

PARTICIPATORY APPROACHES WITH OLDER ADULTS



ABSTRACTS



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“Caring in Vulnerable Constellations of Live-in Care”

25-26 June 2026

Evangelische Hochschule Ludwigsburg, Germany

Although welfare and care regimes differ across European countries, all face the challenge of an increasing number of older adults in need of care. For many older adults and their families, neither family care nor care homes are feasible options. As a result, many families prefer to have a migrant care worker, often from Eastern Europe, who lives in the household and provides continuous care.

However, legal and institutional frameworks vary widely, placing both older adults and live-in care workers in a vulnerable situation. Older adults in need of care may experience violence, neglect, or abuse from the care worker, have different expectations regarding food, hygiene, or care practices, and in some cases even become victims of theft. Care workers, on the other hand, often work beyond legal limits on working hours, face severe exploitation and risks of violence, and spend little time in social contact outside the household. Consequently, they may be deprived of a life alongside caregiving, limiting their participation in broader social life.

The proposed symposium adopts a relational perspective on participation, understanding it as a feature embedded within care constellations and their contexts. It aims to analyse participation within live-in care arrangements and to reflect on participatory research approaches that include those who receive live-in care.

Organisation: Ute Karl, Protestant University of Applied Sciences, Germany
Anne Carolina Ramos, University of Fribourg, Switzerland
Ursula Trummer, Center for Health & Migration, Austria

ABSTRACTS

Thursday, 25 June 2026

Introduction to the Conference

8:40-9:25 – Room 7/8, Second Floor, Building A, Paulusweg, 6, Ludwigsburg

Exploring Participation in Vulnerable Constellations of Live-In Care: Mapping the Field, Perspectives, and Possible Questions for the Two Days

Ute Karl, Protestant University of Applied Sciences, Germany

Looking back over the last twenty to twenty-five years, it becomes evident that there is an increasing and largely differentiated research on live-in care that is mostly and nearly exclusively provided by migrant care workers. At the same time, on the level of the EU and its member states, different politics and strategies are elaborated to improve the conditions of the care workers, the quality of care and thus the situation of the person in need of care, and also for the family carers. On a global level, these developments have to be seen in the light of an ever growing marketization and commodification of care (Aulenbacher et al., 2024). Although there are huge differences between the welfare regimes in Europe, neoliberalism fosters the familialization, individualization and privatization of care work and its organisation, taking it out of the responsibility of the state, the society and the broader community. Political debates and research mostly turn around working conditions of migrant live-in care workers and their legal conditions and circumstances, and the quality of care provided within this frame. Questions of participation, especially civic engagement, and inclusion in the daily life are mostly not a topic, neither in research nor politics.

My presentation will first give an overview of existing research and the different focuses addressed. I will then step into two supranational frameworks (ILO

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Convention C 189, European Care Strategy) and its impact for the national politics and practice. Based on the example of the discourse in Germany I will sketch different positions towards the system of live-in care constellations. I will conclude with reflections on participation and democracy to open the horizon questionings for our symposium.

Ute Karl is a Professor in Social Work at the Protestant University of Applied Sciences in Ludwigsburg, Germany. Recently, she holds a research professorship with a focus on researching (transnational) social support and care in contexts of migration. She has research experience of more than 25 years in the field of ageing, migration, and transitioning to adulthood. Her theoretical approaches are situated in a relational sociology, gender studies and critical social work investigating power relations, agency and care. She applies different qualitative methodologies, including biographic research, social network analysis, conversation and critical discourse analysis.

Panel: Discussing Live-in Care Arrangements – Different Perspectives

9:30-11:00 – Room 7/8, Second Floor, Building A, Paulusweg, 6, Ludwigsburg

Chair: Marion Scheider-Yilmaz, Université de Lorraine, France

Who Cares for the Carers? Access to Social Protection Among Older Ukrainian Care Workers in Italy

Maria Izzo, University of Glasgow, Scotland/Great Britain

Problem: Older Ukrainian women employed as live-in carers in Italy sustain the country's fragmented eldercare system, yet they face major gaps in social protection. These gaps are not incidental. They arise from the marketized familistic character of care infrastructures, which shifts responsibility for eldercare onto families and, in turn, onto migrant workers who are frequently employed in precarious or informal arrangements. As a result, this essential workforce - mostly women who are ageing themselves - is left without stable rights, adequate protections, or long-term security.

Research Question: How do older Ukrainian migrant care workers negotiate access to social protection in a context shaped by gendered labour migration, political upheaval, and persistent underinvestment in formal eldercare? What roles do institutions, communities, and social networks play in shaping their access to welfare?

Theoretical Background/Concepts: The study draws on scholarship on gendered migrant care work and transnational social protection, applying an ageing–migration lens to show how vulnerabilities accumulate across the life course. Care work is conceptualised as:

- a replacement for fragile or insufficient public eldercare;
- an improvised welfare mechanism for both Italian families needing support and migrants lacking robust state protection
- a site of increasing risk as workers grow older without adequate pensions or safety nets.

In this context, protection for migrant workers is co-produced by families, NGOs, churches, local institutions, and migrant networks. Their efforts highlight where formal policy is lacking and how the general absence of recognition for care workers pushes community actors to fill the gaps.

Data/Methods: The research draws on 55 multilingual qualitative interviews and participant observation with Ukrainian care workers and community representatives—including institutional stakeholders, churches, and civil society organisations—in Naples and Milan. Fieldwork (July 2023–January 2024) took place in the aftermath of Russia’s full-scale invasion of Ukraine, which intensified emotional strain, bureaucratic challenges, and uncertainties surrounding mobility, status, and family obligations.

Results: Four key findings emerge:

1. *Access to social protection is uneven and shaped by local governance.* Differences between Naples and Milan demonstrate how city-level welfare infrastructures, labour markets, and social network configurations shape migrants’ real opportunities to obtain health services, pensions, and social assistance.

2. *Cultural norms of ageing and responsibility influence welfare uptake.* Workers’ decisions are shaped by long histories of instability, strong obligations to kin in Ukraine, and a desire to remain economically useful. These factors can discourage engagement with available services or delay access to entitlements.
3. *Community actors serve as essential but overstretched intermediaries.* NGOs, churches, community organisations, social networks offer crucial assistance. Yet care workers’ long working hours, isolation in employers’ homes, and limited awareness often place such services out of reach.
4. *The precarious ageing of migrant care workers exposes the limits of current welfare models.* An eldercare system reliant on ageing migrant workers, without securing their own wellbeing, highlights the unsustainability of family-based and market-driven care arrangements.

Maria Izzo holds a PhD in Health and Social Policy. Her research examines the intersections of care, ageing, migration, and social protection, with a particular focus on older Ukrainian care workers in Italy. She has expertise in multilingual qualitative research and is interested in the ways migration and care arrangements shape experiences of work, wellbeing, and social inclusion.

Home Care Services and Migrant Live-in Care Workers in Vulnerable Care Constellations

Mehtap Kavurmaci, Atatürk University, Erzurum, Türkiye

Problem: Home care services have become a central pillar of long-term care systems across Europe, particularly in the context of population ageing and increasing care needs. A growing share of this care is provided by migrant live-in care workers within private households. While this model enables continuity of care and supports care recipients to remain at home, it also produces vulnerable care constellations characterized by informal employment arrangements, power asymmetries, and limited recognition of care workers’ participation in care-related decision-making.

Research Question: How can the roles, participation, and vulnerabilities of migrant live-in care workers within home care service constellations be conceptually understood and critically discussed?

Theoretical Background/Concepts: The paper is grounded in care ethics, theories of vulnerability, and research on transnational care regimes. Care is conceptualized as a relational practice embedded in social, legal, and institutional contexts. Participation is understood not only as formal inclusion in decision-making but also as everyday involvement in shaping care practices. Vulnerability is approached as a structurally produced condition shaped by migration status, gendered care labor, and welfare arrangements.

Data/Methods: This contribution adopts a conceptual and literature-based approach, drawing on interdisciplinary scholarship from care studies, nursing, sociology, and migration research. Existing empirical findings and theoretical debates are synthesized and critically discussed to examine migrant live-in care within home care services.

Results: The analysis identifies three interrelated dimensions shaping participation and vulnerability in migrant live-in care constellations. First, participation is largely informal and situational. While migrant care workers are deeply involved in daily care routines and emotional support, they are often excluded from formal care planning, resulting in responsibility without recognized authority. Second, vulnerability emerges as a relational and structural condition. Live-in arrangements intensify dependency, as housing, income, and legal status are frequently tied to a single household, limiting care workers' ability to negotiate boundaries and working conditions. Third, the paper highlights boundary work as a central feature of migrant live-in care. Care workers continuously negotiate the blurred boundaries between paid labor, emotional involvement, and private life. These negotiations may enable limited agency but also contribute to invisibility and exhaustion. Overall, the findings suggest that current home care models rely heavily on migrant live-in care workers while offering limited institutional pathways for participation and recognition.

Mehtap Kavurmacı is a professor at the Faculty of Nursing, Atatürk University, Türkiye. Her academic work focuses on home care services, nursing, vulnerable

populations, and related issues in home-based care within changing social and institutional contexts. She has a particular interest in care relations, participation, and inequalities in home care settings. Her research engages with interdisciplinary perspectives from health sciences, care studies, and social theory. Through international academic collaborations and mobility programs, she contributes to discussions on sustainable, inclusive, and ethically grounded care models in Europe.

Participation of Older Adults and Family Caregivers in Care Constellations in Albania: Challenges and Opportunities for Sustainable Support

Ortenca Kotherja, University of Social Sciences, Tirana, Albania

Problem: The population in Albania, like in most countries in Southeastern Europe, is rapidly declining. As a result, the demand for care and support for the elderly is increasing. Although public institutions provide services, these remain limited and poorly coordinated, leaving families and relatives as the main providers of care. This situation places a significant burden on caregivers and undermines the autonomy and well-being of older people. The provision of sustainable care is further challenged by economic constraints, gender-based care responsibilities, and the lack of organized community-based services.

Research Question: How is care for the elderly in Albania improved through their involvement and the support of family caregivers?

Theoretical Background: One of the most profound transformations of our society globally is the rapid population aging. It was estimated that by 2025 population aged 65 or older would double, thus generating great challenges in adequate care and support provision. Family members are the primary caregivers for older adults in most contexts. In low-to middle-income-countries limited public funded care and social norms often push this narrative, whereas in high-income-countries formal services are more common. However, the backbone of long-term care universally remains informal caregivers, spouses, adult children, siblings or other relatives. They assist the older adults with medication management, coordination of medical appointments, emotional support and daily activities. "Care constellations" as a concept contemplates

care as a practice which is socially shared among individuals, families and institutions. Building on family care and social support theories, the active involvement of older adults in the process can greatly enhance their autonomy and sense of control, while providing structured support and trainings for family caregivers can reduce their burden and strengthen their capacity to provide sustainable care.

Data/Methods: Data were gathered through 40 semi-structured interviews, 20 with older adults in need of care and 20 with family caregivers. Interviews were focused on examining their experiences, expectations and needs. The data were thematically analysed. The analysis was guided by frameworks of family care and social support with the objective of identifying both challenges and opportunities within care constellations.

Results: Research findings revealed significant gaps in community-based services, mainly the unequal distribution of responsibility for providing care between the genders and the economic pressure on the families. Older adults emphasized the importance of active participation in decision-making regarding their care and maintaining autonomy and well-being. It was reported that stress of family caregivers was sustainably reduced and their capacity to provide long-term care was enhanced, by structured support, trainings and the formal recognition of their role as caregivers.

Conclusion: Based on these findings, it can be concluded that sustainable care within the care constellation will require an active involvement of the older adults, the support for caregivers to be highly organized, and to integrate policies that connect social and family care systems.

Ortenca Kotherja is a full-time lecturer at the Department of Pedagogy and Psychology, University of Tirana. She holds a bachelor's degree in psychology, a Master of Science in School and Organizational Psychology, and a PhD in Social Sciences (Psychology). With over 15 years of academic and teaching experience, her research focuses on psychological well-being, social participation, and support mechanisms for vulnerable groups, particularly older adults, and informal caregivers. Her scientific interests include care constellations, family caregiving dynamics, psychosocial aspects of live-in care, and sustainable support models in contexts with limited formal care services.

Panel: Live-in Care Arrangements, Unpaid Care Work and the Possibilities for Participation

11:30-12:45 – Room 7/8, Second Floor, Building A, Paulusweg, 6, Ludwigsburg

Chair: Ute Karl, Protestant University of Applied Sciences, Germany

Seen but Not Valued: Unpaid Care, Democratic Participation and the Limits of Recognition within Care Constellations

Maria Cheshire-Allen, Swansea University, Wales/Great Britain

Despite growing recognition of unpaid carers' contribution to welfare systems across Europe, existing frameworks for understanding participation within care constellations tend to focus on service access and carer wellbeing. Less attention has been paid to whether carers are recognised as democratic actors within the systems that depend upon them.

This paper examines that gap, asking what structural conditions facilitate or foreclose the democratic participation of unpaid carers and the civil society organisations sustaining them within care constellations. While unpaid family carers and live-in migrant care workers occupy different positions within care arrangements, both share a structural condition, their labour is counted and depended upon, yet their experiential knowledge is excluded from the deliberative processes shaping care policy.

Drawing on feminist care ethics (Tronto, 2013; Sevenhuijsen, 2003), the paper argues that care is a constitutive democratic practice whose value cannot be captured by existing welfare measurement frameworks. Tronto's principle of attentiveness, the ethical obligation to recognise care needs and respond to them, is absent at a structural level when welfare states count caring labour instrumentally while remaining systematically inattentive to carers' knowledge, agency and democratic needs.

The paper draws on qualitative data from two funded studies, the DISC Social Care Fellowship and the INVALUABLE comparative project (Wales and Basque Country) comprising findings from six focus groups with unpaid carers and fifteen individual interviews with civil society organisations.

Findings reveal a persistent gap between policy commitments to participation and the structural conditions enabling it. Despite formal commitments to co-production, findings suggest that carers' experiential knowledge remains peripheral to the policy processes governing their care. The paper concludes that reframing care labour as civic contribution rather than private burden or economic resource is a necessary precondition for genuinely participatory care constellations.

Maria Cheshire-Allen is a Senior Research Fellow at Swansea University, UK, holding two Health and Care Research Wales Fellowship awards. She is a care ethics researcher with a specialist interest in unpaid care, democratic recognition and social care policy. Her current research examines how unpaid carers are valued and devalued within European welfare frameworks. Maria is also a Trustee of Swansea Carers Centre, Wales.

Caring Across Borders: 24h Live-In and Family Left Behind. How Can This Become a Win-Win Situation? Gains, Losses, and the Health Vulnerabilities of Families in Latvia and Austria

Ursula Trummer, Center for Health & Migration, Austria

Inese Abele, retired care worker, Latvia

Ilze Trapenciene, University of Latvia/Riga Stradins University, Latvia

The provision of 24-hour live-in care for the elderly in Europe relies heavily on migrant carers, creating transnational family constellations exposed to unique vulnerabilities. Our contribution explores the complex dynamics of temporary migration from Latvia to Austria for 24h live-in care. Like for other ageing European countries, Austria is increasingly relying on migrant carers both in institutional as in informal care arrangements. In 2025, Statistik Austria lists 500.554 people in Austria as being in need of care and not living in care institutions, with a steady rise of this group along with the demographic trend of an ageing population. With institutional settings like nursing homes and other long term care organisations suffering from increasing shortages the of work force, care at home gets increasing attention and gains critical relevance along and/or aside the public health system. A highly important resource for

the field of so called “24hour care” or “live-in-care” are women from other European countries (EU citizens), who temporarily migrate to Austria to work as live-in carers. Their work is typically organised in 3-4 week shifts, with transportation often being organised by agencies who act as brokers between demand and supply in a rapidly evolving market of home care. Austria introduced a model to legalise a black to grey labour market of home care in the years 2006-2008 with a complex legislative system that places live-in-carers on the labour market as self-employed “single-person-enterprises”. Economisation of care, language and cultural barriers, insufficient quality assurance both for providers and clients, are some of the leading themes of an ongoing discussion.

Our objective is to analyze this phenomenon using a participatory and holistic approach, examining the interplay between legal frameworks, professional challenges, and individual perceptions of losses and gains concerning family life, health, and well-being for all members involved (carers, care recipients, and families left behind). We do this by introducing the viewpoint of a care person who came from Latvia to Austria to work as a 24h live-in care person.

Our research leverages international cooperation via the European COST Action 21143 Transnational Family Dynamics (TraFaDy). The methodology combines existing qualitative interview data gathered from Latvian women working as live-in caregivers in Austrian private households and a co-created case study of a Latvian care person with an analysis of established legal frameworks and care models.

Preliminary findings demonstrate that the reliance on migrant live-in care creates a constellation of systemic and individual vulnerabilities, both for live-in carers and their families as well as for the person receiving care and the respective family. There is indication that the precarious status of carers and significant emotional and social losses experienced by families results in substantial emotional, physical, and mental health impacts on all family members.

Our study highlights the critical challenge posed by Europe's ageing demographics and the systemic reliance on migrant caregivers in vulnerable private settings. Successfully addressing these demands urgent intersectoral

dialogue that acknowledges these vulnerabilities across national boundaries to shape the well-being of individuals within these specific care arrangements.

Ursula Trummer is Head of the Center for Health and Migration in Vienna, Austria. She is a sociologist and public health expert working at the intersection of migration, health, and social policy. Her research focuses on health equity, social determinants of health, and the needs of migrant and vulnerable populations. She has extensive experience in applied research and policy advising at European and international levels, including collaboration with EU institutions, WHO, and IOM. She also works on health system development and diversity-sensitive healthcare approaches.

Inese Abele is a former care worker with 14 years of experience in 24-hours home care in Austria, working exclusively in private households rather than institutional settings. Her work focuses on supporting daily living, observing general well-being, and communicating with families and healthcare professionals when needed. She holds two degrees and a master's in economics. She is a mother of three and has developed practical experience in communication, basic health observation, and interpersonal support through everyday life and work.

Ilze Trapeniece is a researcher in social policy and sociology at the University of Latvia and Riga Stradiņš University, Latvia. Her work focuses on social inequality, vulnerable populations, migration, and welfare systems, with particular attention to children and families affected by social exclusion. She has extensive experience in applied policy research and international comparative projects in social policy and education. She has contributed to academic publications, book chapters, and policy-oriented studies.

Invited Talk: A Migration Health Perspective on Ageing, Care, and Human Mobility

Davide T. Mosca, Former Director of Migration Health at the International Organization for Migration (IOM), Consultant to WHO, IOM & the UN Migration Network

14:30-15:15 – Room 7/8, Second Floor, Building A, Paulusweg, 6, Ludwigsburg

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Chair: Ursula Trummer, Center for Health & Migration, Austria

Population ageing is transforming societies worldwide, generating growing demands for long-term and home-based care. At the same time, demographic change, labour market dynamics, and global inequalities are increasing reliance on migrant workers to fill critical gaps in care systems. Live-in care has emerged as a prominent response to these challenges, enabling many older adults to remain at home while preserving dignity, autonomy, and quality of life.

This presentation examines live-in care through a migration health lens, highlighting how ageing, migration, labour conditions, gender norms, social isolation, and health challenges intersect within the care relationship. It explores the shared and interconnected vulnerabilities experienced by older adults and migrant caregivers, while extending the analysis to families, transnational care chains, and the broader care ecosystem.

Although migration and health has progressively evolved into a recognized field of policy, research, and practice, the specific realities of migrant live-in care workers have received limited attention within this agenda. As a result, their occupational, mental health, social protection, and well-being needs often remain insufficiently addressed across health, migration, labour, and long-term care policies.

Drawing on established migration health frameworks and principles, the presentation argues that migrant live-in care workers represent an emerging priority for the migration and health agenda. It proposes ways to better recognize, address, and mainstream this issue within migration-sensitive health systems and broader policy responses, while promoting the health, dignity, rights, and well-being of both those who provide care and those who receive it.

Davide T. Mosca is a medical doctor with four decades of experience in global and migrant health, humanitarian response, and emergencies. He served as Director of Migration Health at the International Organization for Migration (IOM), where he advanced the global migration health agenda, contributed to two World Health Assembly resolutions, and co-organized three Global Consultations on Migration and Health. He has advised WHO, IOM, and the UN Migration Network, and he was a Commissioner of the UCL–Lancet Commission on Migration and Health. Prof.

Mosca has authored numerous publications, founded the advocacy network Realizing Health SDGs for Migrants, Displaced and Communities, and is a member of the Lancet Migration Partnership. He holds academic and advisory roles with UCL, Johns Hopkins, and the Center for Health and Migration in Vienna.

Round Table Discussion: Balancing Needs and Fostering Participation in Live-in Care Constellations

15:15-16:15 – Room 7/8, Second Floor, Building A, Paulusweg, 6, Ludwigsburg
Chair: Anne Carolina Ramos, University of Fribourg, Switzerland

Live-In Care for People with Dementia: Challenges, Reflections, and Human Rights

Dianne Gove, Alzheimer Europe

I hope, through this conference, to gain greater insight into the topic of live-in care and how this relates to the care of people with dementia. As with some other conditions, many people with dementia at some point require round-the-clock care. For those who live alone, this can mean having to go into residential care, perhaps losing everything that is familiar/dear to them, including social and family networks, and adapting to the requirements of the living group. This is not a criticism of residential care but of this being the only choice, and so, no real choice. For those who don't live alone, this can, depending on the level of support available, sometimes lead to other people struggling to cope and being desperate to manage, but often leading to a deterioration of their own mental and physical health, employment, and social life. Several years ago, *Alzheimer Europe* set up an ethics working group to explore intercultural care and support, with funding from the *European Commission* and the *Robert Bosch Stiftung*. Whereas our main focus was on people with dementia and carers from minority ethnic groups, we also briefly touched on the topic of professional carers from minority ethnic groups and on the topic of live-in carers. I was particularly interested in the challenges, difficulties, and often insufficient rights

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and protection of live-in carers, as well as issues related to the impact of this arrangement on relationships and on the well-being of all involved.

Dianne Gove joined Alzheimer Europe in December 1996. After obtaining an Honours Degree in Psychology, an MA in Education and Psychoanalysis, and training as an analytical Gestalt therapist, she was awarded a PhD from the University of Bradford in 2013 for her research exploring GPs' perceptions of dementia and how these relate to stigma and timely diagnosis. Dianne contributes towards several EU-funded projects in relation to ethics and Public Involvement, such as AD-RIDDLE, AI4Hope, EPND, PREDICTOM, ACCESS-AD, and PROMINENT, and supports the work of the European Working Group of People with Dementia and the European Dementia Carers Working Group. Alzheimer Europe is an umbrella organisation, based in Luxembourg, of 41 national associations in 36 countries, which seeks to promote the well-being, rights, treatment, and care of people with all kinds of dementia throughout Europe.

Caring in Vulnerable Constellations of Live-in Care

Sven Iversen, Association of German Family Organisations & COFACE Families Europe

An ethically sound examination of live-in care constellations requires equal consideration of all those involved: those in need of care and their families care workers as well as their families in their countries of origin. Live-in care is, amongst other things, a consequence of the combination of inadequate national care systems and income inequalities between countries. This has very practical implications for families in their everyday lives. At the individual level, on the one hand, many carers accept the negative working conditions in order to be able to make what is often a significant contribution to the family income. In addition to often inadequate working conditions, this also includes the strain placed on families in their home countries. On the other hand, families in need of care attempt to meet the otherwise unmet care and support needs by employing migrant carers.

To address the challenges posed by these situations for both sides, action must be taken on several fields: These include the expansion of affordable outpatient services, day and night care, short-term care, and community-based care services in both the host and sending countries. Minimum wage payments, working time regulations and workers' rights must be consistently enforced, and counselling services for all those involved must be urgently expanded. Furthermore, the discussion on live-in care is a task requiring international cooperation. Both government bodies and civil society organisations must not represent solely the interests of their own populations, but must also take into account the situation of carers' families in other states.

A policy brief by the COST Action network 'Transnational Family Dynamics in Europe' explores these challenges in greater depth and offers some solutions: https://transnational-families.eu/policy-brief-livein_care-workers/.

Sven Iversen is managing director of the Association of German Family Organisations (AGF), which promotes the interests and rights of families and campaigns their perspective in politics and society. He also supports dialogue on family policy at national and international level and builds bridges between European and German debates and stakeholders. He represents the perspective of families on various committees and is Vice-President of COFACE Families Europe, Vice-Chair of the Cost Action TrafaDy (Transnational Family Dynamics in Europe) and active in the International Commission on Couple and Family Relations (ICCFR). He is a political scientist and holds an MBA.

Adherence to Medication Monitored by Live-in Care Workers

Marcel Lepée, Gospic Primary Health Centre, Croatia

Since I work with elderly people, I have a lot of experience with not taking medicine, or taking it incorrectly. Because of this, live-in care workers would have to improve their knowledge related mainly to the therapy of chronic diseases in elderly people.

Non-adherence to medication is a significant problem for older adults because it is common and linked to unfavorable outcomes and increased healthcare

expenses. Since drug non-adherence typically has multiple causes, improving adherence requires a multifaceted strategy. Since many obstacles to adherence are within the patient's control, addressing them is an essential first step in enhancing adherence.

Non-adherence to medication is prevalent and associated with adverse outcomes and higher costs of care. There is usually no single reason for medication non-adherence, and therefore must be a comprehensive approach to improve adherence. Common barriers to adherence are under the patient's control, so that attention to them is a necessary and important step in improving adherence.

Empathy and compassion are among the most crucial traits of care workers. One of the care workers duties is to be a part of diagnosing, treating, and preventing human illness and monitoring the adherence to medication. It is crucial that the live-in care workers handle the patient's therapy given his medical condition. The use of therapy for older persons and treatment techniques should be taught to these employees. Many subjects (researchers, co-creators, policy makers, social service providers, and other diverse actors) must be included for this vulnerable constellation to be participatory.

Numerous studies have demonstrated the significance of medication adherence, one of which is presented below. A convenience sample of 635 people who were purchasing medications for the treatment of chronic illnesses completed a 33-item self-administered questionnaire as part of one of our research on medication adherence. Adherents were defined as those who answered "yes" when asked if they "never fail to take their medication on time." The study participants were split into two groups. The study participants completed the questionnaire for the cross-sectional survey, which was carried out at 106 pharmacies in Zagreb, Croatia. Among other things, there were 265 adherent patients (41.7%) and 370 non-adherent patients (58.3%). Non-adherent subjects prevailed over adherent. Diseases of the cardiovascular system (n=500; 36.8%) were the most frequently diagnosed conditions, with hypertension ranking highest. The vast majority of research participants stated that forgetfulness ("I just forgot") was the primary cause of missing drug doses, followed by being away from home and running out of the medication (having used it all).

Marcel Leppée graduated from the School of Medicine at the University of Zagreb. He completed postgraduate studies in public health and epidemiology, as well as in health studies and information systems. He was employed at the Croatian National Institute of Public Health from 1979 to 1984 and, since 1984, has worked at the Department of Public Health and the Department of Pharmacoepidemiology at the Andrija Štampar Institute of Public Health. He is currently employed at the Gospić Primary Health Centre in Croatia. He obtained his PhD in 2008 and is a member of the Croatian Medical Association and the Croatian Society for Public Health. He has authored approximately 250 scientific publications.

“Shared Live”: A Participatory Theatre and Research Project on Precarious Working Conditions in “24-Hour Live-In-Care Work” in Austria

Michael Wrentschur, University of Graz & InterACT, Graz

16:45-17:45 – Room 7/8, Second Floor, Building A, Paulusweg, 6, Ludwigsburg
Chair: Ute Karl, Protestant University of Applied Sciences

Approximately 55,000 personal live-in-caregivers work in Austria. To do so, they repeatedly leave their homes for several weeks at a time. They provide care and support, mostly to the very elderly, in their homes and around the clock. Very often, this is associated with precarious working conditions, a lack of social security, experiences of discrimination and violence, as well as social isolation.

Against this backdrop, the scenic-participatory research and theatre project “Shared Live” was launched in 2025, in which primarily personal live-in-caregivers can participate. As part of the project, the working conditions of 24-hour personal live-in-caregivers and their effects are made visible and negotiable through theatrical performance. The project’s goal is to raise awareness, foster public dialogue about working conditions, develop concrete proposals for their improvement, and implement these changes.

In a series of interactive and participatory theatre workshops held in 2025, personal care workers were invited to share and dramatize their experiences and stories. Together, they identified the greatest challenges and problems in

this care sector and the associated calls for change. The results of the workshops (and research) were incorporated into the Forum Theatre play of the same name, which was performed interactively in Graz in November 2025 and will see further performances in 2026 and 2027—including special vents with political decision-makers.

In my presentation, I will first discuss some empirical findings regarding working conditions in “24-hour live-in-care work” and then introduce the methodological concept. In doing so, I will address some specific moments and challenges in the project process, present some interim results, and connect these with personal reflections.

Michael Wrentschur is an associate professor at the Institute of Educational Sciences at the University of Graz (Department of Social Pedagogy) where he teaches and conducts research; he is the artistic director of InterACT, the workshop for theatre and socio-culture. Main areas of work: theatre work in social fields, poverty and social exclusion, precarious living, housing and working conditions; drama-based-participatory research methods.

Friday, 26 June 2026

Moderated Discussion: Perspectives of Older People and Family Members

9:00-9:40 – Room 7/8, Second Floor, Building A, Paulusweg, 6, Ludwigsburg

Moderation: Sven Iversen, German Association of Family Organisations & COFACE Families Europe

Horst Schöberl, Co-creator in PAAR-Net

The Paradox of In-Home Care: When Presence Creates Loneliness

The so-called “24-hour care” is often presented as an ideal solution, enabling older people to remain in their own homes while giving geographically distant children the feeling that they have “done something.” On closer examination, however, the live-in care model is not a conventional employment relationship but a forced coexistence that both care recipients and caregivers must navigate.

Two examples, discussed within the Co-Creators group during preparations for the symposium and examined comparatively in this contribution, illustrate this dynamic: In Belgium, the encounter between an intellectually active widow and a rural caregiver leads to intellectual isolation, as meaningful exchange on an equal footing is not possible. In Italy, the household becomes marked by paralyzing silence, prompting the Eastern European caregiver to seek emotional refuge with neighbors due to loneliness. In both cases, families delegate care entirely from a distance, resulting in the disempowerment of care recipients and the overburdening of caregivers. Whether exploitation of the foreign care worker also occurs in both cases cannot be stated with certainty, though it is not unusual.

Conclusion: When live-in care is misused as a privately organized substitute for absent family involvement, it is bound to fail. Continuous involvement of relatives, the preservation of decision-making autonomy for care recipients,

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and fair working conditions are essential. When care is treated as a private matter, it merely conceals the structural deficiencies of public services. Home-based care requires the preservation of human dignity and is a collective, societal responsibility.

Horst Schöberl is engaged as a volunteer Co-Creator within the COST Action “Participatory Approaches with Older Adults” (PAAR-net; CA22167), where he represents the perspective of older adults. He is institutionally affiliated with the University of the Third Age (U3L) at Goethe University Frankfurt am Main. In his professional career, he worked as a senior manager in the field of critical infrastructure (electric power supply).

Within the international symposium “Care in Vulnerable Constellations of Home-Based Live-in Care (so-called ‘24/7 care’)”, his contributions focus on the presented case studies from Belgium and Italy. He argues that care concepts fail when they neglect the continuous involvement of relatives, the self-determination of care recipients, and fair working conditions. For him, care is a collective societal responsibility inseparable from the preservation of human dignity.

Sibylle Berg, Family Dementia Group, Ludwigsburg District (Diakonie and Social Care Station)

I am 64 years old, a specialist nurse in anaesthesia and intensive care, and I hold a degree in nursing management (University of Applied Sciences).

I lead the relatives’ dementia support group in the Ludwigsburg district. It meets once a month in two groups: in the afternoon for spouses and in the evening for adult children, who are often still working.

Since dementia is a condition that significantly changes personality, it is necessary to understand each affected person individually. Biographical work can contribute to this. Those affected often live for a long time in their home environment. Despite their limitations, it is important that they are treated with respect on all levels of human existence – mind, body, and soul. People with dementia still retain a sense of whether and how they are loved.

Furthermore, knowledge about the nature of the disease is extremely important in order to avoid conflicts. Contradiction is pointless in interactions with affected persons. The patient is always right. Different types of dementia should also be taken into account and explained. This requires a fundamental openness from families, those affected, and all involved. Care must be shared among many shoulders over time, as the condition is progressive and cannot be managed alone. For this, care interfaces must be clearly defined and continuously adapted.

Gabriele Baderschneider, Responsible for Her Parents' Care Arrangement

Until my retirement in 2020, I held a management position for many years. Topics such as training in nursing, the demand for care workers, and the risks of precarious employment were familiar to me in my professional context.

The role of being responsible for the care arrangement of my parents took place during my active working life. Fortunately, I was able to share the caregiving responsibilities with my sister, who was also fully employed.

My parents' wish to spend their later years at home in a familiar environment guided all decisions. The willingness to accept additional support was a long process. The acceptance of a live-in caregiver was a prerequisite for remaining in the familiar home environment, a benefit for them and a relief for us.

The extended-hours care provided through a German agency, with fair working conditions and a German employment contract for the caregiver, was important to us. Only a good cooperation between the care service, the caregiver, and the still necessary family support made this arrangement possible. Our father ultimately had to be cared for in a nursing home for a short period due to advanced Alzheimer's disease.

In retrospect, I would have been grateful for today's more comprehensive advisory services for relatives and support services for older people. Nevertheless, supplementary family care and/or the commitment of many volunteers remains indispensable.

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The growing need for care workers requires people who are passionate about care professions. This presupposes that care workers receive respect and appreciation and experience fair working conditions.

We need a shared understanding across all levels of society for this major task. The adults and decision-makers of today are the people who may themselves require care tomorrow. We should not forget this.

Moderated Discussion: Perspectives of Live-In Care Workers

9:45-10:25 – Room 7/8, Second Floor, Building A, Paulusweg, 6, Ludwigsburg

Moderation: Ursula Trummer, Center for Health & Migration, Vienna, Austria

Erzsebet Kiss, Professional Care Worker and Social Worker, Live-In Caregiver in Austria

My name is Erzsebet / Elisabeth S. Kiss, I am Hungarian and have been living in Austria for 20 years. At the age of 18, I completed nursing school with a high school diploma. I then went on to train as a midwife.

I worked as a midwife for 21 years. After that, my story in Austria began: first, I worked for two years in 24-hour live-in care. Then, after a one-year recognition process, I have been working as a qualified nurse ever since. In the meantime, I completed a Bachelor's degree in Social Pedagogy. Between November 2025 and March 2026, after my retirement, I once again worked in 24-hour live-in care. I have gained experience as a qualified nurse in various areas of the healthcare system, including hospitals, nursing homes, and home care.

From my professional perspective, the most important person is always the care recipient; however, everyone involved in the care situation should feel comfortable and, as much as possible, satisfied. Care works best when everyone focuses "only" on their own tasks, performs them competently, consistently, yet with empathy, when respectful, constructive, and assertive

communication is maintained among all participants, and when the human being remains at the center.

Haste, business mentality, and arrogance have no place in care.

Inese Abele, Retired Live-In Care Worker from Latvia (Formerly Active in Austria)

I have completed two higher education degrees, one in the technical field and the other in economics. I hold a Master's degree in Economics. I have also raised three children. In everyday life, I have acquired basic knowledge of medicine as well as interpersonal communication.

In Austria, I began working in 24-hour live-in care without specific professional training in this field. A caregiver is not responsible for medical procedures according to the employment contract. This work requires empathy, attentiveness, and understanding. One should respect the culture and language of the host country. Empathy plays a particularly important role, as it fosters a harmonious relationship with the care recipient and their relatives.

As mentioned, empathy and emotional sensitivity are essential. One should have a stable nervous system and a great deal of patience in order to solve problems when needed, face challenges, and make the right decisions. Much also depends on good cooperation with the relatives.

I have not worked in institutional care facilities, only in private homes with people in need of care. The care recipient was regularly visited by a family doctor. A caregiver should be able to describe the health condition of the person accurately and appropriately, and must also know how to act in emergencies and crisis situations.

In 24-hour live-in care, the most important aspect is a harmonious coexistence with the care recipient and their relatives. Good language skills are of course necessary. The caregiver should not impose personal wishes or ambitions on this sensitive social environment. Household rules should be reasonably respected, while at the same time preserving one's own dignity and reliably and politely fulfilling contractual duties. In this way, we foster understanding and respect both for our host country and for our profession.

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I cannot judge which studies or research are required; I am only sharing my experience from 14 years of work in Austria. It is very important to be familiar with the most common age-related and illness-related conditions. One should always strive to improve the quality of life of the care recipient and provide both practical and emotional support in daily life.

Šejla Vojić, German Trade Union Confederation (DGB), Fair Mobility

Šejla Vojić works as sector coordinator for home-based care and as a counsellor within the DGB advisory network Faire Mobilität. In this role, she advises workers on labour and social law issues and supports them in enforcing their rights on the German labour market.

Her responsibilities as sector coordinator include, in particular, nationwide networking with relevant stakeholders, monitoring and analysing developments in the sector, and producing expert analyses, reports, and informational materials. She also regularly shares her expertise through lectures, professional events, and training sessions. Through many years of experience, Šejla Vojić has developed in-depth knowledge of the working and living conditions of migrant workers as well as the challenges of cross-border labour migration. In addition to German and English, she speaks Bosnian, Croatian, Serbian, and Montenegrin, enabling multilingual counselling and support for workers from South-Eastern Europe.

Moderated Discussion: Perspectives of Representatives of Institutional Actors

10:30-11:15 – Room 7/8, Second Floor, Building A, Paulusweg, 6, Ludwigsburg
Moderation: Ute Karl, Protestant University of Applied Sciences, Germany

Kornelius Knapp, Board Member for Social Policy, Diaconal Association of Württemberg

Home Care by Live-In Care Workers: Association Perspective and Position Statement

Providing adequate care for the population is a key concern of the Diaconal Association of Württemberg (Diakonisches Werk Württemberg). Given the growing and increasingly diverse care needs, ensuring comprehensive care coverage is becoming ever more challenging. At the same time, the Diakonie is committed to fair working conditions that prevent and avoid one-sided dependencies and exploitation. This leads to the following positions and recommendations:

- International care workers in private households must be recognized as a real and existing part of home-based care provision. Without these workers, the care system would already have collapsed. There is a demand for their services from both households and care workers. This reality must be acknowledged.
- Transparent and less bureaucratic employment arrangements should be defined and established for mobile workers, taking into account the particular need for protection of live-in care workers.
- Incentives for legal employment should be created. This could be achieved as part of the long-overdue strengthening of home-based care. Such measures should help reduce undeclared work; where this is not sufficient, illegal employment should be addressed through regulatory enforcement.
- The working hours of live-in care workers should be clearly regulated. Even when on-call time is taken into account, it is evident that one worker cannot provide 24-hour care.
- Placement agencies, and depending on the employment model also employing organizations, should be required to operate transparently and be subject to oversight by institutions responsible for quality assurance and legal compliance.
- The work of live-in care workers should meet basic quality standards. Minimum qualification requirements should therefore be defined, and structures for regular practice reviews should be established.

Within the structures of the Diakonie, the Association for International and Intercultural Exchange (VIJ) applies the FairCare model. It is important that live-

in care workers—who can only provide household support and caregiving assistance—work in combination with a professional nursing service.

The Diakonie advocates for a comprehensive reform of long-term care insurance. As part of strengthening home-based care, the legal and fair employment of live-in care workers should be explicitly considered.

Kornelius Knapp is Board Member for Social Policy at the Diaconal Association of Württemberg. He is responsible for the areas of Children, Youth and Family; Health, Ageing and Care; Disability Services; Psychiatry; and Voluntary Services. He represents the Diaconal Association of Württemberg in dealings with state administration, state-level policymakers, and municipal umbrella organizations.

At the national level, he chairs the Steering Committee on Health, Rehabilitation and Care at Diakonie Germany, which developed a position paper on live-in care workers for the entire Diakonie in 2024. Issues surrounding care and long-term care are also central to his work as a member of the Board of Trustees of DEVAP (German Protestant Association for Elderly Care) and as Chair of the Baden-Württemberg State Care Committee.

Across all fields of work, the Diakonie advocates for up-to-date professional quality standards, strong advocacy for clients, and care and support for employees.

Simon Spangenberg & Ludwig Leopold, MiCASA, Stuttgart

Rethinking Home Care: Quality Assurance and Care Structures in 24-Hour Live-In Care and Outpatient Care Services

The German care market is characterized by a structural shortage of skilled workers, rising demand, and fragmented care logics. Mecasa GmbH and Elder-Aid GmbH pursue an integrated approach that links two levels of care: 24-hour live-in care provided by care workers seconded from other EU countries, and hourly outpatient care services in the Greater Stuttgart area. Approximately 400 clients are currently being cared for across Baden-Württemberg.

A central element is quality assurance in the placement process. Mecasa GmbH played a significant role in developing the DIN SPEC 33454 standard and is currently the only company in Germany certified under this standard. The standard creates systematic transparency for the first time in a market that has until now been largely unregulated.

Simon Spangenberg holds a degree in business administration and is founder and managing director of Mecasa GmbH as well as founder and shareholder of Elder-Aid GmbH. His work focuses on quality management, organizational structure, and standardization in home care. He was involved in drafting the DIN SPEC 33454.

Ludwig Leopold studied law at the University of Tübingen. At Mecasa GmbH, he is responsible for business development and strategic partnerships, and is founder and managing director of Elder-Aid GmbH. His areas of focus include the legal framework, care delivery structures, and the entrepreneurial development of care-adjacent service models.

Simone Ries, Professor of Nursing Science, Protestant University of Applied Sciences Ludwigsburg

“Live-in Care” – a Vulnerable Construct

The challenge of a “live-in care” approach represents a discourse between professional nursing care, family-based support, and economic constraints. From the perspective of social work and nursing science, issues such as self-determination, dignity, and participation of “live-in care” workers in a wide variety of constellations need to be strengthened, with regard to structural inequalities and cultural differences (cf. Grenz et al. 2024).

The subjective needs of care recipients and “live-in care workers” must be taken into account, and existing power imbalances must be reduced. The quality of relationships in live-in care should be improved and strengthened through sensitized behavior among all actors involved.

At the same time, a participatory discourse can facilitate the design of care processes. Thus, participation is an essential component in generating

sustainable solutions for a “live-in care” construct (cf. Hartung et al. 2020). In practice, however, it becomes evident that a lack of qualifications, unclear legal frameworks, and insufficient networking between live-in carers and professional care services hinder implementation. The need for structured support through care counselling, supervision, and intercultural training to improve care situations is expressed by various “live-in care” actors (cf. BARMER 2018).

This results in further research needs across multiple fields of action, such as the development of participatory training formats for “live-in care workers,” the implementation of ethical guidelines for cooperation with relatives, and research into successful care constellations involving all stakeholders. The aim is to create participatory structures that sustainably improve not only the quality of life of care recipients but also the working conditions of “live-in care workers.”

Simone Ries has been working at the Protestant University of Applied Sciences Ludwigsburg since 2016. She holds a professorship in nursing science there. Her research focuses on participatory health research, as defined by Wright, in both inpatient and outpatient settings within the health and social sciences. In addition, she explores, amongst other things, the discourse surrounding professional nursing and supportive care services.

Šejla Vojić, German Trade Union Confederation (DGB), Fair Mobility

In light of demographic change and the increasing number of people in need of care, provision in the home environment is becoming ever more important. While the majority of people in need of care are looked after at home and many prefer to lead a self-determined life in their familiar surroundings, staff shortages and limited family resources make it difficult to ensure adequate care provision.

24-hour live-in care is often seen as a cost-effective alternative to residential care. However, various case studies from advisory practice show that this care model is frequently based on problematic employment structures. Violations of labour law regulations are common, including irregular employment

relationships, false self-employment, and non-transparent or unlawful contractual arrangements. In addition, the working and living conditions of predominantly migrant care workers are characterised by long working hours, unpaid overtime, constant availability, social isolation, and insufficient legal protection.

Overall, the findings indicate that the sector of live-in 24-hour care is structurally based on legal violations and exploitation. At present, there is no employment model in Germany that provides a legally sound and socially fair solution for round-the-clock care provided by individuals. Almost all existing employment models involve legal grey zones or clear violations of labour law. Even supposedly legal arrangements such as solo self-employment or posting schemes often lead in practice to systematic deprivation of rights. Legislators have so far taken insufficient action to protect live-in care workers. The lack of clear legal frameworks results in severe overwork and persistent legal uncertainty and social disadvantage for care workers. However, dignified care requires legally secure employment contracts, fair wages, and social protection—not only in the interest of workers, but also for the overall quality of home-based care.

Šejla Vojić works as sector coordinator for home-based care and as a counsellor within the DGB advisory network *Faire Mobilität*. In this role, she advises workers on labour and social law issues and supports them in enforcing their rights on the German labour market. Her responsibilities as sector coordinator include, in particular, nationwide networking with relevant stakeholders, monitoring and analysing developments in the sector, and producing expert analyses, reports, and informational materials. She also regularly shares her expertise through lectures, professional events, and training sessions. Through many years of experience, Šejla Vojić has developed in-depth knowledge of the working and living conditions of migrant workers as well as the challenges of cross-border