goggles in dementia session demonstrations: "*we put the relatives in wheelchairs and fed them '…' to give them a little sense of what it's like to be on the other side*" (ACK). The goal is not spectacle, but empathy translated into action: understanding an older person with dementia; sensing confusion through VR can change the pace of a conversation and the choice of words.

POST-TRAINING CONTINUITY

The course does not end at session 10. The carers who finish with the trainings are supported to find a group of relatives, and such a group then continues to operate for at least a year. Two leaders are selected from the volunteers and trained from within the cohort of carers, and professional support is provided during the first year. The group leaders are usually women, freshly retired, extrovert, but their characteristics can vary greatly. The support they receive is supervision for the whole first year, by a training facilitator, who visits their every meeting and also provides material, ideas to talk about at their meetings. In practice, these groups become small, reliable doors into the local system. They are places where new carers can arrive, where alumni bring new problems, and where invitations to district nurses, physiotherapists, pharmacists, or association staff can be made by people the carers already trust. A typical size of the group would be around 10 informal carers, but the size varies greatly. Groups consist of active or recently active informal carers. There are no formal carers in these groups.

FINANCING AND MATERIALS

Financing has always required a mix of national and municipal support. As Ajda said, "We have had this program partially co-financed for 15 years" and at the local level, "co-financing by municipalities is essential '…' Ideally, at least 80% should be paid by the municipalities" (ACK). In some cases, they had 90% participation from the municipal budget, and 10% from the ministry. A full round "comes to around six to seven thousand Euros" adds, which includes 10 meetings and one year of support for the family group, leader training, travel, and literature. These arrangements demonstrate municipal ownership and make it possible to keep participation free or very low-cost for carers.

MAIN OUTCOMES

Individual gains are consistently described by participants and partners. Weekly sessions are "*a kind of break '…' among people who understand them*" (ACK) a small dose of respite linked directly to learning. The facilitators who asked carers for self-ratings of caring knowledge at the beginning of the first session and then at the end of the last session, observed that participants graded it as "*five, six, and at the end eight*" (KR) which is a simple but telling pattern. Over 500 questionnaires have been filled out since the start of the practice. A health-sector partner ties these feelings to function: "*people who have been educated do not burn out, are empowered and function more easily, and continue to seek help in a timely manner*" (AD). These remarks, repeated across municipalities, show why the model has traction: it combines emotional validation with practical progress.

Recipient-level outcomes

Oral feedback is given after each training session and carers regularly report that care recipients benefit when carers adjust their approach. After VR glasses technology exposure in a session where they learned and tried to understand dementia one of them "*said that it was the first time she had seen and experienced her mother '…' in such distress and how she could really approach her in a different way*" (ACK). Small changes in tone, pacing, and routine in carers can reduce conflict and fatigue, making both care and family life less brittle.

Community-level outcomes

Municipal partners and facilitators notice effects beyond the one that happens in a household: "in the environments where we have provided training, social capital accumulates, which then manifests itself as an increase in volunteering" (KR). Furthermore, some alumni go further and find a job in formal caregiving or by doing volunteer work, and some take on leadership roles in the relatives' groups. These outcomes matter because they help expand local capacity for care, often at minimal cost and with high legitimacy.

Evaluation and learning

As a public program, the practice has standardised end-of-course questionnaires which is administered and analysed internally by the training facilitators but also analysed by the Social Protection Institute of the Republic of Slovenia (IRSSV). Over 500 filled out questionnaires have accumulated since the start of the practice: "*We now have hundreds and hundreds of these questionnaires. We enter certain indicators '…' and then forward them to the Institute for Social Welfare*" while adding "*open questions '…' for development*" (KR). This rhythm of delivery and reflection helps the ATI facilitators keep content up to date and be responsive to potential new needs of carers and their relatives.

CARE PARTNERSHIPS

Partnership must be practiced, not merely planned. Because, as Ajda says, "this exchange of knowledge takes place all the time '…' we are not the only lecturers, but there is a constant exchange of experiences, especially from people to people, among themselves" (ACK), so carers finish the course with faces and names attached to services. They carry away the option of calling someone who can understand their situation and can relate. The municipal partner observed how this led to "a kind of mutual recognition that everyone needs help '…' that slowly developed into another formal care relationship" (MSK). In other words, partnerships begin as conversations and become pathways.

The practice builds relationships on purpose. "If possible, we always invite a physiotherapist and a district nurse from the local area '…' because they have the most insight into their environment and

know the people who come" (KR). Representatives of organisations (for example community nurses or physical therapists etc.) respond to invitations to be part of the training cohorts. Informal carers themselves sometimes invite various experts and associations. Like in one municipality, where relatives invited a pharmacist from the local pharmacy. Ajda describe that "this exchange of knowledge takes place all the time '…' we are not the only lecturers '…' [and] it is a great added value if someone is also a formal carer" (ACK). These partnerships outlast the course because participants leave with contact information of the participants who they can later call if they need someone to talk with: "this feeling that you have the option of calling someone '…' that you know who that person is, is invaluable" (AD).

The simulation centre is where partnerships start. That is where the participants receive training in the physical demands of care (moving a person, changing continence pads and so on). A municipal partner describes "*a kind of mutual recognition that everyone needs help '…' and this slowly developed into another formal care relationship*" (MSK). Because the training convenes carers and professionals in a low stake setting, the first call for help becomes easier to make and easier to receive.

SUSTAINABILITY

Municipal anchoring and national developmental support have underwritten continuity, and several municipalities, such as municipality of Brežice, municipality of Postojna, municipality of Domžale etc. embed the training in action plans: "*we have included this initiative '…' in our two-year action plan '…' and it has been approved by the municipal council*" (MSK). At the same time, policy change introduces uncertainty: "*Then the question arises: what about funding for the rest? It could very quickly happen that the ministry will '…' withdraw from full co-financing*" (KR). Recognising this, practitioners argue for stable formulas that keep preventive, community-based training available to all carers, not only to narrowly defined statutory categories.

TRANSFERABILITY

Practitioners from municipality management and healthcare consider the model transferable, especially if there is good coordination and will at a municipality level: "*I think it is very easy to transfer. All that is needed is coordination and the goodwill of the municipality '…' smaller municipalities could implement it effectively 100%*" (MSK). A participant medical nurse looks at it as something that should be organised at a national level as is a nation-wide issue: "*it would make sense for this to be organised in the same way at the national level '…' because we are all in this together*" (AD). The combination of a clear spine, one co-designed session, and a year of group support gives other regions a template that is simple to adopt and adapt.

STRENGTHS

Carer participants and facilitators give verbal group feedback after each session where they repeatedly highlight personal contact, an informal environment, and flexibility as specific elements that worked well and that were the strengths of the practice. As the Director of Municipal Administration pointed out, "*personal contact, an informal environment, and flexibility in the topics '…' made participants feel supported and understood*" even with "*ten training sessions in a row is quite a lot, we did not expect participants to stay until the end. We were pleasantly surprised*" (MSK) by attendance and engagement. The cultural foundation is expressed by the maxim that 'all teachers are students.' By refusing to cast carers as passive recipients of knowledge, the training speeds up the practical application of learning and strengthens mutual respect.

WEAKNESSES/CHALLENGES

Practical challenges remain. Family Carers training facilitators sometimes must present pathways to services "that (unfortunately) do not work well in practice or are inaccessible to many carers and care recipients due to financial or staffing constraints in the care sector" (KR) which can cause frustration for carers. This is also a reminder that relational work depends on relational people. Finally, because the most meaningful effects are often relational, such as less loneliness and smoother days at home, standard indicators can miss them unless evaluation tools evolve so they can better represent the relational effects of the practice

Main challenges experienced over the years

Content has through the years expanded in response to voiced needs of participating carers. Ksenija recalls moving from teaching or offering communication training towards adding specific knowledge, listening to the actual needs of carers, and making explicit that there is nothing wrong with leaving care to professionals (i.e. moving a care recipient into a home for older people) when that is the right decision. At the same time, the team has tried to protect the group's emotional climate by being supportive, honest, and oriented to small, doable changes each week.

POTENTIAL IMPROVEMENTS

Informants suggest system and operational steps. A system-wide review of all the existing carer training initiatives and programmes would prevent duplication and expose gaps. Ajda recommends that "*training should also be recognised by the social chamber (for family carers – at least partial recognition of competencies)*" (ACK) and they call for more options like temporary accommodation to prevent burnout. Municipal partners ask for greater integration with the healthcare system where this training would be a part of the healthcare system and accessible to all, also via selective use of digital formats for those who have difficulty attending in person. These suggestions are tuned to the everyday constraints that carers face.

Also, the use of public-program questionnaires would ensure accountability. The practice has questionnaires, but future, perhaps different evaluation can better catch the relational dividends that carers describe. Including a set of indicators on burnout risk, loneliness, and navigation success, alongside tracking of volunteering and employment transitions, would perhaps take the evaluation further.

CONCLUSIONS

Across interviews and a number of years of delivery of the practice, several lessons recur. First, a humane space is important, i. e. a space, where people are seen and heard. Participants affirm that supporting each other in the same situation is invaluable, and the weekly rhythm becomes, a kind of break from care among people who understand them. In addition, learning attaches to that feeling of recognition: problems feel less personal, carers feel less lonely, options multiply, and carers try out new approaches at home.

Second, partnerships in training start as ongoing exchanges of knowledge and experiences, fostering personal connections that evolve into formal support networks for carers.

Third, continuity of practice matters. The handover to a group of relatives continues to operate for at least a year after the training finishes, with two leaders trained from within the cohort. This continuity keeps momentum, makes it easier to absorb new shocks, and gives carers a place to return that is already attuned to their reality.

Fourth, responsiveness of the practice is favourable compared to a one-size-fits-all. The design choice that one training meeting is deliberately undefined ensures that each cohort can decide, together, to spend dedicated time on the topic that they are interested in the most at that period in time.

Fifth, measurement of the practice must be carried out in a meaningful way.

Finally, sustainability of the practice requires clear policy and financing. Municipal embedding, such as including the practice in a municipality action plan is a strong foundation, but policy change, such as the ministry withdrawing co-financing, can unsettle expectations. Stable co-financing that explicitly keeps preventive, community-based training open to all carers would protect a practice that, helps people not burn out, keeps families afloat, and builds local capacity through volunteering and leadership.

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8. E-QALIN - Quality Management Model

ABSTRACT

The E-Qalin model (Quality Management Model) is a long-term care specific quality framework introduced in Slovenia through a European project between the years 2004 and 2007, initially piloted in several nursing homes for older people. To understand this model better in practice, we interviewed three key informants, that are directly or indirectly involved with the model. E-Qalin was adopted because most nursing homes for older people lacked any structured quality model and directors valued its resident-centred approach and strong employee involvement. The main target groups are long-term care workers of all profiles, management, residents/users, their relatives and nursing homes for older people as a learning organisation. Care recipients include residents of nursing homes for older people and users of other social care services (e.g. centres for persons with disabilities).

On the ground, E-Qalin operates through a list of criteria, mixed quality groups (staff, residents, relatives), a development group (managers from different areas, representative of residents or users and a representative of relatives) and recurring three-year self-assessment and external certification cycles, carried out by the company Fabrika. It is largely self-funded by nursing homes for older people and supported nationally through training provided by Feris Imperl, networking and comparative satisfaction surveys. Reported outcomes include better-structured processes, gradual culture changes toward resident and employee focus, stronger staff empowerment and improved satisfaction of residents, relatives and employees. The model explicitly fosters care partnerships through the formal inclusion of residents and relatives in quality work.

Key strengths are continuous improvement, broad participation, clear structures of participants and participating groups, and adaptability to different settings, such as social work centres and different nursing homes for older people. Main limitations relate to dependence on key individuals, time and staffing constraints and lack of formal national recognition and funding. Lessons learned underline that sustainable quality improvement in long-term care requires a structured LTC-specific model, systematic participation by all involved actors (target groups, nursing homes for older people, Feris Imperl, Fabrika), continuous measurement by both nursing homes for older people and Fabrika, and strong system-level support by the Ministry of Solidarity-Based Future.

INTRODUCTION

Name of the good practice: E-Qalin – Quality Management Model.

Country of implementation: Slovenia.

Implementation level: National.

Leader organisation: FIRIS Imperl d.o.o. (Slovenia). A company that has been providing training for social welfare employees.

Contacts: Tanja Imperl, Director; BSc Sociology; tanja@firis-imperl.si.

Website: http://www.firis-imperl.si.

Date of data collection: WELL CARE case study interviews, November 2025.

Description of the organisational structure of the practice:
The E-Qalin quality model, that originated in Austria was introduced in Slovenia in the mid-2000s as part of a European project E-QALIN (European quality-improving learning). At that time, Slovenian partners were invited into the international partnership and, as the national educator Tanja recalls, "*we realized that homes for older people in our country did not have any quality models in place. Only a few homes, maybe four or three, had the ISO standard. So basically, no one else had anything*" (TI). Under these conditions, E-Qalin was piloted in five homes - Ljutomer (Municipality of Ljutomer), Šentjur (Municipality of Šentjur), Ptuj (Municipality of Ptuj), Črnomelj (Municipality of Črnomelj) and Šmarje pri Jelšah (Municipality of Šmarje pri Jelšah), located in the Pomurska, Štajerska, Dolenjska, Savinjska regions, which tested the initial version of the model and helped to adapt it so that it would be as suitable as possible for the homes. Directors Suzana from the nursing home for older people Šentjur recognised the value of its resident-oriented approach and the strong emphasis on involving employees in questions of quality and development, even though such models were not yet common in Slovenia. In one of the homes for older people Šentjur included in this report, the model first appeared during the national pilot (around 2006-2008) but only started to be introduced a little more intensively in 2012, when the new director of the home for older people Šentjur, who is also quality manager, actively took it forward. Her motivation was "*a focus on development, a desire for something more '…' a desire to introduce innovations, a desire for some structure*" (SK), as she felt that, even when many good things were happening in the institution, "*something is missing if there is no structure that allows me to see the whole map of the individual islands that we have inside. E-Qalin enables just that*". Over time, the model was extended beyond nursing homes for older people to other social-care institutions such as centres for persons with disabilities and home help services, while in individual homes for older people it evolved into a sustainable, continuous process and "*a permanent structure, a pillar of our home's operation*" (SK). The following sections

describe in detail how E-Qalin started and developed, who it targets, how it operates on the ground and what outcomes, strengths and challenges have emerged from almost two decades of implementation in Slovene long-term care.

START AND STATUS OF THE PRACTICE/INITIATIVE

WHEN DID IT START

The E-Qalin (European quality-improving learning) quality model was developed as a European project between 2004 and 2007. The Slovenian interviewee who is a national educator explained that the project ran from 2004 to 2007 and that they (i.e. Firis, a company that deals with training employees in social care, located in Logatec) were invited as partners from the beginning and have since then been educators for Slovenia. The initiative originated in Austria, where the founder of several homes for older people wanted a quality model for their homes and couldn't find a suitable one, and did not want a generic model that could simply be adapted, but "*a model that was tailored to this industry*" (TI). At the time of its introduction in Slovenia, most homes for older people did not have any quality model. As the educator recalls, "*we realized that homes in our country did not have any quality models in place. Only a few homes for older people, maybe four or three, had the ISO standard. So basically, no one else had anything*" (TI).

Within Slovenia, a pilot project E-Qalin/A was implemented in five homes (Ljutomer (Municipality of Ljutomer), Šentjur (Municipality of Šentjur), Ptuj (Municipality of Ptuj), Črnomelj (Municipality of Črnomelj) and Šmarje pri Jelšah (Municipality of Šmarje pri Jelšah), located in the Pomurska, Štajerska, Dolenjska, Savinjska regions) to test the initial version of the model in real settings. This was done as part of the 2004-2007 project. Not all pilot homes continued later, often because of changes in directors or because some homes chose to stay with ISO, but this pilot phase laid the foundation for wider dissemination.

At the level of one specific home for older people, the director reports that her organisation took part in the national pilot when E-Qalin started in Slovenia in 2006-2008, but that it "*didn't really take off as much as it could have*" (SK) in her home for older people at that time. She explains that they started to push things a little more intensively in 2012 and that she herself became deeply involved as quality manager from the year 2017 onwards.

REASONS FOR STARTING

The main reasons for starting the practice in Slovenia were the lack of existing quality models in homes and the perceived advantages of E-Qalin's resident-oriented approach and emphasis on employee involvement.

In the specific home (i. e. Home for older people Šentjur), the director describes the motivation as "*a focus on development, a desire for something more '…' a desire to introduce innovations, a desire for some structure*" (SK), noting that an institution can do many good things, but without a clear structure, she says, "*that allows me to see the whole map of the individual islands that we have inside*" (i.e., allows her to hear from each individual about their needs, wishes, etc., as each person is different), something is always missing, and adds, that E-Qalin enables just that.

At national level, the model continues to be implemented by Firis Imperl. Currently, based on the information on the Firis Imperl website (2025), the model is being implemented in 25 homes for older people. The educator Tanja notes that after an initial expansion there was a decrease, but now, she says, "*we have, I would say, a permanent circle of institutions that use E-Qalin*" (TI), and that some homes for older people still join from time to time. E-Qalin, originally designed for homes for older people, has been adapted to other fields such as sheltered workshops (VDCs)[3], Training, Work, and Protection Center (CUDVs) and home help, while social work centres are currently not implementing it after a reorganisation.

All interviewees describe the model as ongoing and cyclical. In the home for older people where one of the interviewees works, the practice is ongoing. When asked whether the model is still implemented, the director Suzana responds that it is, and it will continue to be. She describes E-Qalin as not being a one-year project, but rather "*a never-ending journey that we must embark on if we want to talk about the quality of services*" (SK) for residents, employees, management, the environment and the learning organisation. She also emphasises that E-Qalin is a sustainable, continuous process and that each three-year period of monitoring is followed immediately by another, so that it becomes "*a permanent structure, a pillar of our home's operation, without which I cannot imagine this path*" (SK).

TARGET GROUP(S)

In the specific Home for older people Šentjur, the director Suzana defines the main target group of E-Qalin very broadly as the residents, employees, management, the environment, and the learning organisation. She explains that the model covers a very broad structure which is then divided into areas and groups for the assessment of individual criteria, such as the satisfaction with an individual service and its importance, which first determines the level of satisfaction with a particular service and then provides information on the degree to which expectations or needs in this area have been

[3] Protective work centers are "for people with moderate, severe, and profound mental and physical disabilities. These centers offer adapted forms of work under special conditions for people who are unable to live and work independently and need assistance with care (Ministry for Solidarity-Based Future, 2024).

met. with representatives of employees, residents and relatives included. From the national educator's perspective, the principal target group are workers in long-term care institutions. She states that they include all workers in these institutions and clarifies that this includes everyone, from professionally qualified medical staff to housekeepers, therapists and other profiles, as well as technical staff. In other words, E-Qalin addresses nurses, nursing assistants, social workers, therapists, domestic staff (i. e. cleaning, kitchen, laundry), maintenance and technical staff, administrative staff and managers as part of one interconnected system.

Both interviewees confirm that the workforce in this sector is predominantly female. The director of the home notes that "most of them are women, that men are rare in these social care professions, that we have maybe 15% of them, and the rest are women" (SK). The educator agrees that "there are definitely many more women than men" (TI), but she does not have precise figures and explains that more detailed socio-demographic anonymised data might be obtained from the Fabrika questionnaires on satisfaction, which contain optional demographic questions.

CARE RECIPIENTS

Regarding care recipients, the educator explains that the care recipients reached through E-Qalin include older people living in nursing homes for older people, persons with disabilities using sheltered workshops (VDCs) and Training, Work, and Protection Centres (CUDVs), including children in those centres, and people receiving organised home help. She also mentions implementation in home help and other social service sectors. In the home for older people, residents are central. The director underlines that in a nursing home with 177 residents there are numerous processes and that each resident enters the home with their own life story, so a system is needed to avoid chaos while still recognising individual needs, and all directly affected by the way care processes are organised and improved through E-Qalin. For these residents, the model is used to create a clear, structured system under one roof so that necessary routines are in place but can still be adapted to individual needs and preferences.

The practice primarily supports people who receive long-term care in institutional and community-based social services. At the outset, E-Qalin was focused on nursing homes for older people, with the national educator explaining that this is how it started, and that the first care recipients were residents of homes for older people.

Both interviewees stress that E-Qalin is strongly resident- or user-oriented. In quality groups, staff are encouraged not to solely think from the institution's point of view but to ask what residents would like and then consider how the home can make this possible in practice. For example, discussions may focus on how to maintain residents' established habits or how to adapt routines around meals and daily schedules to individual wishes, rather than requiring everyone to follow a single institutional timetable. In many institutions, residents have their own quality groups where

discussions proceed slowly, adapted to them, or individual residents are included in mixed groups with employees, so that their views on care directly shape decisions about care processes.

Relatives of residents and users are also treated as part of the extended circle of care recipients, in the sense that the quality of support provided to their family members and the quality of communication with the institution affects them directly. Relatives are included in satisfaction surveys and are represented in development groups that decide which improvement proposals to implement. The director underlines the link between residents' emotional state and relatives' experience, noting that "*a satisfied resident is much more stable '…' and as a result, their relatives are also more satisfied, with fewer complaints*" (SK), which she describes as one of the gems of the model's impact.

OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE

AIMS

According to the national educator Tanja from Firis Imperl, the most general aim of E-Qalin is to raise the quality of care in institutions and to increase the satisfaction of everyone involved, i.e., residents, users, employees, and relatives. She highlights more specific objectives such as greater involvement of employees in the development of the institution, greater empowerment of employees, strengthening their sense of meaning in their work, cooperation with the local community and developing the institution as a learning organisation that involves as high a percentage of employees as possible in the quality model.

In the Home for older people Šentjur, the director Suzana describes the main goal as the continuous development and improvement of structures and work processes as such, with a constant overview of where the institution stands: "*where we are now, where we are good, where we could improve*" (SK), especially by taking up ideas that come from employees and turning them into minor changes or projects, when larger issues are addressed. She sees the conceptual design of E-Qalin as "*a key segment in the development of the institution into something better*" (SK), enabling a screening of which processes are okay and which need to be improved.

The educator stresses that E-Qalin is really designed for this area of long-term care, and that unlike some other models where institutions simply describe and monitor their existing processes, E-Qalin defines a set of important processes that institutions might otherwise overlook. She notes that "*E-Qalin, in essence, really wants to orient institutions toward development*" (TI) and that its procedures are updated every few years to reflect current challenges and trends.

Both interviewees also explicitly link E-Qalin with employee wellbeing and mental resilience. The educator sees the main contribution in the systematic inclusion and participation of employees, which brings them into development processes and acknowledges them as active participants rather than mere performers of tasks. The director emphasises that when employees feel included, make suggestions and see that something is implemented, this significantly empowers them, makes them more autonomous and encourages them to speak up, which in turn has positive effects on residents and relatives.

The combination of E-Qalin with the programme 'Culture of harmonious relationships' model is considered promising. The aim of the programme is to create a new culture in the home for older people, where individuals are heard, understood, and respected (Feris Imperl, 2025a). Homes for older people that use both introduce very good practices by linking specific suggestions from both.

HOW DOES IT OPERATE

Operationally, the model is built around a catalogue of criteria and indicators (48 in total) that describe key structures and processes in long-term care institutions. As stated on the Firis Imperl website (2025), it enables the quantification of an institution's performance in three quality perspectives: (1) the user perspective, (2) the employee perspective, and (3) the perspective of the user's relatives or carers. The satisfaction measurement research model is based on measuring two dimensions: satisfaction with an individual service and its importance, which first determines the level of satisfaction with a particular service and then provides information on the degree to which expectations or needs in this area have been met (Firis Imperl, 2025). Each institution writes down how these prescribed processes and structures work in their case, and this documentation serves as the basis for quality group work.

In practice, homes form various quality groups. There is a specific quality group for management, several quality groups for employees and one or more quality groups for residents or users; relatives are also encouraged to form their own group. These groups are guided by trained moderators, who are employees, trained by Firis Imperl. They meet, for example, eight times a year, usually once a week for an hour, and each time they discuss a different criterion or topic, such as nutrition, moving into the home, the maintenance of residents' habits and needs, employee motivation, balancing personal and family life, opportunities for advancement or cooperation among staff.

A key operational principle is that employee quality groups must be multidisciplinary and reflect the composition of the staff in the institution. An employee group may include "*three or four employees from nursing '…' a housekeeper, someone from administration, someone from technical services, from the laundry*" (TI), bringing different perspectives to the topic under discussion.

The director confirms that in her home the groups are deliberately mixed, from cleaners to nurses and residents, and that they try to review one criterion per meeting so as not to overload staff and to respect their time.

During meetings, groups discuss how a specific area works in practice, what is positive, where they see problems and what they suggest. They review the documentation and organisation of work so that they are familiar with the process on how it is done and then score the criterion as part of an internal self-assessment. All discussions and proposals from the quality groups on their needs, wants and satisfaction are written down.

These notes are forwarded to a development group within the institution. This group is composed of managers from different areas and must include a representative of residents or users and a representative of relatives. The development group reviews all proposals, decides what will be implemented in each period and what is not feasible (for example, because of limited resources), and must always justify why a proposal will not be implemented. It then provides feedback to employees, residents and relatives. A list of accepted improvements is drawn up. After that, responsible persons or project groups are appointed and deadlines for implementation are set.

The entire self-assessment cycle with quality groups takes about two months each year. Each certification period lasts three years, during which all 48 criteria are reviewed (16 per year). After three years, the institution can order an external assessment. External assessors visit the home, review documents and talk to residents, employees and relatives to evaluate the quality, and if standards are met, the institution receives an E-Qalin quality certificate. "*Then it starts all over again from the beginning, so it's a never-ending story*" (TI).

Initially, there were problems with an external assessment provider who, according to the educator Tanja, did not sufficiently understand the model. Institutions complained, and that created a bit of a crisis. This was resolved by engaging a new organisation Fabrika, accredited by European E-Qalin, with which homes for older people are now highly satisfied. European E-Qalin, as stated on the Firis website (2025), "was developed by an expert group comprising quality management experts, educational institutions, directors and other senior staff from nursing homes, representatives of professional associations, founders of nursing homes and users. The participating organisations and individuals were from Austria, Slovenia, Italy, Germany, Luxembourg, and the Netherlands. The model was tested in a pilot phase by 29 nursing homes in Austria, Germany, Italy, Luxembourg, and Slovenia, based on which an evaluation was carried out and a final version for homes for older people was developed. Following a three-year project to develop the E-Qalin model (2004-2007), the non-profit company E-Qalin GmbH was founded in Vienna on January 21, 2008. Its purpose is to further develop the E-Qalin quality management model."

Regarding resources, both interviewees emphasise that institutions do not receive dedicated funding for implementing E-Qalin. The educator Tanja states clearly that homes do not receive any

additional financial resources for this and that quality managers must do E-Qalin tasks in addition to their other duties, sometimes even in their free time. The director Suzana K. notes that for decades homes for older people were "*literally left to their own devices*" and that only recently has there been a call for proposals in the field of quality, which she feels is very focused on healthcare and risks losing the social aspect.

To support implementation, national educators Firis provide training for process managers and moderators and maintain ongoing contact with institutions. They have created an E-Qalin Slovenia Facebook page, and an online newsletter, which was started about three years ago and publishes twice a year, to foster a sense of community and share information about training, events, new certificates and key quality features identified in external assessments. Regional meetings for process managers have replaced earlier annual conferences and serve as spaces for sharing practices and providing motivational input when institutions experience dips in enthusiasm.

MAIN OUTCOMES

In the home for older people Šentjur, the director Suzana reports that the main results are improvements in the ongoing practices of daily work processes. In a home with 177 residents there are many processes, and E-Qalin ensures that these are documented, structured in some way, while each year "*brings a bunch of changes*" (SK). Suzana argues that in a large institution there must be a system, otherwise there is chaos, and that the model's major contribution is improving processes and structures while simultaneously empowering, including and integrating employees.

The educator TI believes that "*those who work so regularly will see a real change in culture in a few years*" (TI), and that E-Qalin has an impact on the culture in the home, leading to "*a greater focus on residents and also on employees*". Although staff turnover has increased in recent years, she notes that E-Qalin helps by bringing new employees into contact with key practices more quickly. She notes that over time, E-Qalin really does bring about small improvements, small steps forward, such as improving relationships and communication between different (care) workers, older people (users) and their relatives. Training and community support are also important outcomes, as E-Qalin relies on people being able to and willing to run it well over many years. Training is essential for implementation and consistency of the model, ie. to keep the cycle running in a structured way. Community support keeps motivation of the individuals and learning alive over the long term, as the model is cyclical and enthusiasm can drop after the initial novelty. Furthermore, community support compensates for limited system-level resources, as homes for older people don't receive dedicated founding for E-Qalin, so networking becomes even more important to sustain the work without burning people out.

Both interviewees connect the practice explicitly with mental wellbeing and resilience. The educator points to inclusion, participation in groups and connecting different professional groups as central mechanisms. The director stresses that when someone feels included, suggests and then sees that it is implemented, this is "*a significant step towards empowering individual team members, making them much more autonomous and encouraging them to speak up*" (SK). She emphasises the 'closed circle' in which a more satisfied resident is much more stable, with fewer health complications if they are in a good emotional state, leading to more satisfied relatives and fewer complaints. She describes these outcomes as "*some of the gems that this whole thing brings with it*" (SK).

Satisfaction surveys are a key outcome-monitoring tool, either prepared and conducted by Fabrika or by homes for older people themselves - but in both cases analysed by Fabrika. Every year, a satisfaction survey is conducted among residents, employees and relatives. This is well established in Slovenia and covers many homes for older people, allowing comparative analyses, which is an anonymised analysis where the survey results are evaluated by comparing satisfaction of homes for older people. Institutions often use the Fabrika questionnaire, which measures satisfaction with individual services and their importance, i.e., it first determines the level of satisfaction with a particular service and then provides information on the degree to which expectations or needs in this area have been met. It processes and analyses results and provides comparative rankings so that homes can see whether they are above or below average in areas such as employee satisfaction with the organisational climate. Where results are poor, institutions are expected (to receive the certification from Firis) to take active measures to improve.

CARE PARTNERSHIPS

E-Qalin explicitly promotes care partnerships by including residents and relatives in quality assurance and in the development groups, alongside staff. Residents often have their own quality groups, where the pace and communication are adapted to their needs. This approach emerged as an adaptation of the model when homes found that including residents directly in employee groups was too demanding. The national educator describes this as one of the good practices that later spread to other institutions.

Relatives are also involved in their own groups and represented in the development group, which ensures that their views are considered when deciding which proposals to implement. The director explains that the systematic implementation of the quality model "*absorbs, connects, and restructures*" processes so that stakeholders "*are intertwined all the time and work hand in hand, because there is no other way*" (SK).

With respect to informal carers more broadly, the interviews with TI and SK focus on relatives of residents and users within institutional care. The director notes that home care is not yet included

in E-Qalin in her home but states that "*when we set up the structures, we will definitely start when we transition to long-term care, when the team is strengthened*" (SK), indicating a plan to extend the model to home care in the future.

SUSTAINABILITY

Both interviewees portray E-Qalin as inherently designed for long-term sustainability. The educator TI explains that the model has been present since the mid-2000s and is periodically updated at European level to keep pace with emerging problems and trends. She describes the three-year certification cycles followed by new cycles as a" never-ending story".

The director similarly sees E-Qalin as a sustainable, continuous process and "*a permanent structure, a pillar of our home's operation*" (SK). For her, long-term sustainability is supported by clear three-year monitoring periods, the integration of modern innovative concepts into the model and the fact that E-Qalin links different legal and systemic changes into one coherent quality framework.

At the same time, several conditions for sustainability are identified. Both interviews underline the importance of committed leadership. Changes in directors or key process managers have, in some institutions, led to stagnation or withdrawal from E-Qalin. The director notes that when process managers set up the structure too broadly or in a way that cannot be managed, this can also undermine the system.

Sustainability is also affected by staffing and time constraints. With no additional funding or dedicated quality posts, E-Qalin work often relies on staff who implement it alongside their regular duties. At the national level, the director calls for a national quality programme that would recognise E-Qalin and allow homes the choice between ISO and E-Qalin, arguing that it would be "*a real shame if homes that have been working on this model for a decade were to opt out or have two quality models*", which she finds "*absurd given the staffing structures*" (SK).

TRANSFERABILITY

E-Qalin was originally designed for nursing homes for older people but was quickly adapted for other fields. Based on the Firis Imperl website data (2025), E-Qalin is operating at a national level, as 25 homes for older people across Slovenia are currently using it. At the initiative of a sheltered workshop (VDC), it was adapted for their sector, later for outpatient care (home care) and for social work centres, with catalogues specifically tailored to each type of institution.

Although social work centres temporarily stopped implementation after a reorganisation, this history demonstrates that the model is transferable across various social-care contexts.

The director strongly believes that the model is transferable to other countries and settings. She states that "*it is definitely transferable. There is no doubt about that*" (SK), particularly due to the structure of the model which can be adapted to the needs of people, institutions and country-specific environment (e.g. to different profiles of care workers or workers in general that perhaps in Slovenia don't exist). She refers to experience from a project on palliative care in Greece, where they collaborated on good practices, and concludes that integrating such a model in another environment is possible if employees are empowered and every working environment has clear structures and processes that can be 'packaged' into a quality model.

STRENGTHS

Across the two interviews, several main strengths emerge. The director highlights continuous improvement of existing practices, innovations arising from the integration and empowerment of employees, and gaining a realistic picture of where the institution stands. She also notes that E-Qalin fosters trust and reveals hidden potential, remarking that "*a cleaner can have a lot of skills*" (SK) and that the model allows staff to open up, especially in working groups focused on residents and processes.

The educator considers the systematic involvement of employees to be particularly innovative: employees discuss various aspects of work and are treated as "*active participants, not just performers of certain tasks*" (TI), involved in all steps of the improvement cycle. She stresses that E-Qalin defines important processes that institutions might otherwise forget to document or develop and that it regularly updates these processes to address current challenges.

Both interviewees emphasise the value of satisfaction measurement and comparative analysis. The nationwide use of the Fabrika questionnaire and its comparative reports are highly valued by institutions because they allow them to see whether they are ranked above or below average and to interpret critical scores appropriately. The director appreciates that staff do not have to perform complex analyses themselves and can instead focus on residents and co-workers. This is also a strength, as both older residents and participating relatives are given a voice to express their needs, desires, complaints, and actively participate with the care workers. Furthermore, it can contribute to strengthening their relationship and contribute to mutual understanding.

Training and community support are also seen as major strengths. Finally, the combination of E-Qalin with the 'Culture of harmonious relationships' model is considered promising. The educator explains that the latter is a content-oriented model focused on residents and employees, with concrete goals about what makes work meaningful, and that it overlaps very well with E-Qalin. Homes for older people that use both introduce very good practices by linking specific suggestions from the culture of harmonious relationships to the open framework of E-Qalin.

WEAKNESSES/CHALLENGES

The interviewees also identified several weaknesses and limitations. One of the main weaknesses mentioned by the director is staff turnover and the dependence on key individuals. When some key stakeholders change, especially those who have managed E-Qalin for many years, it is difficult for successors to 'step into the shoes' of their colleagues. She notes that there is "*quite a lot of staff turnover in homes*" (SK) and that this can have a real impact, particularly if process managers have set up the structure too broadly or in a way that is difficult to manage.

The educator similarly points out that changes in directors and management have led some institutions to discontinue E-Qalin, and that decisions about joining or leaving often depend on a director's previous experience with other quality models such as ISO.

Time and staffing constraints are another significant limitation. With no dedicated funding for quality managers, they must implement E-Qalin in addition to their regular duties, sometimes in their spare time. In some institutions it is difficult to free staff for the required hours of group work, especially in the context of staff shortages.

The external environment also presents challenges. The director stresses that the current call for quality projects is "*very focused on the field of healthcare*" (SK), which risks marginalising the social aspects that E-Qalin emphasises, and she argues for integrating healthcare quality requirements into the existing model rather than having homes operate two parallel systems.

On the motivational side, the educator notes that enthusiasm tends to wane over time: at the beginning, institutions see E-Qalin as 'something interesting', but after years of implementation, motivation declines and they need a little motivation from outside. This has led to the development of regional meetings, Facebook communication and newsletters to maintain engagement.

Key challenges over the years have included the need to replace the external assessment provider due to insufficient understanding of the model, managing staff changes and succession in quality roles, preventing the system from becoming overly broad and unmanageable and sustaining motivation in the long term. In addition, the reorganisation of social work centres led to the discontinuation of E-Qalin in that sector, and despite some initiatives, it has not been reintroduced so far.

POTENTIAL IMPROVEMENTS

The interviewees suggesested that improvements could come from several directions. At national level, the director argues for a comprehensive quality programme that would formally include E-

Qalin, secure financial resources, clarify staffing structures and standards for quality work and recognise that homes for older people are "*not just healthcare providers, but much more*" (SK). She insists that institutions should be allowed a choice on whether they decide on ISO or E-Qalin, instead of being forced into one model.

Both interviewees see value in training more process managers within institutions so that quality work does not depend on a small number of individuals and so that structures can be set at a manageable breadth. Continued development of motivational supports (such as regional meetings, newsletters, Facebook community) is also considered important for sustaining engagement and preventing burnout.

In terms of supporting mental wellbeing and resilience of long-term care workers, the educator emphasises the potential of integrating E-Qalin more closely with the culture of harmonious relationships model, which provides very concrete goals related to what makes employees' work meaningful and how institutions can make employees feel better.

The director suggests that including home care in E-Qalin once structures and staffing are in place will be an important next step for strengthening care partnerships. E-QALIN/D which is an E-QALIN model adapted to social work centres isn't being used in the social work centres in Slovenia and it has been used only for a very short time (TI).

CONCLUSIONS

Several major lessons emerge from the two interviewees that are particularly relevant to WELL CARE's focus on mental wellbeing and resilience of both care recipients and LTC workers. First, a structured, long-term-care-specific quality model that clearly defines important processes and is regularly updated can provide a solid framework for continuous development and supports psychological safety and resilience through preparedness. In the words of the educator Tanja, E-Qalin "*really wants to orient institutions toward development*" (TI) and addresses issues that need to be thought about now, rather than when problems become acute years later, and so helps reduce avoidable stressors for residents, relatives and LTC workers, and creates more predictable, stable care environments.

Second, employee involvement is crucial both for quality and as a wellbeing intervention for LTC workers. Systematic inclusion of staff from all professional groups in quality discussions, combined with feedback and implementation of their suggestions, transforms them from mere performers of tasks into "*active participants in the development of an institution*" (TI). This, as the director notes, significantly empowers team members and contributes to strengthening agency, recognition and

team cohesion. These are protective factors for mental wellbeing and resilience in demanding care work. In addition, it is a virtuous circle in which satisfied, empowered, and engaged staff support more stable and emotionally secure residents and more satisfied relatives.

Third, the interviews show that resident-centred thinking can be nurtured systematically, as a pathway to emotional security. Quality groups, especially those that include residents or are dedicated to them, help employees think from the residents' perspective, focusing on their habits, needs and wishes and seeking practical ways to accommodate them within institutional routines. This can reduce distress, support dignity, and strengthen care recipients' sense of control and belonging, all of which are central to mental wellbeing.

Next, continuous measurement and feedback loops are essential. Annual satisfaction surveys and internal indicators give institutions a data-based picture of their strengths and weaknesses, track progress, and, through comparative analysis, help them interpret their own scores realistically. They also contribute to resilience by making wellbeing-relevant issues visible, discussable and actionable. For relatives, being asked and listened to can also enhance trust, reduce uncertainty, and improve their confidence that their concerns will be addressed.

Furthermore, long-term sustainability depends not only on the design of the model but also on system-level support, stable leadership, adequate staffing and recognition of social-care-specific quality models in national policy. Without these, personal commitment and local enthusiasm may not be enough to maintain the practice. There are also direct benefits for the LTC staff, namely empowerment and inclusion, as the model systematically involves staff from all professional groups, and contributes to improving relationships and communication between them. Direct benefits for residents include residents-centred care in daily routines, as they train workers to think from residents' perspective. As relatives are included in groups and surveys, they are more satisfied.

Finally, the experience of the national educator Tanja and the director Suzana suggest that investing in people through training, mentoring, empowerment and careful succession planning is the key to making E-Qalin work in practice and for sustaining its wellbeing effects. As the director summarises, the main advantages of E-Qalin are continuous improvement of existing practices, innovations arising from empowered employees and "*a realistic picture of where we are*" (TI). These lessons arise directly from their experience of working many years with the model and underline the importance of combining structured quality frameworks with genuine participation and partnership in care. The interviews suggest that E-Qalin's value for WELL CARE lies in combining a clear quality framework with genuine participation and partnership, creating conditions that strengthen mental wellbeing and resilience simultaneously for residents, relatives, and LTC staff.

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9. Assertive Community Treatment (ACT)

ABSTRACT

Assertive Community Treatment (ACT) and its adaptations, Flexible Assertive Community Treatment (FACT) and Resource Group Assertive Community Treatment (RACT), were developed to address persistent challenges in the care of individuals with severe and complex mental illness. Traditional, clinic-based care models have often failed to provide the continuity, coordination, and holistic support required for recovery (Nordén et al., 2012). FACT and RACT offer community-based, multidisciplinary approaches designed for people whose mental health needs exceed what standard psychiatric or social services can provide (Bond & Drake, 2015; Rydell et al., 2016; van Veldhuizen & Bähler, 2014).

FACT is organised through interdisciplinary teams that combine continuous outpatient care with the capacity to temporarily intensify support when a person's condition deteriorates. This flexible model ensures stability and minimizes service gaps (van Veldhuizen & Bähler, 2014; Rydell 2013). RACT centers care around a "resource group" consisting of the client, relatives, and key professionals, with the client determining who participates. This group jointly plans, implements, and evaluates interventions, emphasizing autonomy, shared decision-making, and relational continuity.

Evidence suggests that both models improve collaboration between services, enhance continuity of care, and support recovery (Trane et al., 2021; Martinsen et al., 2025; Svensson, Hansson & Lexén, 2018; Nordén et al., 2012; Sjöström et al., 2021). FACT has been associated with greater coordination and reduced hospitalisation rates (Trane et al., 2021), while RACT has demonstrated improved functioning, engagement, and cooperation among clients, relatives, and professionals (Nordén et al., 2012). A key insight from both approaches is the central role of family members and informal carers as active partners in care, not merely as supporters (Rydell, 2013; Rydell et al., 2016).

Implementation experiences from Sweden show that sustainability depends on clear inter-agency agreements, managerial commitment, and adaptation to national organisational and legislative frameworks, according to representatives interviewed for this study. Beyond their specific settings, the models highlight core principles essential to effective mental health care: continuity of relationships, interdisciplinary teamwork, and the active inclusion of relatives and social networks in long-term recovery processes.

INTRODUCTION

Name of the good practice: Assertive Community Treatment (ACT) / Flexible Assertive Community Treatment (FACT) / Resource group Assertive Community Treatment (RACT).

Country of implementation: Sweden, the Netherlands, USA, Denmark, Norway.

Implementation level: Local/Regional.

Leader organisation(s): There is no single lead organisation for ACT or FACT in Sweden. Implementation is carried out locally by regional and municipal services. For RACT, national knowledge exchange has been supported through the National Knowledge Support for the RACT Case Management Model (Nationella kunskapsstödet för case managementmodellen RACT, NKCM), which functions as a professional network rather than a coordinating authority. Cecilia Fjellsson, interviewed for this case study, is chairperson.

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Website / online sources:

- ACT Malmö: https://vard.skane.se/psykiatri-skane/mottagningar-och-avdelningar/vuxenpsykiatrimottagning-psykos-act-malmo/
- ACT Gothenburg: https://www.sahlgrenska.se/omraden/omrade-2/psykiatri-psykos/enheter/act-mottagning-goteborg/
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- FACT Helsingborg: https://helsingborg.se/omsorg-och-stod/psykisk-funktionsnedsattning/personligt-stod/fact-vardprogram/
- FACT Unga Stockholm Young people Stockholm: https://www.bup.se/om-oss/nyheter/genom-fact-ung-fangar-vi-upp-unga-med-stort-vardbehov/
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Date of data collection: WELL CARE data collection, individual interviews October and November 2025. Data have also been collected from documents such as handbooks and manuals that describe the design and use of the models, for example Rydell et al. (2016); Region Skåne (2017), and van Veldhuizen & Bähler (2014).

Description of the organisational structure of the practice:
This report focuses on Assertive Community Treatment (ACT) and primarily its adaptations, Flexible ACT (FACT) and Resource Group ACT (RACT), both of which are based on the core principles of ACT. ACT was developed in the 1970s by Drs. Arnold Marx, Leonard I. Stein and Mary Ann Test at the Mendota Mental Health Institute in Wisconsin, USA. No clear national introduction date in Sweden is documented, but the earliest identified example is a modified ACT model implemented in Uppsala in 1998 (Bodén et al., 2010). ACT is a community-based model for individuals with serious mental illness, based on the principle that support and training are most effective when provided directly in the community rather than in hospital settings. The model delivers holistic, personalised care addressing mental health, medication, housing, finances, and daily living needs through multidisciplinary teams with low client-staff ratios, frequent contact, and 24/7 availability. ACT integrates services directly rather than relying on referrals, tailors interventions to individual goals, and offers long-term, continuous support, enhancing engagement, recovery, and quality of life. Its theoretical foundation emphasises in vivo learning (meaning providing support in real-life settings rather than in hospitals to help and prepare individuals for community living), assertive outreach, and meeting clients where they are to promote meaningful community integration (Bond & Drake, 2015; Socialstyrelsen, 2018b; Region Skåne, 2015).

Both FACT and RACT retain ACT's emphasis on outreach, recovery orientation, and integration across psychiatric, social, and practical support services. FACT was developed in the Netherlands by psychiatrist J.R. van Veldhuizen and psychologist M. Bähler. The model was introduced in Sweden in 2007 (Rydell, 2013) and began to spread more widely around 2013 (Svensson et al., 2017). FACT integrates regular outpatient care with the ability to temporarily intensify support when participants experience deteriorating mental health (Region Skåne, 2017). RACT, developed by professor of psychiatry Ian Falloon, at the University of Auckland, New Zealand, and introduced in Sweden by associate professor of psychiatry Ulf Malm, Gothenburg University in the early 2000s (Rydell et al., 2013), centres care around a "resource group" constructed with the participant's active input. This group typically includes the participant, their case manager, relatives, and other professionals deemed important by the participant (Lundmark et al., 2020). Both models are designed for individuals whose needs exceed what standard mental health and social services can provide, targeting those requiring coordinated, long-term, and multidisciplinary support.

Both FACT and RACT share ACT principles such as multidisciplinary teamwork, community-based outreach, person-centred care, and recovery orientation. The term participant is used because, according to the interviewees, it emphasises that relationships should be equal and that the individual is actively involved in the team or group, rather than positioned as a passive recipient of care. One of the models' main difference lies in the role and structure of the social network. FACT has a pre-established multidisciplinary team of professionals who provide continuous support, and additional participants – such as family members or external professionals – can be added as needed depending on the participant's situation. In contrast, RACT starts with only the case manager and the participant, who together build a resource group according to the participant's needs, preferences, and priorities. FACT emphasises flexibility and team-based responsibility to respond efficiently to fluctuating needs, while RACT focuses on empowerment, relational continuity, and long-term stability (Svensson, Hansson & Lexén, 2018; van Veldhuizen & Bähler, 2014).

Both models consider the participant's network and family as crucial partners in recovery. In FACT, relatives may be included if the participant consents, and their perspective is considered valuable for supporting wellbeing and maintaining continuity. The team encourages involvement in planning, evaluation, and self-help initiatives, but relatives can step back if they feel burdened (Sahlgrenska Universitetssjukhuset, 2024). In RACT, family collaboration is deemed essential. Among those initially invited to the resource group, relatives and family members are of particular importance and are engaged from the outset, contributing to goal-setting, intervention planning, and follow-up, which enhances trust, empowerment, and long-term sustainability (Sjöström et al., 2021; Malm et al., 2015).

To summarise, FACT and RACT are both ACT-based, recovery-oriented approaches that address gaps in traditional mental health care. FACT relies on a flexible, pre-established professional team with optional, although preferred, inclusion of others, whereas RACT builds the care network collaboratively from the participant's perspective. Both emphasise continuity, person-centred care, and family involvement, offering effective strategies for supporting individuals with severe and complex mental health needs in their everyday lives.

START AND STATUS OF THE PRACTICE/INITIATIVE

WHEN DID IT START

For ACT, no clear national introduction date (in Sweden) is documented, but the earliest identified example is a modified ACT model implemented in Uppsala in 1998 (Bodén et al., 2010). FACT was introduced in Sweden in 2007 (Rydell, 2013) and began to spread more widely around 2013 (Svensson et al., 2017). RACT was implemented in the early 2000s (Rydell et al., 2016).

REASONS FOR STARTING

Assertive Community Treatment (ACT) was developed in the 1970s by Drs. Arnold Marx, Leonard I. Stein and Mary Ann Test at the Mendota Mental Health Institute in Wisconsin, USA, in response to recurring challenges in the care of individuals with severe mental illness. Many clients who were discharged from inpatient care in stable condition were soon readmitted, creating a cycle of repeated hospitalizations and unstable community living. This situation placed a heavy burden on both healthcare systems and informal/family carers, as many service users struggled to maintain stability and adequate support at home (Rydell et al., 2016). Traditional mental health care was largely clinic-based and fragmented, typically involving separate professionals such as psychiatrists, psychologists, social workers, and nurses, who provided services independently. Coordination between them was often limited, and opportunities for family and social networks to participate in care were minimal. As a result, individuals with the most complex needs frequently fell through the cracks of the system (Nordén et al., 2012). ACT emerged to address these systemic shortcomings by offering continuous, community-based, and multidisciplinary support for people whose mental illness significantly impaired their ability to manage everyday life or engage in standard outpatient treatment. The model aimed to reduce unnecessary hospitalisations, prevent homelessness, and promote community integration by bringing coordinated medical, psychological, and social support directly to the person and their family (Rydell et al., 2016).

ACT, FACT, and RACT are all in use across various regions in Sweden, although their prevalence and scope vary. There is no comprehensive national registry documenting exactly which health care regions have implemented and currently use these models; however, information is available from providers' own websites. ACT is offered in Malmö for adults with psychosis and related conditions (Psykiatri Skåne n.d.), and in Gothenburg for individuals with severe mental illness and substance use disorders (Sahlgranska, 2024). FACT has become particularly prominent in Region Skåne, where it has been integrated widely into psychiatric services in cities such as Malmö, Lund, and Helsingborg (Vetenskap & Hälsa 2019, Helsingborg 2025). FACT has also been adapted for children and adolescents through the FACT Unga teams in Stockholm (BUP – Barn och Ungdomspsykiatrin, *Child and Adolescent Psychiatri* – Stockholm 2023) and Malmö (Vården Malmö, n.d.), demonstrating the model's expansion to younger populations. In February 2026, a substance dependency care service was launched at Södra Älvsborg Hospital in collaboration with municipalities in the Sjuhärad area (West Sweden), based on FACT principles (Vårdsamverkan Sjuhärad, 2025). RACT is used at Sahlgrenska University Hospital in Gothenburg, West Sweden and associated psychiatric services in the West Sweden health care region, where resource-group meetings involve family members in care planning (Sahlgrenska, 2022). Overall, community-based mental health models - ACT, FACT, and RACT - remain actively used in multiple Swedish regions, including Skåne South Sweden), Västra Götaland (West Sweden), Stockholm, Malmö (South Sweden), and Sjuhärad West Sweden), reflecting ongoing implementation and regional adaptation in psychiatric care.

TARGET GROUP(S)

ACT and its adaptations focus primarily on the recovery of the care recipient themselves (described below). However, the care recipient's network, family, and friends are regarded as an essential part of the recovery process.

While FACT teams mainly consist of professionals, such as psychiatrist, psychologist, nurse, social worker, and occupational therapist, collaboration with the participant's formal and informal networks is considered a central component. By involving both family members, close relations, and professional actors, a coherent support system is created that enables the participant to take control of their recovery process as quickly as possible (Region Skåne, 2017). The team ensures that the treatment period is as long as necessary but as short as possible, while providing the participant and their network with the necessary support during and after the FACT intervention. An important aspect is the active inclusion of the network in follow-ups and evaluations, and the team also encourages and facilitates the creation of self-help groups for relatives. FACT is based on close collaboration between various actors within the participant's social context. In addition to the professional FACT team and other professionals, family members, friends, and neighbours may also be involved (van Veldhuizen & Bähler, 2014). To enable recovery across all areas of life, a broad and active professional network is needed that includes both internal and external partners. The intensity of cooperation varies depending on the participant's needs and shared goals, but good relationships, clear communication, and mutual appreciation are considered crucial for effective collaboration (Region Skåne, 2017).

An important part of FACT work is maintaining and developing these network relationships. The FACT teams organise information meetings, offer consultations, invite partners to treatment conferences, and express appreciation for the collaboration. A FACT representative interviewed for this case study explained that the FACT team can offer family-based crisis interventions during new episodes of illness, lecture series to educate relatives about diagnoses, and support sessions with the team's social worker or psychologist. When more extensive counselling is needed, family members can be referred for longer-term support. By regularly evaluating satisfaction among participants, relatives, and partners, the working methods can be improved and adapted over time. In this way, the network becomes not only a support system but also an active and sustainable resource in the participant's recovery process (Region Skåne, 2017).

In RACT, work with family members and close relations is a central component of the model. The service user decides who should be included in the resource group, which may consist of both professionals and individuals from the user's personal network, such as family members or friends. Once the resource group has been formed, family members and other close relations are

interviewed individually by the case manager to identify their perspectives, resources, and how they can best support the user. Case managers often belong to the healthcare services, but the role itself is not tied to any specific profession; rather, it should be held by the person best suited to the participant's situation and needs. Research has shown that recovery and prognosis improve when relatives are engaged early in the treatment and rehabilitation process (Rydell et al., 2016). A RACT representative interviewed for this case study described family members as essential partners in RACT, since they - rather than professionals - often have the most continuous and long-term contact with the user. She also highlighted the impact on relatives, explaining that feedback from family members indicates the model helps reduce their stress, as they feel secure knowing the resource group shares the responsibility. She noted that relatives have been able to return to work and even take vacations: "*Family members were losing jobs, losing pension, losing their social life because they were taking care of their loved one*". With the resource group, "*they no longer have the constant fear that the person might die*" (CF).

Within RACT, it is acknowledged that family members themselves need support and knowledge to manage their key role and the everyday challenges of living close to someone with mental health difficulties. Family based interventions such as education for both users and family members is offered as part of the RACT process. Knowledge about the illness, treatment, and available support services reduces stress, prevents misunderstandings, and strengthens self-esteem and hope. Joint education for users, families, and networks promotes understanding and cooperation among all parties, which in turn improves treatment outcomes. Education can be provided individually, to a single family or resource group, or in study circle formats involving several families with similar experiences. Education for family members and other close relatives can reduce stress and prevent misunderstandings for all involved. It helps create a sense of calm, strengthens understanding of the situation, and offers hope. Increased knowledge also supports better collaboration between care professionals, the service user, and their family members (Rydell et al., 2016).

CARE RECIPIENTS

The target groups of FACT and RACT vary somewhat depending on local guidelines and the definitions of target populations in the different health care regions and organisations, for example in psychosis care, addiction services, or child and adolescent psychiatry, where the model has been implemented. Overall, the target groups consist of individuals with extensive psychiatric disorders that make it challenging to manage daily life independently, and for whom standard care and support services are considered insufficient.

The models are aimed at individuals who live with severe and persistent mental illness and have complex needs that are not adequately met within standard psychiatric care, addiction services, or municipal support. These individuals often require coordinated efforts across healthcare and social

services, for example due to difficulties in maintaining contact with treatment providers, managing daily life independently, or securing stable housing. The models primarily work with adults aged 18-65, but the age range covered by FACT and RACT depends on regional service guidelines. In some regions, psychiatric services are specifically organised for older adults, which means that this population is not included in FACT or RACT. Importantly, there is nothing inherent in the FACT or RACT models that excludes children, adolescents, or older adults; for example, FACT has also recently been implemented within child and adolescent psychiatric services in Stockholm, Sweden (BUP Stockholm, 2025).

Care recipients with psychiatric diagnoses often experience stigma associated with their condition. This can lead to feelings of shame, low self-esteem, and social withdrawal, which in turn can worsen their mental health and reduce both social contacts and help-seeking behaviours. According to the World Health Organization (2001), stigma represents a mark of shame or disapproval that results in rejection and exclusion from social participation. Individuals who are labelled as mentally ill frequently describe a profound change in how others perceive and treat them, leading to isolation and discrimination. FACT and RACT models work actively to counteract stigma and promote social inclusion by fostering person-centred, recovery-oriented approaches that emphasise empowerment, participation, and respect for the individual's potential and dignity (Rydell et al., 2016, Rydell, 2013).

Typical target groups include people diagnosed with schizophrenia, schizophrenia-like disorders, bipolar disorder, psychosis, depression, anxiety disorders, and substance use disorders, whose psychiatric and social difficulties significantly affect their ability to function in everyday life. The model may also encompass individuals with other severe psychiatric conditions, such as serious anxiety or neuropsychiatric disorders, personality disorders, or comorbid substance use. Many in this group are at increased risk of self-harm or suicide and need comprehensive, long-term, and integrated support.

In practice, the approach is applied flexibly to meet the needs of different populations and local contexts. It is sometimes used within child and adolescent psychiatry, for instance in programs designed for young people with complex psychiatric and social challenges, for example FACT Ung in Stockholm, the West Sweden region, and Malmö. The model can also be adapted to include people whose difficulties arise from a combination of psychiatric illness, substance misuse, and social vulnerability.

OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE

AIMS

Assertive Community Treatment (ACT) is a community-based approach to treatment and rehabilitation, developed in the 1970s by Drs. Arnold Marx, Leonard I. Stein and Mary Ann Test at the Mendota Mental Health Institute in Wisconsin, USA (Region Skåne, 2015). It was designed for individuals with severe mental illness and significant functional impairments—particularly those who are difficult to engage in traditional services and are at risk of repeated hospitalisations, homelessness, or social marginalisation (Socialstyrelsen, 2018b). The model emphasises assertive outreach, long-term engagement, and intensive, person-centred support provided directly in clients' everyday environments. The overall aim is recovery from mental illness. This also entails improved quality of life, improved social relationships, opportunities for employment, and the ability to manage daily life independently. ACT and its adaptations additionally aim, throughout the process, to prevent hospitalizations, self-harming behaviors, inadequate contact with healthcare services, and situations where the individual experiences fragmented care and support, leading to discontinuity of care.

HOW DOES IT OPERATE

Assertive Community Treatment (ACT) is a community-based, multidisciplinary approach for individuals with severe mental illness, designed to provide comprehensive, coordinated support while promoting recovery and independence. ACT centres on holistic, personalised care addressing mental health, medication, housing, finances, and daily living needs through multidisciplinary teams with low client-staff ratios, frequent contact, and 24/7 availability. Teams typically include a psychiatrist, nurse, social worker, substance abuse specialist, and often an Individual Placement and Support coach or peer specialist, serving around 100 clients with low caseloads to ensure continuity of care (Socialstyrelsen/National Board of Health & Welfare Sweden, 2018; Sahlgrenska University Hospital, 2022). Services cover psychiatric and medical treatment, psychosocial support, housing and daily living assistance, and substance use interventions, delivered largely through home visits and direct engagement in clients' living environments. ACT emphasises accessibility, persistent outreach, and integration across healthcare and social services, aiming to reduce hospitalizations, enhance housing stability, and improve quality of life (Region Skåne, 2015; Socialstyrelsen, 2015). In practice, however, strict program requirements, such as 24/7 availability and low caseloads per staff member, are challenging within Swedish health care organisational frameworks. To better align with regional conditions, two adaptations have emerged: Flexible ACT (FACT), which allows more cases per staff member and the intensity of support to be scaled to the participant's needs, and Resource Group ACT (RACT), which centres on collaboration between professionals and the individual and their relatives. Both models retain the core ACT principles while accommodating practical and structural realities in Swedish health and social care.

FACT was developed primarily in the Netherlands by psychiatrist J.R. van Veldhuizen and psychologist M. Bähler and later implemented and disseminated in Sweden (Region Skåne, 2015). The model was designed to integrate the principles of traditional ACT with regular outpatient care within the same multidisciplinary team. A typical FACT team usually consists of a psychiatrist, psychologist, nurse, social worker, occupational therapist, peer support, physiotherapist (Region Skåne, 2017). According to a FACT representative interviewed for this case study, the aim is for the team collectively to cover medical, social and somatic needs. Unlike the original ACT model, which primarily targets individuals in acute need of intensive treatment, FACT offers both continuous outpatient care and the capacity to temporarily intensify support to full ACT-level intervention when required. The team's caseload should not exceed 220 participants (van Veldhuizen & Bähler, 2014), and the participant-to–full-time staff ratio should not exceed 30:1, with a preferred ratio of 15:1 (Region Skåne, 2017). A "crisis board" is used to identify clients in need of heightened support and to coordinate immediate team action. This flexible structure allows one team to provide comprehensive and individualized care, adjusting treatment intensity according to fluctuations in mental health status. As a result, participants can receive appropriate, recovery-oriented care from the same organisation regardless of their current level of functioning (Socialstyrelsen, 2018; Region Skåne, 2017).

The FACT model combines medical and psychosocial treatment, rehabilitation, and practical daily support, with an emphasis on maintaining social participation and autonomy. Interventions are primarily conducted through home visits and community-based interventions, allowing close engagement with clients and their natural support networks. Care plans are developed collaboratively between the team, the client, relatives, social services, and primary health care, reflecting a recovery-oriented and person-centered approach. Key features of the model include stepwise and flexible care, individual goal-setting, active teamwork, and the client's participation in decision-making (Region Skåne, 2019). The team as a whole shares integrated responsibility for outcomes, emphasizing evidence-based interventions and best clinical practice. A hopeful and respectful team attitude is viewed as essential for recovery, ensuring that treatment acknowledges each person's strengths, cultural identity, and emotional experiences while actively countering stigma and fostering empowerment. Routine outcome monitoring is conducted at least annually to evaluate progress in mental and social functioning, needs, quality of life, and recovery, ensuring systematic follow-up and continuous quality improvement (Region Skåne, 2019).

RACT is another adaptation of the ACT model, originally developed based on the work of professor of psychiatry Ian Falloon, University of Auckland, New Zealand, through the *Optimal Treatment Project* (OTP), and introduced in Sweden by associate professor of psychiatry Ulf Malm, Gothenburg University (Rydell et al., 2016). The person responsible for the work is a case manager trained in RACT. Case managers often belong to the healthcare services, but the role itself is not tied to any specific profession; rather, it should be held by the person best suited to the participant's situation and needs. The model places the client's own social network at the centre of treatment and recovery

and builds on ACT's principles of outreach, multidisciplinary collaboration, and person-centered care. It can be implemented in specialized psychiatric services, primary health care, and in collaboration with social services. Care is organised around a *resource group*, which usually includes the client, their case manager, relatives, and other key professionals (for instance a psychiatrist, social worker, housing support worker, and/or community nurse), individuals chosen by the client. This group meets regularly to plan, implement, and evaluate interventions, with the client's personal goals and priorities guiding all activities (Lundmark et al., 2020.).

Working with RACT begins with a focus on the service user's participation. This is followed by an assessment phase involving alliance building between the service user and case manager, home visits, mapping, and individual interviews with the service user and their relatives. Once the resource group has been formed, preparations are made for and a resource group meeting is held, during which the service user's personal goals are formulated and a plan for continued work is established. The next phase includes specific strategies such as problem analysis, communication training, family intervention, and stress management. Finally, with continuous follow-up within the resource group, recovery-oriented goals are monitored. The resource group regularly reviews progress toward these goals, determines whether they are being achieved, and decides whether adjustments or additional resources are needed. There are also quarterly evaluations which function as formal checkpoints rather than continuous monitoring and are the responsibility of the case manager. Progress is documented using standardized assessment instruments, including Self-ConSat, GAF Functioning, and GAF Symptoms. Data from these assessments are compiled, analysed, and visualised using the Quality Star to illustrate change over time. The results are jointly discussed by the participant and the case manager, focusing on the meaning of the findings and whether revisions to plans or interventions are required (Rudell et al., 2016). To structure the work of the resource group, worksheets are used. The RACT manual includes 37 worksheets linked to different modules of the model, which can be used as appropriate depending on the participant's goals and needs. The worksheets are used collaboratively within the resource group and may, for example, involve creating a network map, rating satisfaction across different life domains, describing a typical day, or using interview templates to identify early signs of relapse. Some of the worksheets are intended for use by the case manager, for example when interviewing individuals who are to be included in the resource group. However, the majority of the worksheets are designed to be used, reviewed, and completed by the participant together with the rest of the group (Rydell et al., 2016).

RACT emphasises the client's social network as a fundamental resource for recovery, fostering empowerment, autonomy, and sustainable progress (Lundmark et al. 2020). The resource group is intended to function as a flexible support system, with different participants becoming more or less central depending on the client's condition and circumstances, meaning not all members need to be involved in every aspect of recovery work, though they should be available if needed. The case manager plays a central role in coordinating care and ensuring collaboration across services. While

its use has decreased as FACT has become more widespread, RACT remains an important approach for recovery-oriented, socially grounded, and collaborative psychiatric care (Rydell et al., 2016).

MAIN OUTCOMES

Research on psychiatric treatment shows that without treatment, about 80 percent of participants with schizophrenia experience a psychotic relapse within one year. Among those treated with antipsychotic medication, approximately 40 percent relapse within a year. For those who receive both medication and psychosocial interventions, the relapse rate drops to around 20 percent. When medication and psychosocial interventions are systematically coordinated - as in the ACT model and its adaptations, FACT and RACT - the relapse rate can be reduced to as low as 10 percent (Sahlgrenska University Hospital, 2022).

FACT teams conduct recurrent evaluations to ensure the effectiveness of the model for each individual participant. Evaluation and systematic follow-up of treatment are conducted in collaboration with the participant and, where appropriate, relatives and the wider professional network. At least once a year, the team jointly evaluates the participant's treatment plan together with the participant and, if the participant so wishes, family members. This collaborative evaluation also includes structured follow-up using Routine Outcome Monitoring (ROM) to refine individual goals and care plans, based on standardised measures of mental and social functioning, needs, and quality of life and recovery. When periods of intensive interventions are concluded, the case manager carries out a focused evaluation of the intensive phase together with the participant and family members, addressing whether the interventions were helpful, whether the desired support was provided, and whether any elements were overlooked or unnecessary. Throughout this process, treatment planning, implementation, and evaluation are embedded in a clearly documented planning and follow-up structure, with decisions made collectively by the team, the participant, relatives, and collaborating services such as social services and primary care (van Veldhuizen & Bähler, 2014; Region Skåne, 2017). In addition, the team regularly conducts satisfaction surveys among participants, relatives, and collaborating partners in order to systematically evaluate its work and, when necessary, revise its working routines (Region Skåne, 2017).

Research on the outcomes of FACT indicates that the model can strengthen collaboration between services, improve continuity of care, and support recovery for individuals with complex mental health conditions. The model might also contribute to reduced stress among health and social care staff. A Norwegian study, based on five focus group interviews were conducted with 40 service providers from both primary and specialist healthcare across different Norwegian regions, found that FACT teams act as an important *bridge* between different levels of care. Team members from both primary and specialist health services described how the FACT model helps to connect fragmented systems by understanding perspectives from both sides, providing care to participants

across levels (Trane et al., 2021). A Norwegian qualitative study conducting focus group interviews with 41 family members, mostly parents, shows that while family members do not receive formal treatment themselves, they report receiving important support from FACT teams, including practical and emotional assistance, improved care coordination, and recognition of their involvement in treatment. The introduction of FACT was perceived as a turning point, improving continuity, integration of care, family involvement, and access to support, including outside regular office hours. The study also highlights their desire for additional support, such as psychoeducational programs, opportunities to share experiences, and extended team availability to better manage everyday challenges and enhance their wellbeing (Martinsen et al., 2025).

A Swedish quantitative study investigated the social situation, daily functioning, and use of healthcare services of 93 people with psychosis, receiving support from six FACT teams. The study reported that clients with psychosis who received support through FACT showed improvements in both practical and social functioning. These outcomes are particularly meaningful, as engagement in everyday activities and social connectedness are key aspects of mental health recovery. Having supportive social relationships was identified as a crucial factor in sustaining recovery and improving quality of life (Svensson, Hansson & Lexén, 2018). Furthermore, the FACT manual published by Region Skåne (2017) states that evaluation results show that Swedish psychosis teams have great potential to implement FACT in a program-faithful manner, achieving positive outcomes for the service users they support, while team members experience better control and reduced stress in their work. Similarly, a Danish quantitative quasi-experimental study compared FACT with standard community mental health teams (CMHT) and traditional ACT teams. The results suggested that FACT can deliver a more intensive and continuous form of care**,** with higher levels of outpatient contact and engagement than both CMHT and ACT. This finding highlights the model's flexibility and its potential to provide individualized support at varying levels of intensity depending on the client's current needs (Munch Nielsen et al., 2021a).

Research on RACT consistently shows positive outcomes, including improved functioning, greater wellbeing, stronger engagement in care, and enhanced collaboration between participants, relatives, and healthcare professionals. According to a meta-analysis by Nordén et al. (2012), RACT has proven to be an effective method for individuals with psychiatric diagnoses, particularly those with psychotic disorders. The review, which included 17 studies conducted between 2001 and 2011, showed consistently positive outcomes compared to standard care. The strongest effects were seen in improved daily functioning and overall wellbeing, while reductions in psychiatric symptoms were also evident. Overall, the results indicated that RACT supports better recovery for people with psychosis and may also be beneficial for individuals with other psychiatric conditions.

In a study by Sjöström et al. (2021), 139 family members (79 connected to RACT and 60 not) completed questionnaires measuring family involvement, carer burden, and experiences of stigma,

to examine the experiences of relatives of people with severe mental illness who participated in RACT. Relatives involved in RACT reported more positive relationships with healthcare professionals, felt more included in care, and experienced less alienation compared to those not involved in the model. They also expressed less fear that their ill family member might harm others. Although no major differences were found in perceived burden or stigma, the findings suggest that RACT helps strengthen cooperation and trust between families and healthcare staff. Malm et al. (2015) found in a meta-analysis that RACT led to clear improvements in both participant functioning and satisfaction with care. participants involved in the model became more engaged in their treatment and experienced a stronger sense of empowerment and control over their recovery process. The inclusion of the participant's close network in the Resource Group strengthened continuity and coordination of care, contributing to more stable treatment outcomes. The study also indicated that the collaborative and psychoeducational approach of RACT enhanced motivation, communication, and mutual understanding between participants, relatives, and healthcare professionals.

CARE PARTNERSHIPS

According to the FACT-representative interviewee (BS) family members are viewed as essential partners in the FACT model, both as a resource for recovery and as individuals who themselves may need support. Their perspective is considered vital, as they often hold unique knowledge about the participant's daily life, challenges, and strengths. The interviewee described how the team works to motivate participants to provide consent for family involvement, explaining that recovery tends to progress more effectively when relatives are part of the process. Once consent is established, involving family members becomes an expected and integrated part of FACT practice. They are invited to participate in planning, reviewing, and revising care and recovery plans, helping to identify what truly supports wellbeing in everyday life. At the same time, the interviewee highlighted that family members are often under strain and may at times need to step back. This withdrawal is not viewed negatively but as a sign of trust:

"They are often burdened and affected, and with certain participant groups we see that family members want to step back. When they feel secure, when they know that the team is working in this way, that we cooperate closely with the municipality and with all care and support partners … they are incredibly grateful to be able to step back in some cases" (BS).

Thus, FACT allows relatives to resume their natural role as parents, partners, or siblings rather than informal care providers, thus supporting relatives' mental health and wellbeing by reducing stress and enabling them to return to their everyday roles.

In RACT, collaboration between professional care staff and the family members of the participant is the very foundation of the approach. The model builds on the idea that effective care and recovery require close cooperation among all key actors in the person's life. Family members are not viewed merely as supporters but as active partners in the care process, contributing valuable knowledge about the participant's needs, preferences, and everyday context. The RACT-representative interviewee (CF) emphasised that relatives often experience great relief when the RACT model functions well - some family member are even able to return to work or resume activities they had to give up due to caregiving responsibilities. One of the model's primary aims is to reduce the heavy burden placed on informal carers, as the emotional and practical strain of caregiving can have far-reaching negative effects on health, employment, and social life.

RACT is therefore motivated by the desire to create a stable and supportive network around the participant while helping family members regain balance and autonomy in their own lives. As the interviewee explained: "*It's the relatives who carry the burden, how do we relieve them and help them get their lives back?".* From this perspective, RACT is seen as particularly effective in fostering meaningful cooperation between formal and informal carers. The interviewee compared RACT to FACT and reasoned that: "*If you think from that perspective [of the WELL CARE project, meaning fostering partnerships between informal and formal carers], FACT is good, but RACT is better. Relatives are always included, always. It's the case manager, the person, and the relatives – that's the foundation*" (CF).

SUSTAINABILITY

In Sweden, extensive efforts are underway to transform primarily psychosis teams into FACT teams. In 2012, the Swedish Association of Local Authorities and Regions (SALAR) provided funding for the development of integrated and outreach services, with FACT being given particular priority. At that time, there was only one FACT team in Sweden that had been certified by the Dutch Institute responsible for program fidelity assessments, CCAF (Centrum Certificering ACT en FACT). With support from SALAR, an additional seven teams were established, all of which were evaluated in terms of program fidelity, treatment outcomes, and staff experiences of transitioning to work according to the FACT model. For many teams in the country currently engaged in implementing FACT, this includes fourteen psychosis teams in the Skåne Region (Region Skåne, 2017). FACT has also been implemented in child and adolescent psychiatry, as well as in forensic psychiatry.

According to the FACT-representative interviewee (BS), several measures have been taken to ensure the sustainability and spread of the FACT model. Formal agreements between regions and municipalities have been established to prevent the model from disappearing when leadership changes, thereby securing long-term continuity. State authority directives emphasizing person-centred care where the participant is an active co-creator of their treatment - which is in line with the approach used in FACT - further support sustainability and dissemination. The FACT-representative interviewee (BS) highlighted that the model spreads not only through top-down

directives but also via curiosity and interest from other areas and teams. Successful implementation relies on integrated work, collaborative approaches, coordination between healthcare and social services, and fostering a staff mindset focused on the individual. These factors, in the interviewee's view, are crucial for maintaining both the sustainability and fidelity of FACT across different settings. The sustainability of FACT is further illustrated by Lund University currently offering a course titled "Integrated Care and Support Interventions According to the FACT Model" (7.5 credits), demonstrating formal educational dissemination of the model.

The sustainability of RACT is not fully secured. According to the interviewee, the model gained significant traction in the early 2000s: *"It was a huge thing back then, with lots of training and enthusiasm"* (CF). But over time, the conditions for maintaining it have weakened. After the initial momentum, organisational priorities shifted, and RACT gradually became confined to smaller groups of practitioners who continued the work on their own initiative. In regions such as Skåne, RACT has largely been replaced by FACT, a development the interviewee links to structural and practical constraints: RACT requires considerable time and long-term commitment, which often runs counter to the short-term priorities seen in healthcare systems. The FACT-representative interviewee (BS) described RACT as a long-term investment, ideally spanning at least two years, but often much longer, in order to build and maintain a stable and supportive group for individuals with enduring psychiatric conditions. However, this long-term nature also makes RACT more resource-intensive, which can be a challenge in organisations focused on efficiency and measurable outcomes.

In the past, formal written agreements between regional and municipal actors helped to sustain collaboration, but these have often been forgotten as new managers and organisational reforms have emerged. This has made it necessary for practitioners themselves to remind their organisations: *"We have this model — this is what we are supposed to work with"* (CF). The RACT-representative interviewee (CF) further noted that new staff are rarely trained in RACT, leaving implementation dependent on individuals who take the initiative to educate others and advocate for the model. Without dedicated leadership and structural support, the long-term sustainability of RACT remains uncertain. The interviewee emphasised that more research evidence demonstrating the effects and long-term outcomes of RACT is needed to strengthen its legitimacy, motivate continued use, and ensure its organisational sustainability.

TRANSFERABILITY

Both FACT and RACT are designed for individuals whose needs exceed what standard mental health and social services can provide. They target people requiring coordinated, long-term, and multidisciplinary support – often those with severe and persistent mental illness or complex psychosocial difficulties. If these criteria are met, the models can in principle be applied to individuals with a wide range of conditions. Both approaches are community-based and emphasise

close collaboration between health and social care systems, which means that transferring them across national contexts requires adaptation to country-specific organisational and legislative frameworks. Differences in how health and social care are structured, financed, and governed strongly influence implementation and sustainability.

According to the FACT-representative interviewee (BS), FACT has been successfully transferred and adapted to several areas beyond psychosis care, including addiction services, child and adolescent psychiatry, and forensic psychiatry. Most FACT participants have psychotic disorders, but other common conditions include depression, bipolar disorder, personality disorders, autism spectrum disorder, ADHD, learning disabilities, substance use disorders, or combinations of these (van Veldhuizen & Bähler, 2015). Individuals often struggle in multiple life domains – physical health, employment, education, social relationships, and community functioning.

FACT is currently used in several countries. According to CCAF (Centrum Certificering ACT en FACT), FACT has been established in the Netherlands, Norway, Denmark, Sweden, Ireland, England, Bonaire, Aruba, Belgium, the Czech Republic, Moldova, and Canada (CCAF, n.d.). Its flexibility makes it adaptable to local health systems while maintaining its core principles of continuity, shared caseloads, and outreach.

RACT also encompasses a broad range of target groups. As described in the FACT manual published by Region Skåne (2017), it is a community-based program for treatment and rehabilitation of all forms of mental illness, such as depression, schizophrenia, other psychoses, anxiety disorders, and substance use disorders. According to the RACT-representative interviewee (CF), RACT should not be limited by diagnosis but rather by need—anyone who requires coordinated, person-centered support can receive it. While RACT is primarily implemented in adult psychiatry, it could also be applicable to child and adolescent services when relevant. As a formalized model, RACT is most thoroughly documented in Sweden, but its foundational principles are reflected in international practices under related concepts such as Integrated Psychiatry, Case Management, and Resource Group Methods (Sahlgrenska, n.d.). These parallels suggest that the RACT framework is both transferable and adaptable across settings, provided local structures enable the necessary collaboration and long-term commitment.

STRENGTHS

Both FACT and RACT share several key strengths rooted in the ACT model. A central feature of both approaches is interdisciplinary teamwork, where multiple professional perspectives are integrated to meet complex needs. They are outreach-based, working where participants live and spend their time rather than being tied to office settings. This method increases accessibility and engagement, particularly for individuals whose psychiatric conditions make it difficult to maintain contact with healthcare services. Both models emphasise person-centered and recovery-oriented practice.

participants have a high degree of influence over goal setting and planning, and relatives or informal carers are actively involved as partners in care. This collaboration fosters continuity, shared responsibility, and reduced fragmentation between organisations and sectors—key factors in preventing participants from "falling between the cracks". An additional strength of the models is the involvement and support of family members, which enhances continuity of care, promotes shared decision-making, and acknowledges the important role relatives play in the participant's recovery.

In FACT, flexibility and collective responsibility are defining strengths. The model allows the team to intensify or scale down support depending on the participant's situation, which promotes both sustainability and efficiency. According to Munch Nielsen et al. (2021b), daily FACT board meetings enhance communication and coordination across professions, creating shared awareness of those with increased needs. The FACT-representative interviewee (BS) described FACT as providing team-based safety and stable care delivery, as participants are supported by the whole team rather than a single practitioner. This allows practitioners to take time off or stay home with sick children "without worrying" knowing that the team will continue to provide support, which reduced work-related stress. The model's structure enables consistent follow-up and draws on multiple professional competencies - psychiatric, social, and psychological - to create a more coherent and responsive system.

RACT shares these person-centered and collaborative elements but places stronger emphasis on partnership, empowerment, and individualised support. At the core is the resource group, consisting of the participant, the case manager, relatives, and relevant professionals. This group is jointly responsible for setting goals and following up on progress. According to Sjöström et al. (2021), relatives involved in RACT reported more positive encounters with healthcare professionals and a greater sense of inclusion and trust. In interviews, RACT was described as a holistic and sustainable approach, in which the participant's own choices shape who is involved in their care. The model provides a sense of security and continuity for the participant, as the resource group often remains in place for 10 years or more. The resource group is flexible, its composition changes as the participant's situation evolves, and the case manager acts as an advocate for the participant, promoting autonomy and long-term empowerment. Early investment in relationship-building was seen as yielding strong long-term outcomes for both participants and relatives.

WEAKNESSES/CHALLENGES

Both FACT and RACT encounter challenges that are often organisational rather than methodological. According to the FACT-representative interviewee (BS), the main limitations are not inherent to the models themselves but rather relate to organisational alignment and sustainability. Successful implementation requires commitment across all levels from top management to frontline staff, and clear agreements between health and social services to ensure long-term stability. Managers must

understand the model and what it entails in practice, ensuring that the principles of FACT are embedded throughout the organisation. Without such anchoring, programs risk fragmentation or loss of coherence when key individuals leave or priorities shift. Sustained collaboration also depends on formal structures. The interviewee stressed the importance of clear agreements and joint frameworks between services to ensure stability over time. For FACT specifically, the interviewee emphasised that practical collaboration is a central, such as between healthcare services and social services, challenge. Effective cooperation between different services and stakeholders is "very difficult" (BS) and requires continuous effort. Building strong network relationships, understanding each other's roles, and cultivating a sense of shared purpose are essential, particularly in times of crisis when teamwork and mutual trust are critical. As highlighted by Munch Nielsen et al. (2021b), FACT teams also face pressure from high caseloads and a broad geographic area, which can limit the ability to reach participants who are difficult to engage. Some adaptations of the model are therefore necessary to fit local capacities, but these adjustments may reduce standardization and complicate evaluation. Regarding RACT, considerable investment is needed initially, often during the first year, but once a functional resource group and effective strategies are established, the investment pays off over time. The interviewee stated that: "*This approach requires significant time and resources, particularly for those implementing it, which is one of its main drawbacks*" (CF). Another challenge has been that municipal social services must grant formal support, for example providing a housing support worker who can participate in the resource group.

POTENTIAL IMPROVEMENTS

The RACT-representative interviewee (CF)viewed the recent changes in the Swedish Social Services Act positively, as they allow more to be done without means-testing or formal assistance, aligning well with the RACT approach and promoting its implementation. The interviewee also reflected on why FACT seems to have replaced RACT in several municipalities and regions, suggesting that it is because FACT is easier to assess and evaluate, has a more standardized approach, whereas RACT requires evaluating the participant's experience. She reasoned that more research and evaluations are needed to provide evidence for the value of RACT.

CONCLUSIONS

Research and evaluations of FACT (Trane et al., 2021; Martinsen et al., 2025; Svensson, Hansson & Lexén, 2018) indicate that the model can strengthen collaboration between services, improve continuity of care, and enhance recovery outcomes for individuals with complex mental health conditions. It has also been associated with higher satisfaction among clients and relatives, and in some studies with reduced strain among staff through clearer team roles and shared responsibility. Findings from RACT research (Sjöström et al., 2021; Malm et al., 2015) show consistently positive results, including improved functioning, greater wellbeing, and stronger engagement in care.

Importantly, RACT appears to facilitate cooperation between participants, relatives, and professionals, leading to more coherent and person-centered support.

A key insight from both models is the recognition that recovery from severe mental illness is not achieved by professional interventions alone. The role of family members and informal carers is crucial. In FACT, relatives and close relations are viewed as essential partners – both as a resource for recovery and as individuals who themselves may need support. Their perspectives provide valuable insights into the participant's daily life, challenges, and strengths, which helps tailor interventions more effectively. RACT takes this even further: collaboration between professionals and family members is at the very foundation of the model. By actively involving relatives and other significant people in the resource group, RACT creates a joint structure of accountability, where decisions are made together and where the person's social environment becomes a vehicle for recovery rather than an afterthought. The models' emphasis on teamwork and collaboration offers valuable lessons for mental health systems more broadly. Both FACT and RACT demonstrate the importance of continuity, interdisciplinary integration, and sustained relationships in care for people with complex and long-term mental illness. They show that outcomes improve when professionals from different sectors share responsibility and when family and social networks are seen as part of the care process rather than as external to it. These elements are particularly relevant for healthcare systems that remain divided between health and social services, or where short-term, episodic interventions dominate over long-term, relational work.

In terms of sustainability, FACT has gained increasing traction in Sweden, where significant efforts have been made to transform existing psychosis teams into FACT teams. The Swedish Association of Local Authorities and Regions (SALAR) has supported this development since 2012, promoting integrated and outreach-based services as a national priority. RACT, by contrast, experienced a strong period of implementation in the early 2000s, but its spread and continuity have varied across regions. In some areas, such as Skåne, RACT has gradually been replaced by FACT. Nonetheless, the core principles of RACT - user participation, inclusion of family, and collaborative goal setting - continue to influence how recovery-oriented care is designed and delivered. Regarding transferability, both FACT and RACT are community-based models that rely on close collaboration between health and social care systems. While they can, in principle, be applied in any context where individuals have complex and coordinated care needs, their implementation requires adaptation to national and local conditions. Differences in how health and social care are organised, financed, and governed strongly influence the feasibility of these models. Successful transfer therefore depends on alignment with existing systems, sufficient managerial support, and formal structures for interagency cooperation. Despite their strengths, FACT and RACT also face challenges. Many of these are organisational rather than methodological. Sustaining integrated models requires long-term commitment from both management and frontline staff, as well as clear agreements between sectors. When such anchoring is lacking, teams risk fragmentation, inconsistent practice, or loss of key competences when staff members leave. Interview data and research alike highlight

that for these models to function effectively, they must be embedded not only in policy documents but in the daily routines, values, and leadership priorities of the involved organisations.

In conclusion, the experiences from FACT and RACT offer important lessons for the broader field of mental health care. They illustrate that effective support for people with complex needs depends on three interlinked factors: continuity of relationships, interdisciplinary collaboration, and the genuine inclusion of family and significant others in the recovery process. These principles are transferable across contexts and remain central to building mental health systems that are both person-centered and sustainable over time.

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10. Carers' Outcome Agreement Tool (COAT)

ABSTRACT

The Carers' Outcome Agreement Tool (COAT) was developed in Sweden as a response to the increasing burden on informal carers. Research (e.g. Johansson et al., 2003) showed that family members were assuming greater responsibility for care without a corresponding increase in formal support, and that there was no systematic or evidence-based method for investigating and planning carer support. In 2005, the National Board of Health and Welfare Sweden (NBHWS) was commissioned by the Ministry of Health and Social Affairs to develop methods to monitor and improve support for informal carers. The COAT project, conducted in collaboration with ÄldreVäst Sjuhärad Research & Development Centre, West Sweden, the University of Borås, and the University of Sheffield, and initially with the NBHWS, involved the development of COAT itself and pilot studies in three Swedish municipalities between 2006 and 2008.

COAT is a structured planning tool designed to improve both the quality of life of informal carers and their capacity (for those informal carers who wish to do so) to provide good care for their older relatives. It targets informal carers who provide regular, help, support and even in some instances, care to older relatives living at home, and, in particular the municipal carer advocates, but also other professionals, such as Needs Assessors, responsible for planning and following up carer support. The model is based on dialogue and partnership, acknowledging experienced carers as experts with regards to their their own caring situation. Using a standardised questionnaire divided into three parts; support for caregiving, the carer's own wellbeing, and the wellbeing of the care recipient, the tool facilitates structured conversations leading to a support plan with goals, responsibilities, and scheduled follow-up and evaluation of the agreed support provided.

COAT has been evaluated in the three Swedish municipalities of Borås, Härnösand and Jönköping, using surveys and telephone interviews with informal carers, and focus groups with carer advocates. In Quebec (Canada), practitioners and carers participated in focus groups and individual interviews (Hanson et al., 2006; Hanson et al., 2008; Lévesque et al., 2010; Magnusson et al., 2009a, Magnusson et al., 2009b, Magnusson & Larsson-Skoglund, 2009). Evaluations have shown positive outcomes. Participant informal carers report feeling heard, respected, and better able to reflect on their situation. Participant professionals (carer advocates, Needs Assessors) describe improved understanding of carers' needs, better communication, and strengthened trust. Field trials in Borås, Härnösand, and Jönköping municipalities demonstrated that COAT increased security, knowledge, and support for carers. The method has since been implemented in several Swedish municipalities.

Overall, COAT provides a sustainable tool for carer support, fostering collaboration, participation, and individualised care planning (ibid.).

INTRODUCTION

Name of the good practice: Carers Outcome Agreement Tool (COAT).

Country of implementation: Sweden.

Implementation level: Local at the level of the municipality.

Leader organisation: Jönköping municipality, Sweden.

Contacts: Johanna Karlsson, Head of Dementia and Carer Support Unit, Eldercare, johanna.karlsson@jonkoping.se.

Website:
Nationellt kompetenscentrum anhöriga's (NKA) homepage with a description of the implementation of COAT in Jönköping Municipality:

https://anhoriga.se/anhorigomraden/anhoriga-till-aldre-

personer/intressanta-exempel-pa-anhorigstod/individualisering-

utvardering-och-utveckling-av-anhorigstod/ett-anhorigstod-i-partnerskap-

foljs-upp-med-hjalp-av-coat-i-jonkoping/

A report from the NBHWS on the development,

implementation and evaluation of the COAT model:

https://www.hb.se/globalassets/global/hb---externt/fous/forskning-och-

utveckling/aldre/coat/planeringsinstrument-for-anhorigstod-

socialstyrelsen.pdf

FoU Sjuhärad välfärd's (Sjuhärad Research & Development Centre's) homepage with a description of the COAT model:

https://www.hb.se/fous/publikationer/coat/

A research article on implementing COAT in Canada:

https://stm.cairn.info/journal-recherche-en-soins-infirmiers-2009-2-page-

63?lang=en

A research article on implementing COAT in Sweden:

https://journals.sagepub.com/doi/10.1177/1744987108095161.

Date of data collection: WELL CARE case study interviews, October and November 2025, Data have also been collected from documents such as plans and reports that describe the design, use and results of the models, for example Hanson, Nolan, Magnusson, Sennemark and Nolan (2006), Hanson, Magnusson and Nolan (2008), Lévesque, Ducharme, Caron, Hanson, Magnussone, Nolan and Nolan (2010), Magnusson, Hanson, Walkhamre and Larsson-Skoglund (2009a), Magnusson, Hanson, Jansson and Larsson-Skoglund (2009b), Magnusson and Larsson-Skoglund (2009), National Board of Health and Welfare Sweden (2005).

Description of the organisational structure of the practice: COAT is embedded within existing municipal services for support to informal carers and is not organised as a separate programme or organisational unit. The practice is implemented at the local (municipal) level and carried out by dedicated carer advocates as part of their regular professional responsibilities to support informal carers. Organisational responsibility rests with the municipality, and implementation arrangements may vary between municipalities. In some cases, such as Jönköping municipality, the use of COAT is regulated through formal political decisions, ensuring systematic and continued application.

START AND STATUS OF THE PRACTICE/INITIATIVE

WHEN DID IT START

As part of the national action plan for eldercare 1999-2001, a special government grant - Anhörig 300 - was allocated, totalling 300 million SEK, to stimulate municipalities to develop support for informal carers (Swedish Ministry of Finance 2007). Many development projects were initiated at the municipal level, but most were not formally evaluated by informal carers themselves, prompting the NBHWS to advocate for more systematic approaches to supporting and assessing the support provided to carers. COAT was one such initiative that was actually evaluated by informal/ family carers themselves. Thus, the starting point of COAT became the understanding that each care situation is unique and must be seen in its specific context and in relation to the phase of caregiving the carer is in. The COAT initiative was developed in the early 2000s and entered municipal practice in 2005 in Jönköping municipality, Småland, south Sweden, Borås municipality, West Sweden and Härnösand municipality, north Sweden.

REASONS FOR STARTING

The Carers' Outcome Agreement Tool (COAT) was developed as a direct response to the growing burden placed on family members caring for relatives, combined with decreasing resources within public health and social care services. Research had shown that spouses and adult children were increasingly taking responsibility for providing care as the public sector contracted, yet support for informal carers had not increased correspondingly and remained an underdeveloped area.

Moreover, there was a lack of knowledge about which forms of support were most effective, and no scientifically developed tools for evaluating or following up carer support were available, particularly within a Swedish context. The need for reliable, evidence-based methods and instruments to monitor and plan carer support was therefore emphasised in several reports issued by the National Board of Health and Welfare, 2005).

In early 2005, the National Board of Health and Welfare Sweden (Socialstyrelsen-NBHWS) was commissioned by the Ministry of Health and Social Affairs to develop methods for monitoring the development of carer support in municipalities during the period 2005-2007. The initiative was founded on the recognition that traditional assessment methods often fail to capture the individual circumstances of carers, and that a more dialogue-based and partnership-oriented approach is necessary to strengthen both carers' and professionals' participation. This work aimed to create and test an instrument for the planning, monitoring, and evaluation of support for informal carers, namely COAT. The project was carried out in both Sweden and England and was based on previous research on carer support, user participation, and partnership models conducted at ÄldreVäst Sjuhärad, the University of Borås, and the University of Sheffield, UK. It was a collaborative project financed by ÄldreVäst Sjuhärad, and the National Board of Health and Welfare Sweden (NBHWS, 2005).

COAT is used on a regular basis by carer advocates in the municipality of Jönköping since 2005. Borås and Härnösand municipalities used the tool during the period 2005-2010. In Härnösand, COAT was applied until a change of care manager in 2010, after which it was no longer used routinely. In Borås, the tool was implemented and a 2009 evaluation reported positive results; however, middle management regarded the approach as too time-consuming, leading to its discontinuation after 2010. During the broader implementation period (approximately 2003-2010), Limhamn-Bunkeflo, Varberg, and Uppvidinge municipalities also adopted COAT. By 2016, a total of 134 municipalities were formally registered as COAT users, although the exact number that continue to use the tool today is not known.

TARGET GROUP(S)

COAT was developed based on the recognition that the family plays a strategic role in enabling society to achieve its goals within health and social care. In Sweden, one in six adults provides care or support on a regular basis to an older relative or someone close to them. Among these, almost one third devote more than 10 hours per week to caregiving (NBHWS, 2023). Interviewees in this case study noted that the informal carers they most often meet are women, primarily wives and daughters. They reflected on whether this might be because men seek help less frequently, but also observed that many of these women are unaccustomed to considering their own wellbeing, having spent years managing work, household responsibilities, and family care simultaneously. Family carers perform extensive practical, organisational, and emotional work that significantly relieves pressure on the formal health and social care system and thus play a crucial role in sustaining the

welfare state. By law, the care provided by relatives is intended to be voluntary. The responsibility for ensuring that individuals receive the care and support they need lies with the public sector (health and social care services), not with families. However, in practice, many informal carers have little real choice regarding how, when, and to what extent they provide care. Emotional bonds, loyalty, and a sense of moral duty often blur the line between voluntary and involuntary caregiving. When public services are inadequate or unavailable, the burden on family members increases, leaving them with limited opportunities to set boundaries around their caregiving responsibilities (NBHWS, 2021).

Providing care for an older family member can be a deeply meaningful and enriching experience. It can strengthen relationships, offer new perspectives on life, and foster a sense of purpose and reciprocity. Many carers describe satisfaction in knowing they are helping someone they love. However, the caregiving role also entails considerable strain and can have serious consequences for the carer's physical and mental health, financial stability, social inclusion and overall quality of life. For some, caregiving is an ongoing and demanding commitment that can last for years, even decades (NBHWS, 2023). Around-the-clock responsibility for an older parent or partner often limits opportunities for rest, employment, and social interaction. This constant strain can lead to exhaustion, social isolation, and emotional distress. Financial difficulties may arise when carers reduce working hours or leave employment altogether, which in turn can worsen stress and health problems. The negative consequences of caregiving often reinforce one another. Stress and fatigue can diminish the carer's capacity to maintain social relationships or manage other life responsibilities, creating a cumulative impact on wellbeing. Even when the caregiving itself is limited, the emotional burden – worry, guilt, or grief – can still be overwhelming (NBHWS, 2021).

To develop successful strategies and models for carer support, previous attitudes and working methods needed to be reconsidered. It was emphasised that carers should not only be seen as recipients of support, but also as individuals with their own resources, strengths, and competences. An important principle became to acknowledge and build upon the expertise that carers possess in caring for their relatives. The development work highlighted the need to identify factors that have direct value for carers and can lead to real improvements in their daily lives. It was also considered essential to plan and evaluate support measures according to criteria that reflect families' own goals, needs, and ambitions.

Municipal carer advocates play a central role in this work: they are responsible for identifying carers' needs and offering tailored support. COAT serves as a practical tool in this process, helping professionals structure conversations and jointly plan measures that benefit carers. As the tool is designed to support the advocates themselves in their work, they are also to be considered a key target group. However, one interviewee noted that outreach remains a significant challenge, as she felt that those who are most socially and economically vulnerable are often underrepresented: "*Socioeconomic background and all that – I wouldn't dare make any claims. I would say the group is*

quite broad, but I don't feel that we reach the most vulnerable. We don't reach those with a different cultural or immigrant background to any greater extent. Very little" (JR).

CARE RECIPIENTS

COAT was specifically designed for carers of older adults, focusing on situations where the care recipient is an older person living at home with long-term care needs and supported by a family member. In Sweden, a substantial majority of older adults remain living in ordinary housing rather than transitioning to institutional care. Approximately 85% of individuals aged 80 years and older live at home in regular housing settings (Boverket, 2025). In this same age group, approximately 9% have been diagnosed with dementia (Ding et al., 2024). The probability of experiencing a wide range of health problems and functional decline similarly rises with increasing age (Wennberg et al., 2022). The phenomenon of ageism, meaning discrimination or stereotyping based solely on a person's age, further complicates the lives of older people living at home. Research in Sweden found that roughly one quarter of individuals aged 66+ reported perceiving negative attitudes toward older adults, and those perceptions were associated with lower life satisfaction and health-related quality of life (Bratt & Fagerström, 2023). While formal age discrimination is prohibited in Swedish law, older persons still face marginalisation in decision-making, under-representation in political forums, and assumptions about fragility, dependency and restricted potential. Ageism can thus reduce older people's access to meaningful participation, undermining their autonomy even when they live at home and receive formal support.

Older adults living at home, aged 65 or above, have varying needs for daily support. Many receive municipally administered services alongside informal care from family or friends. According to the NBHWS (2024), approximately 352,000 people aged 65 and over were granted some form of assistance under the Social Services Act, including home care. Among these, about 11.7% of women and 8.4% of men received home care services. Home care commonly includes help with personal care, meals, cleaning, shopping, and safety-related services. It also aims to promote social interaction and preventing loneliness – key elements in maintaining quality of life among older adults. The overarching aim is to enable individuals to remain in their own homes while supporting independence, wellbeing, and participation in everyday life. Socialstyrelsen emphasises that such care should be individually tailored according to each person's capacities, preferences, and needs. The group of home care recipients is diverse but often characterised by vulnerability, with large variations in health status, resources, and life circumstances. Among adults aged 80 and above in Sweden, around one quarter receive home help in ordinary housing. This indicates that a majority of the oldest old continue to live at home, often with support rather than in special housing. Research further shows that more than 80% of older adults have an adult child living within 50 kilometres, which may have important implications for informal caregiving and social contact (Malmberg et al., 2025).

OVERALL CHARACTERISTICS OF THE PRACTICE/INITIATIVE

AIMS

The Carers Outcome Agreement Tool (COAT) aims to enhance the quality of life for both older persons and their informal/family carers, as well as to improve the quality of carer support provided by municipalities. The tool was developed, in collaboration with informal carers and their organisations and health and care professionals working in the municipality, to further develop and individualise carer support through an approach based on partnership working between family carers and health and social care professionals. Through COAT, the goal is for health and social care practitioners to gain deeper insights into the specific needs and preferences of family carers within each municipality – what types of support are perceived as most valuable in helping them care for their relatives, and which measures contribute to improved quality of life both for the carers and for those they support. The overarching objective has been to create a tool through which family carers and professionals can jointly identify, plan, and follow up on individually tailored support that meets the carer's own needs and goals. The work is grounded in the ambition to build genuine partnerships with carers – both in the development of the tool itself, in close collaboration with carers, carer advocates and needs assessors (see Hanson et al., 2006), and in the planning and evaluation of carer support. The approach emphasises that outcomes should be defined and documented from the carer's perspective and be specific and relevant to the individual. Mutual understanding and agreement on expected outcomes should be reached through careful and sensitive assessment. Family carers are actively involved as experts in identifying and following up on results, and the evaluation process begins by clarifying which goals are intended.

HOW DOES IT OPERATE

In daily practice, COAT is used to support informal carers by providing a structured framework for identifying their needs and preferences for support, planning support, and following up on support interventions implemented. Carer advocates employed by the municipality come into contact with informal carers in different ways. In some cases, the informal carer contacts the carer advocate directly. Sometimes, it is a relative of the informal carer who has identified a need, in which case the carer advocates may reach out to the informal carer and ask if they wish to establish contact. Occasionally, contact is initiated by other professionals, such as Needs Assessors. Once contact has been established, a mutually convenient time is agreed upon to meet and review the informal carer's situation and potential support needs and goals. The carer can choose whether the meeting takes place in their own home or at the office of the staff member they usually interact with. Before the meeting, the carer receives a letter from the municipality including the COAT questionnaires and a user guide. Informal carers can choose to complete the questionnaires in advance or wait until the meeting. This preparation allows them to start reflecting on the questions and discuss them with the care recipient, other family members, or friends if they wish.

During the meeting, the informal carer and staff member go through all questions together, discussing each area of need. Based on these discussions, a personalised support plan is developed,

prioritising the aspects that are most important to the carer. The informal carer receives a copy of the completed questionnaires and the support (action) plan, enabling them to review the decisions and agreements afterwards. Follow-up is conducted every six months, or sooner if the informal carer's situation changes. A full reassessment, including a new support (action) plan, is carried out annually. The focus is on evaluating whether the informal carer's needs have been met, assessing the quality of support provided, and identifying current needs for future planning.

The COAT assessment covers three main areas:

- Part A: Helping you provide care – Practical help, information, or advice to support the carer in their caregiving role.
- Part B: Making life better for you (the carer) – Issues that could enhance the carer's quality of life and wellbeing.
- Part C: Making life better for the person you care for – Aspects that may contribute to improving the quality of life of the person receiving care.

A corresponding support (action) plan is made for each of the three domains.

Each area has a corresponding questionnaire, which the carer receives along with a user guide. Informal carers are encouraged to review the questions and indicate how valuable they find each type of support. There is also space to add comments or additional needs not included in the standard questions. Background information, such as age, gender, health, relationship to the care recipient, and current municipal support, is collected using questions adapted from the Carers of Older People in Europe (COPE) questionnaire (McKee et al., 2003). Informal carers are invited to reflect on each question and answer based on their own caring situation, with no right or wrong responses. The method is flexible: informal carers can go through the questions sequentially or focus on the areas they consider most valuable. The aim is to ensure that the process works for them.

The meeting also results in a clear plan for the type/s support to be provided, including what help is needed, when and by whom it will be delivered, the goals of the support, and criteria for evaluating whether the goals have been achieved. Carers can expect that the discussion takes place at a convenient time and location, that sufficient time is allocated to cover their concerns, and that they are fully involved in the conversation. They also receive copies of all completed forms and know who to contact with any questions or concerns about the support they receive.

MAIN OUTCOMES

Field testing of COAT in the three Swedish municipalities of Borås, Härnösand and Jönköping 2006 – 2008 indicated a wide range of positive effects for both participating carers and practitioners. Carers reported that the tool helped them raise issues of concern and discuss them openly, leading

to new insights into their caring situations. Many carers described gaining a broader perspective on their roles and needs, and several noted that COAT enabled them to reflect on aspects of their daily lives that they had not previously considered. The structured nature of the discussions was experienced as helpful, allowing carers to organise their thoughts and communicate more clearly with practitioners. Importantly, all carers described the experience positively, particularly appreciating that practitioners spent dedicated time focusing on their situation and needs. Compared with previous assessments, COAT was perceived as offering a more personal and meaningful dialogue where carers could fully express their views and feel validated in their experiences.

Participant practitioners (carer advocates, Needs Assessors) likewise identified significant benefits from using COAT. They reported that the tool facilitated in-depth, individualized conversations about each caring situation and promoted a more comprehensive understanding of carers' experiences. Even those with extensive prior knowledge of the families found that completing COAT provided new insights and perspectives. Practitioners noted that carers tended to speak more openly about their situation and reflect on their own quality of life and wellbeing. The process also allowed practitioners to begin addressing immediate concerns by providing information, advice, or emotional support. Several described the reflective and collaborative nature of the conversation as potentially therapeutic in itself, as it often had a positive emotional impact on carers. Overall, the pilot testing suggested that COAT supported more person-centred and constructive communication, strengthening mutual understanding and trust in the caring partnership (Hanson et al., 2006).

In Borås municipality, 10 informal carers participated in telephone interviews, 168 informal carers responded to a survey on carer support, and a focus group involved five staff who had conducted COAT conversations, and the project manager. Evaluations showed that articipation in the COAT project contributed to a sense of security, new knowledge, and an important social function for carers. They appreciated that their situation was acknowledged and reported that participation led to concrete help and support. The psychological and emotional value of being seen, feeling safe, and having someone to talk to was particularly emphasised. Most caring situations were functioning well, as eight out of 10 participants stated at the final COAT meeting that they were satisfied with the help and support they had and had no immediate plans for change (Magnusson et al., 2009a).

In Härnösand municipality, 20 informal carers participated in telephone interviews, 289 informal carers responded to a survey on carer support, and a focus group was held with the project coordinator, a project manager, seven COAT representatives, and two carer advocates. Staff observed effects of COAT at several levels – among carers, personnel, and within the organisation. Participant carers increasingly shared their concerns, asked questions, and felt more recognized. They became more active in local activities and requested respite care more frequently. Ongoing COAT conversations helped staff identify needs more quickly and communicate them to Needs Assessors. Over time, discussions became more efficient, and carers spoke more openly about their situation (Magnusson et al., 2009b).

In Jönköping municipality, 10 informal carers took part in telephone interviews, 96 informal carers responded to a survey on carer support, and a focus group included the project coordinator, the project manager, two COAT representatives, and the carer advocate. The COAT project was described as having generated effects on multiple levels – municipal, political, staff, and carer levels. COAT contributed to a clearer focus on carers rather than solely on the care recipient. Summaries of COAT discussions provided valuable first-hand information about carers' actual needs, helping future decisions and planning to be based on carers' own voices rather than intermediaries. The project also influenced local understanding of carer support, shifting attention from financial compensation toward more individualized and relational forms of support. Participants in focus groups and interviews noted a gradual, positive change in attitudes toward carers among municipal staff, supported by the project's good results, communication, and personal experience (Magnusson & Larsson-Skoglund, 2009).

In Canada, COAT was tested in a modified version called the Family Carers Support Agreement tool (FCSA) within homecare services in Quebec (Lévesque et al., 2010). The study included six practitioners (nurses and social workers) and 17 family carers of frail older adults. The results showed that the FCSA, like the original COAT, helped to establish a partnership between carers and professionals. Through the tool, conversations deepened, carers' needs were identified, and support plans were developed in dialogue. Both carers and practitioners described the process as being characterised by trust, openness, and reflection, which led to new insights into the caregiving situation. The study also showed that the instrument promotes an equal collaboration rather than a one-sided professional perspective.

The carer advocates interviewed for this case study suggested that COAT could also be used as a basis for developing the support offered to family carers. Based on the needs expressed by carers and the support most frequently requested, COAT can enable carer advocates to gather information, organise support groups, or establish channels of contact to meet the needs of informal/family carers in their municipality. Together, these evaluations demonstrated that COAT effectively fostered communication, insight, and recognition across multiple levels of care. In addition, the tool can provide a foundation for shaping support and assistance that addresses the needs of the wider community of carers. The tool not only provided carers with an opportunity for reflection and validation but also supported practitioners and organisations in developing a more person-centred and partnership-oriented approach to carer support.

CARE PARTNERSHIPS

COAT is, according to its creators, designed to promote an *exchange* of views between carers and practitioners. The use of COAT enables support to be *negotiated*, leading to more sensitive, appropriate, and acceptable services. The overarching aim is to foster partnerships between family and formal carers and to recognise the expertise of both parties (Hanson et al., 2006). However, the

interviews conducted for this WELL CARE case study report were held with informal carer advocates who themselves do not provide direct care to care recipients, but work exclusively with support to informal carers. Consequently, the case study interview material did not indicate that COAT directly promoted partnerships between informal and formal carers – such as through information exchange concerning the care recipient. However, to strengthen the carer perspective and enable partnership, the interviewees suggested that long-term care staff need additional training. The areas covered by COAT could serve as part of such training, helping to highlight and discuss carers' needs and preferences. The interviewees suggested that the tool substantially strengthened the relationship between carer advocates and informal carers. Furthermore, participants noted that the COAT framework enabled them to offer advice and support to informal carers on how to communicate effectively with, for example, long-term care workers providing home-based care, thus improving collaboration between these groups.

SUSTAINABILITY

In Jönköping, a political decision has been made requiring all municipal informal carer advocates to use COAT in every meeting with informal carers. This decision effectively ensures the *sustainability* of the approach within the municipality. COAT is also being used in other Swedish municipalities; by 2016, a total of 134 municipalities were formally registered as COAT users, although it remains unclear where and to what extent. Case study interviews with staff involved in Jönköping's informal carer support indicated that long-term sustainability could be further strengthened if the tool were revised and updated in accordance with the carer advocates' experiences and suggestions.

TRANSFERABILITY

The WELL CARE interview participants agreed that COAT could advantageously be applied to other groups of informal carers, particularly the section focusing on what might improve the informal carer's own quality of life (Part B). They reflected that what informal carers often share - regardless of the care recipient's specific needs - is a tendency to be preoccupied with the needs of the person they care for, which can lead them to neglect their own wellbeing. A tool like COAT is therefore valuable because it highlights the informal carer's own needs and preferences, making it relevant and beneficial also for other target groups.

The findings from Canada (Lévesque et al., 2010) confirmed the previously positive experiences from Sweden and the UK (Hanson et al., 2006), indicating that the core idea of COAT - to strengthen partnerships and systematically identify carers' needs - is transferable across different countries and contexts.

STRENGTHS

COAT has several clear strengths that have been highlighted by both carers and practitioners in interviews and evaluations (Hanson et al., 2006; Magnusson et al., 2009a; 2009b; Magnusson & Skoglund-Larsson, 2009). The tool provides a structured and comprehensive framework that covers all relevant areas of the caring situation, ensuring that no important aspects are overlooked. It allows carers to talk openly about their experiences and needs, and helps them to reflect on their own wellbeing as well as the care they provide (Hansson et al., 2006). A major strength mentioned by the interviewees was that COAT promotes fairness and legal security, since all carer advocates ask the same questions and follow the same structure. This creates equal conditions for all informal carers and ensures that everyone receives the same opportunity to express their needs and views. The interviewed practitioners also valued having a standardised tool that supports quality and consistency in their work. COAT also helps to build trust and strengthen the relationship between carers and practitioners. Carers interviewed for the field studies described feeling listened to, understood, and supported, and they appreciated that someone took time to talk about their needs (Hanson et al. 2006, Magnusson et al. 2009a). Practitioners found that the conversations became deeper and more meaningful, and that COAT often led to new insights even when they already knew the particular caring situation well (Hanson et al., 2006; Magnusson et al., 2009b). Local evaluations showed that COAT contributed to increased security, new knowledge, and concrete support for carers (Magnusson et al., 2009a). It also helped professionals to identify needs earlier and to adapt the support more effectively (Magnusson et al., 2009b). In Jönköping, COAT was reported to have encouraged a more personal and partnership-based way of working with carers and to have strengthened the overall focus on carers within the municipality.

In the interviews conducted for this case study, participants emphasised that the very fact that the COAT framework is based on the carer's own needs and preferences holds great intrinsic value. These are individuals, they noted, who have often spent a long time helping and supporting a care recipient. One interviewee explained: "*It's a bit sad, I think. When you get that response, when I ask, 'How are you doing?' and they say, 'This is probably the first time in years anyone has asked how I am.' 'I think that's one of the things… at least that's been my experience, that it makes them feel like, 'Someone actually sees me when they [carer advocates] call, and it's such a relief to finally talk about how I'm doing' "* (CL).

Having the opportunity to talk about themselves, their feelings, and their thoughts, and to feel seen and acknowledged by an external professional, was experienced as highly positive by the carers, according to the interviewees.

Overall, COAT is seen as a structured, fair, and supportive tool that helps both carers and practitioners to communicate better, understand each other more deeply, and create more individualized and relevant support (Hanson et al., 2006; Magnusson et al., 2009a; Magnusson et al., 2009b; Magnusson & Larsson-Skoglund, 2009; interviews).

WEAKNESSES/CHALLENGES AND POTENTIAL IMPROVEMENTS

In the evaluations of the pilot projects (Magnusson et al., 2009a, Magnusson et al., 2009b; Magnusson & Larsson-Skoglund, 2009), certain barriers and challenges with the instrument were identified. For example, a lack of resources was highlighted as a major limiting factor. More resources are needed for carer support in order to be able to help and support informal carers more effectively. Another barrier concerned attitudes – the partnership model is not fully integrated throughout the organisation, from the highest municipal management level down to home care services.

Further difficulties included the lack of time to conduct the questionnaire, as well as, in some cases, challenges in guiding the informal carer to the appropriate service when the help requested did not fall within the scope of existing available carer support. In the interviews conducted for this case study, participants also stated that a limiting factor is that informal carers are not always in a position to go through the relatively extensive questionnaire, or that the home situation is so acute and demanding that there is no space to reflect on their own needs.

Of the 48 number of carers contacted in Jönköping municipality during the past year, 32 had participated in COAT conversations. One interviewee went through their documentation and read: "*It's the family carer who declined in seven of the sixteen cases, and in nine of the sixteen it was us who assessed it as not appropriate. And the reasons were things like: 'Live in another municipality,' 'Didn't feel relevant based on support needs,' 'Didn't have the energy,' 'Lack of time,' 'Doesn't want to,' 'Spouse in short-term care waiting for a nursing home placement,' 'Very sensitive or stressed about the topic,' 'A support plan not considered beneficial at this point.' So, a mix of different things…It can be that they're in an acute crisis, that they simply can't focus on an instrument*" (JR).

In some cases, the idea was that COAT conversations would take place later, for example when the acute situation had been managed. Other limitations raised in the interviews included that the questionnaire contains many questions, which require time and can be perceived as exhausting for carers. The interviewees also reflected that Part C, which contains questions about what could improve the life of the care recipient, sometimes felt awkward since the care recipient did not participate in the conversation. Talking about their needs and wishes could therefore feel like speaking *for* rather than *with* the care recipient. It could also be the case that the carer believed that the care recipient had certain needs that the care recipient did not agree with. Furthermore, the interviews raised questions about how the carer advocates should relate to certain areas of the questionnaire.

Finally, the interviewees raised concerns about the technical aspects of the COAT form. One participant explained that one of the COAT computer files contained a bug, making it difficult to work with. It was also difficult to fill in responses and action plans directly in the PDF version, which

meant that the carer consultants had to manually rewrite the questions and answers in Word. These minor technical issues made the instrument hard to use and could advantageously be addressed to make it more user-friendly.

CONCLUSIONS

COAT is based on the recognition that the family plays a crucial role in enabling society to meet its objectives within healthcare and social care. The planning tool is intended for informal carers who provide regular support to older or ill relatives in their own homes, as well as for staff working with supporting and following up the support provided to informal carers. The aim is to strengthen both the carers' own quality of life and their ability to provide good care to their relatives. Through structured conversations between the informal carer and a professional, the carer's needs and potential support measures can be identified. The work is guided by the goals and improvement areas that are most meaningful for the individual carer.

The primary recipients of care by informal carers are older adults over the age of 65 who require help with activities of daily living due to illness, disability, or reduced functional ability. Many older people with long-term care needs also receive municipal services, such as home care, while others rely entirely on family or civil society. The needs vary but often include personal care, meals, cleaning, shopping, and social support.

Evaluations of COAT show positive results (Hanson et al., 2006; Hanson et al., 2008; Lévesque et al., 2010; Magnusson et al., 2009a, Magnusson et al., 2009b, Magnusson & Larsson-Skoglund, 2009). Informal carers reported that the discussions provided an opportunity to raise issues that might otherwise have gone unnoticed and to reflect on their own situation. Many carers described feeling seen, heard, and taken seriously. For staff, COAT contributed to a more nuanced understanding of carers' needs and circumstances. Even experienced professionals reported gaining new insights, and that the conversations improved communication and trust. Evaluations of field trials in Borås, Härnösand, and Jönköping consistently showed that COAT contributed to increased security, new knowledge, and support for carers. International experiences, including from Canada, have also demonstrated that the method promotes equitable collaboration between informal carers and professionals and fosters a more reflective and person-centered discussion climate.

In Jönköping municipality, a political decision requires all carer consultants to use COAT in meetings with informal carers. This ensures the long-term sustainability of the approach within the municipality. The tool is also used in other Swedish municipalities, though the extent varies. To enhance sustainability, staff have suggested updating the instrument based on practical experiences, and providing training in COAT's focus areas to additional professional groups within healthcare and social care.

COAT's main strengths lie in its structure and breadth. It provides a clear framework for discussions about both practical and emotional support, and promotes equity by giving all carers the same opportunity to express their needs. Both carers and staff highlight that COAT fosters trust, participation, and legal certainty in support provision. Challenges primarily relate to the time required and workload, as well as the perceived length of the questionnaire for some informal carers, particularly in acute care situations. Technical difficulties with digital handling of the forms have also been noted. Overall, experiences indicate that COAT is a useful and sustainable tool that strengthens collaboration between informal carers and professionals and contributes to more individualised carer support.

COAT highlights the value of systematically making informal carers' needs visible. By structuring conversations around both practical and emotional support, the tool enables carers to express challenges and priorities that might otherwise go unnoticed, strengthening their sense of being seen and heard. Professionals gain a deeper understanding of the carer's everyday life and the care recipient's situation, fostering more informed and tailored support. The approach emphasises collaboration and mutual understanding, empowering carers while enhancing the quality of care they provide, and demonstrating how structured dialogue can reveal important insights for both carers and service providers.

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