[1]Transforming Care Conference, Programme at a Glance
University of Helsinki, Main Building, Fabianinkatu 33
TP = Thematic panel
S = Symposium
OS = Open session

Wednesday 25 June 2025

			Small Hall	F3003	F3017	F3020	F3005	F3010	F3006	F3004	U3039	U3029	U3040	Fuksi
10:00	Registration opens	Main Building												
11:00	Lunch	Main Building: Agora												
12:15	Opening	Main Building: The Great Hall												
12:45	Keynote 1: Margarita León	Main Building: The Great Hall												
13:45	Break (with refreshments)	Main Building: Agora												
14:15	Parallel sessions 1	Main Building	TP13a	S2	S7	TP21a	TP3a	S4	S12	S15	OS8	OS3a		Meet the authors 1
15:45	Break (with no refreshments)													
16:00	Parallel sessions 2	Main Building	TP18a	TP26a	TP25a	TP1a	S11	TP17a	TP8	S3	OS4	OS3b	OS6	Meet the authors 2
17:30	Early Career Researcher Meeting	Pub Thirsty Scholar, Fabianinkatu 37; meet in the Entrance Hall Fabian in the Main Building												
19:00-20:30	Welcome reception	Helsinki City Hall, Pohjoisesplanadi 11-13												

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Thursday 26 June

			Small Hall	F3003	F3017	F3020	F3005	F3010	F3006	F3004	U3039	U3029	Fuksi
8:15	Registration open	Main Building											
8:45	Parallel sessions 3	Main Building	TP26b	TP18b	TP22	TP1b	OS1	TP17b	S9	TP7	S14	TP16	
10:15	Break (with refreshments)	Main Building: Agora											
10:45	Keynote 2: Tom Shakespeare	Porthania Building: PI											
11:45	Break (with no refreshments)												
12:00	Round table	Porthania Building: PI											
13:00	Lunch	Main Building: Agora											
14:00	Parallel sessions 4	Main Building	TP26c	TP13b	TP19a	TP25b	TP3b	TP21b	OS9	S10	S13	S8	
15:30	Break (with refreshments)	Main Building: Agora											
16:00	Parallel sessions 5	Main Building	TP13c	TP9	TP19b	S5	TP11a	TP14	TP5	TP23	OS2	OS7	Meet the authors 3
17:30-18:30	TCN Members' panel	Main Building: Small Hall											
19:00-23:00	Conference dinner	Meripaviljonki, Säästöpankinranta 3											

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Friday 27 June

			Small Hall	F3003	F3017	F3020	F3005	F3010	F3006	F3004	U3039	U3029	Fuksi
8:30	Registration open	Main Building											
9:00	Parallel sessions 6	Main Building	TP13d	TP18c	TP2	S6	TP11b	TP4	TP10	TP6	OS5		
10:30	Break (with refreshments)	Main Building: Agora											
11:00	Keynote 3: Håkan Jönson & Tove Harnett	Main Building: The Great Hall											
12:00	Closing session	Main Building: The Great Hall											
12:30	Lunch	Main Building: Agora											

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Wednesday 25 June, Keynote 1: Professor Margarita León, Universitat Autònoma de Barcelona, Spain

Room: The Great Hall

Time: 12:45-13:45

Chair: Professor Sirpa Wrede, University of Helsinki

Margarita León (BA, MA, PhD London School of Economics) is Professor of Political Science at the Autonomous University of Barcelona. Previously she held a lectureship in European social policy at the University of Kent (2003-2010) and a Marie Curie postdoctoral fellowhsip at the European University Institute in Florence (2001-2003). In 2018 she was a Fulbright Visiting Scholar at University of Berkeley, California. Her main areas of research are comparative social policy and welfare state reform. She has published in numerous international peer-reviewed scientific journals; co-edited with A. Guillén The Spanish Welfare State in European Context (2011, Routledge) and edited The Transformation of Care in European Societies (2014, Palgrave). She is also the author of The Social Contract: Inequality, social pact and the welfare state published in Spanish in 2023.

Title: Children's Rights and Welfare Paradigms?

This keynote examines the evolving discourse on social and human rights in care, with a focus on children's rights. Over recent decades, the human rights approach has gained prominence in care-related policy frameworks in Europe and globally. For children, this shift has been transformative—moving from viewing them as passive recipients of care to recognizing them as rights-bearing citizens. Advances include heightened awareness of discrimination, policies targeting their wellbeing and life-course opportunities, and the promotion of their participatory rights. However, significant challenges persist. The keynote will explore children's rights from the perspective of a capacitating welfare state that prioritises universal rights, tackles entrenched inequalities, and treats children's rights as democratic entitlements. A crucial aspect is ensuring children’s meaningful participation in decisions affecting their lives. By critically assessing progress and ongoing barriers, the discussion reflects on the need for policies that not only protect but also empower children, fostering inclusive and equitable societies where their voices are integral to democratic processes.

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Wednesday 25 June: Parallel sessions 1

TP13a: Dark side of care

Room: Small Hall
Time: 14:15-15.45
Chairs: Tiina Sihto, Paula Vasara

Presentations

- 322 Marja Lönnroth: Navigating the complexities of caring for people with dementia- Moral distress experienced by informal carers
- 102 Åsa Alftberg & Camilla Malm: Dark emotions and emotion work: family caregiving and dementia
- 158 Daniel Offei: Well-Being Gains and Losses from Unorganized Caregiving for Older Adults in Ghana
- 434 Vera Ylinen: The Biopolitical Governance in Times of Covid-19: Elderly services reduced to bare life

Short presentations

- 390 Young Joo Hong: Emotions and caring practice in contermporary South Korean context

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Navigating the complexities of caring for people with dementia- Moral distress experienced by informal carers

Marja Lönnroth[1], Ulla Halonen[1], Lina Van Aerschot[1,2]
[1]University Of Jyväskylä, Finland, [2]Tampere University, Finland

This study explores the experiences of moral distress among informal carers of people with dementia (PWD). The analysis is based on group interviews with 24 carers, including adult children and spouses. The analysis indicates that informal carers experience a restricted moral agency. They often feel unable to act in ways they consider morally appropriate, which results in emotional and psychological strain. Moral distress in this context arises from challenging decisions that may conflict with the PWD's autonomy and self-determination, as well as from perceived inadequacies in care received by PWD. The results show that informal carers face unique challenges due to the ambiguous nature of their role and the lack of guidelines and support. This thematic analysis underscores the need for comprehensive support systems and resources to alleviate moral distress and enhance the well-being of both carers and care recipients. Addressing these issues is crucial for improving and supporting the socio-emotional wellbeing and resilience of family carers.

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Dark emotions and emotion work: family caregiving and dementia

Åsa Alftberg[1], **Camilla Malm**[2], Elizabeth Hanson[3]
[1]Malmö University, Sweden, [2]Kristianstad University, Sweden, [3]Linnaeus University, Sweden

A growing number of older people living with dementia continue to live in their own homes for an extended period of time. Consequently, there is a rising group of family carers. An ageing population and neoliberal austerity politics contribute to increased family-provided care instead of formal care services. This becomes particularly noticeable in a Nordic context, where the welfare state has traditionally been based on universalizing policies designed to mitigate inequalities. The aim of this paper is to explore the emotional side of family caregiving, with a particular focus on difficult, or dark, emotions. It will also analyse the emotion work, as defined by Hochschild, that carers perform. This emotion work should be regarded as part of a responsibilisation process, i.e. societal expectations on family carers' responsibilities and social constructions of how a good carer should be. The empirical material consists of qualitative interviews with 16 family carers caring for a spouse or parent living with dementia, which forms part of an ongoing project funded by the Kamprad Foundation (2024-2026). The findings highlight how family carers struggle – and work – with their feelings of grief, anger and frustration in everyday life, knowing that some of those emotions, or an excess of them, are not necessarily in keeping with the ideals or norms of a loving carer. Likewise, for spousal carers, maintaining the feeling of couplehood demands further emotion work: the carers strive to uphold their relationship to the person living with dementia, whilst also a carer.

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Well-Being Gains and Losses from Unorganized Caregiving for Older Adults in Ghana

Daniel Offei[1], Ulrika Enemark[2], Charles Godfred Ackah[1], Robert Darko Osei[1], Derek Asuman[2]
[1]University Of Ghana, Ghana, [2]Aarhus University, Denmark

Abstract
Background: In Ghana, where formal caregiving is scarce, informal caregivers provide crucial support to older adults, often at the expense of their well-being. Despite their contributions, caregiving is undervalued and unsupported, leading to issues like burnout and financial strain. While caregiving offers emotional rewards, its impact on caregivers' well-being remains under-researched, highlighting gaps in understanding and policy.

Objectives: The study examined the relationship between caregiving tasks, specifically, personal care, household support, mobility and errand support, emotional support, and the well-being of unorganized caregivers in Ghana with a further focus on gender and family relational dynamics. It also estimated the monetary value of well-being gains and losses associated with these caregiving tasks.

Results: Caregiving tasks such as personal care, household support, and mobility assistance were significantly associated with declines in overall well-being, whereas emotional support was linked to improved well-being. Providing emotional support to a partner was associated with higher well-being for both male and female caregivers. In contrast, male caregivers who provided household support to parents experienced a significant decline in well-being. Mobility

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and errand support negatively affected the well-being of female caregivers caring for partners and parents. Personal care and mobility support were associated with the highest well-being loss, while household support incurred the smallest loss, averaging GHS 47 per hour, equivalent to 7.8% of monthly income.

Conclusion: The findings highlighted the effects of caregiving and the importance of developing gender-sensitive and relationship-aware caregiving policies and recognizing the economic value of informal care in low-resource settings like Ghana.

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The Biopolitical Governance in Times of Covid-19: Elderly services reduced to bare life

Vera Ylinen[1]
[1]Tampere University, Finland

Covid-19 was a global event that threatened not only public health but also the foundations of modern life. According to Giorgio Agamben, the pandemic diminished social and political life by reducing individuals to 'bare life'—a state of mere biological existence, controlled by biopolitical governance and devoid of political agency. Biopolitical governance of the pandemic raised serious concerns about the realization of social and human rights for older adults, especially those dependent on social care services. Due to the increased risk of severe illness and mortality in high-risk groups, many restrictive measures were particularly enforced on them.

This study examines the effects of the biopolitical governance of the Covid-19 pandemic on elderly service users in Finland, as viewed from the perspectives of their professional care workers and social workers. It employs deductive qualitative content analysis to examine open-ended survey responses from social and health-care professionals, as well as data from focus group interviews with social workers. The study draws on the concept of bare life to highlight the coercive nature of the measures imposed, the lack of agency granted to both older adults and the professionals working with them, and the disregard of their knowledge and expertise.

The results indicated that from the perspective of the professionals, many older adults dependent on care services were reduced to bare life during the Covid-19 pandemic. These individuals were excluded from society when isolated from their social networks and stripped of political agency, as their voices were not considered in pandemic management.

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Emotions and caring practice in contemporary South Korean context

Young Joo Hong[1]
[1]Faculty of Humanities, University of Turku, Finland (Originally from South Korea)

With the statistical expectation of the reach of the super-aged society in 2025, the issue of elderly care in Korea has become a significant social problem. Although the elderly care service has been expanded since 2008, caregiving for older adults in Korea, however, has been largely provided by their family caregivers. The everyday realities and practices of care, including caregiving stress, depression, and anxiety Korean family members are facing in terms of elderly care, have been silenced in the construction of social and institutional contexts. The subject

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matter of this study is the emotional implications of elderly care and its cultural understanding of caregiver burden.

This study aims to research the carer's emotional issue and the dark side of care in the contemporary Korean context. To do this, I selected various sources as study materials including reader letters of newspaper articles, documentaries, essays, and an array of broader cultural and social commentary on elderly care in Korea. The special focus is on the question of how the family carers have been affected through the caring practice and which emotions they experienced on the one hand, and what narratives were employed in the context of caregiving discussions and in consequence how the caring practice identified as a form of societal ills, paradoxically, transformed into “the personal” emotional experience, on the other.

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S2: The impact of financial costs of care

Room: F3003
Time: 14:15-15:45
Chairs: Minna Zechner, Karen Duncan
Discussant: Robert Anderson

Access to public health and long-term care helps ensure a life of dignity and equality, protecting rights of older adults in need of care and family carers who provide most of that care. However, UN Sustainable Development Goals indicators include household expenditure on primary health care but not on long-term or social care, and the European Commission identifies financial resources as significant barriers to long-term and social care access. Care-related out-of-pocket expenses (OPE) by older adults and family carers may exceed their disposable income, forcing impossible choices among life essentials like food, medicine, and care services. In the United States one in six older adults with care needs face catastrophic expenses (>40% of disposable income), while nearly18% of Canadian family carers reported that OPE caused them financial hardship.

This symposium focuses on care-related OPE by care receivers and carers and resulting consequences such as insufficient or inadequate care, unsafe living environments, deteriorating health, and financial insecurity. Four symposium papers address the costs of care from diverse perspectives: social and policy contexts (North America, Europe, Asia), care sector (care receivers, family carers and public services), expense type (goods and services) and via qualitative and quantitative data.

Rainville et al. share estimates of US caregivers' OPE from survey and diary data. Duncan et al. examine the relationship between OPE and financial hardship for low- income carers in Canada. Niemelä et al. report on qualitative interviews with Finnish care receivers about what care costs they consider excessive v. value for money. Ikeda et al. discuss implications of Japan's long-term care insurance scheme for working caregivers and the expenses of private services. Discussants Robert Anderson and Päivi Topo will highlight the symposium's key question as to whether private care-related expenditures deprive care receivers and carers of fundamental rights to adequate care and financial security.

Papers:

Karen Duncan, Shahin Shooshtari, Janet Fast, & Md. Aslam Hossain (University of Manitoba & University of Alberta, Canada): 'Financial hardship among carers in low-income: The role of care-related out-of-pocket expenditures.' The most recent Canadian survey data are used by the authors to investigate the relationship between care-related OPE and financial hardship among carers in low-income. The results have implications for the ability of carers to provide for their own care needs in later life.

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Viivi Niemelä, Minna Zechner, Motoko Ishikawa & Laura Saarukka (University of Helsinki, Finland): ‘Out-of-pocket expenditure: Value for money or not worth spending?’ Qualitative analysis of interviews with older adults and their carers on what they consider expensive and value for money regarding OPE are provided by the authors, who also supplement their work with survey data on older adults’ views on affordability of health and social care.

Shingou Ikeda (Japan Institute for Labor Policy and Training, Japan): ‘Expectation and Reality of out-of-pocket expenses of services for combining work and elder care’. Analysis of quantitative survey data on out-of-pocket expenses to provide care to later life families, focusing on working carers who report that Long-term Care Insurance care services are insufficient to enable combining work and care. The Japanese government stresses expanding private care services in addition to public long-term care insurance services to support working carers. The OPE of private care services create a financial strain on working carers.

Discussant:

Robert Anderson, Chairperson of the Administrative Board, Family Carers Ireland; Chairperson of the Advisory Board, ESRC Centre for Care, Sheffield; former Head of Social Policies, Eurofound will compare the presentations in light of policy frameworks and instruments.

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S7 Understanding inequalities in long-term care needs and care provision using quantitative methods: QAR-Net Care Network

Room: F3017
Time: 14:15-15:45
Chairs: Jingwen Zhang, Maria Petrillo

The Quantitative Analysis and Research Network for Care (QAR-Net Care) is an innovative initiative designed to address the existing gap in quantitative care research. Despite burgeoning new care-related data and the advancement in quantitative methods, there is still a lack of care research exploiting these new developments. QAR-Net Care aims to fill this gap by bringing together a diverse group of researchers who are enthusiastic about understanding care inequalities and promoting methodological advancements in care research.

This symposium will showcase works from the QAR-Net Care members focusing on socioeconomic and health-related inequalities in care needs, as well as informal and formal care work. The first paper, by Dr Javiera Cartagena-Farías, explores the relationship between fuel poverty and the development of long-term care needs using Structural Equation Modelling. Next, Dr Baowen Xue discusses the findings from a longitudinal study investigating the changes in cognitive function before and after the transition into care, and whether this depends on care characteristics. Thirdly, Dr Maria Petrillo explore the gendered landscape of informal caregiving, and the effect and socioeconomic inequalities in England. Lastly, Harriet Ann Patrick and Christie Butcher will present their research on the employment-related outcomes of care provision across different social groups in the UK. They will discuss how they approach this topic by triangulating different quantitative methods.

Dr Jingwen Zhang will conclude the symposium with a discussion on learning from these four studies, and the future directions of quantitative research in care inequalities. We will also open the floor for questions, encouraging active audience engagement and dialogue around the presented research.

Papers:

Long-Term Care Needs and Fuel Poverty Among Older People: Beyond Energy Consumption and Affordability (Dr Javiera Cartagena-Farías)

Association Between Becoming a Carer and Changes in The Trajectory of Cognitive Function: Results From the English Longitudinal Study of Ageing (Dr Rebecca Lacey)

The gendered Landscape of Informal Caregiving: Effect and Socioeconomic Inequalities in England (Dr Maria Petrillo)

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Labour Market Participation and Unpaid Care Work in the UK: An Intersectional Analysis (Christie Butcher & Harriet Ann Patrick)

Discussants: Dr Jingwen Zhang

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TP21a Autonomy in long-term care: ideas, discourses, regulations, and practices

Room: F3020
Time: 14:15-15:45
Chairs: Ralf Och, Olivier Giraud

Presentations

- 104 Claude Martin: Autonomy as an horizon concept for LTC policy framing in France
- 398 Thurid Eggers: Different faces of autonomy: Explaining different paths in German and English long-term care policies
- 352 Marie-Victoire Bouquet & Loïc Trabut: Autonomy: uneven appropriations and contrasting interpretations of a central concept in long-term care (LTC) policy in France.
- 353 Shajeela Shawkat: Reimagining Autonomy in Rehabilitation: Intimacy, Care, and the Social Body in Spinal Cord Injury in Bengaluru, India

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Autonomy as an horizon concept for LTC policy framing in France

Claude Martin[1]
[1]Cnrs-Arènes, France

The concept of ‘autonomy’ is highly malleable and has enjoyed undeniable success in many sectors of public policies in France, the main national basis of this presentation. In the education sector, it is referred to as ‘pupil autonomy’, in the employment sector as ‘worker autonomy’, and in the social policy sector as ‘youth autonomy’, ‘autonomy of the elderly’ or ‘autonomy of the disabled’.

However, this concept is heavily criticised, as it seems to be primarily in line with the neo-liberal policies that have developed since the 1990s. One of the characteristics of neoliberal ideology is that it denies the social and material conditions of autonomy, i.e. the inequalities in the exercise of autonomy. This is why autonomy is sometimes perceived as being in itself a myth and a form of injunction that makes individuals responsible for their successes as well as their failures.

While there is a functional model of autonomy, there is also a legal model, found in a number of texts, notably the UN Convention on the Rights of Persons with Disabilities (2006). In this model, autonomy, considered as a horizon concept, can only be built if we avoid an injunction's logic. In this perspective, autonomy could complement the discussion of care policies as the debates on social care seem to share many points with the debates on autonomy taking place in France. Autonomisation in a vision of interdependencies could be a way out for such a discussion.

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Different faces of autonomy: Explaining different paths in German and English long-term care policies

Thurid Eggers[1]
[1]University Of Bremen, Germany

Since the 1990s, the autonomy of older people in need of care became a key issue in the development of long-term care (LTC) policies in many European welfare states. From a social citizenship perspective, the concept of autonomy in relation to care can concern different dimensions such as the degree to which welfare states enable care recipients to handle their care arrangement self-determinedly and the extent to which welfare states cover the costs of care. While most welfare states extended older people's autonomy in choosing and organizing their care arrangement, they differ in their concepts of autonomy when it comes to the extent of social rights to publicly-funded care.

The study aims to explore why welfare states differ in this regard. Using the method of policy document analysis, the study focuses on the LTC policy development in England as liberal and Germany as conservative regime type since the mid-1990s. It argues that the ideas around older care recipients' autonomy functioned in both countries as "coalition magnets" that appealed to political actors with different party ideologies along the left-right spectrum and different interpretations of autonomy. Variations in the concepts of autonomy can to some extent be linked to differences in the characteristics of welfare regime types, especially with regard to the strict means-testing applied in English LTC policy. The regime-atypical extension of social rights to publicly-funded care in the conservative German regime can, however, be better explained by the role of party constellations and coalition-building between conservatives and social democrats.

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Autonomy: uneven appropriations and contrasting interpretations of a central concept in long-term care (LTC) policy in France

Marie-victoire Bouquet[1], **Loïc TRABUT**, Patrik MARIER, Virginia MELLADO

[1]Ined, France

This paper looks at how the notion of "autonomy" is used by those in charge of steering and implementing LTC public policies at regional level in France. Since the early 2000s, the term "autonomy" has become a central concept for thinking about the social objectives of LTC policies, building a sector of public action that decompartmentalizes care for the elderly and the disabled, and qualifying the instruments that fall within this field of intervention. Based on a qualitative survey carried out in two French départements with a large and varied sample of stakeholders involved in the ecosystem of territorial deployment of public policies for the elderly and disabled people, we will highlight the contrasting interpretations of this notion and its unequal appropriation. For administrative staff in charge of policy management, the notion makes sense both in its practical use - to build a sector of public action - and in its normative use - to guarantee the conditions for the exercise of citizenship. On the other hand, those working "in the field" (managers of care devices) often use the term in a distanced way, using it

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to describe administrative agencies and their instruments, but rejecting it as a concept that allows them to think about individual freedom of action and choice. To this term, which is negatively associated with welfare policies, these professionals prefer concepts disseminated by rights defense movements, in particular the concept of self-determination, which is used in systems for both the elderly and the disabled.

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Reimagining Autonomy in Rehabilitation: Intimacy, Care, and the Social Body in Spinal Cord Injury in Bengaluru, India

Shajeela Shawkat[1]
[1]Leiden University, , Netherlands

Autonomy is often framed as a central goal in long-term care (LTC) and rehabilitation, yet for individuals with spinal cord injuries (SCI), autonomy is not merely a matter of regaining physical independence but a process negotiated through relationships, care practices, and social expectations. This paper draws on ethnographic research at a rehabilitation center in Bangalore, India, to critically examine how SCI individuals navigate the tensions between autonomy, dependency, and interdependence in their everyday lives.

While formal rehabilitation structures emphasize physical recovery and self-sufficiency, this research demonstrates that autonomy in practice is shaped by affective, social, and material conditions. Peer mentors, caregivers, and informal networks—such as WhatsApp groups and community-led initiatives—play a crucial role in supporting decision-making and self-determination, often outside formal LTC frameworks. At the same time, intimacy, sexuality, and relational touch emerge as contested spaces within rehabilitation, revealing how some forms of dependency (such as receiving care for daily activities) are normalized, while others (such as romantic and sexual relationships) are stigmatized or invisibilized.

By engaging with feminist disability studies, critical rehabilitation studies, and theories of relational autonomy, this paper challenges dominant policy discourses that equate autonomy with self-sufficiency. Instead, it argues for a broader understanding of autonomy—one that recognizes care, intimacy, and social connectedness as integral to personhood. This perspective offers new insights into how LTC policies and rehabilitation practices might move beyond narrow biomedical models to support autonomy as a lived, relational, and evolving process, shaped by structural, cultural, and affective forces.

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TP3a New technologies in care work: imaginaries, phantasms and new practices of care

Room: F3005
Time: 14:15-15:45
Chairs: Annette Kamp, Hanne Marlene Dahl, Agnete Meldgaard Hansen

Presentations:

- 184 Kate Hamblin & Grace Whitfield: New mediations of care work in England: how digital care systems reorder and reconceptualise care tasks
- 381 Niels Christian Mossfeldt Nickelsen: Privacy with AI sensor technology in care homes
- 388 Hilde Thygesen: Digital exclusion and technology workarounds in care homes for the old
- 101 Gloria Ziglioli: Digital care imaginaries: An evolution of socio-technical transformation in Norwegian care

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New mediations of care work in England: how digital care systems reorder and reconceptualise care tasks

Kate Hamblin[1], **Grace Whitfield**[1]
[1]University Of Sheffield, United Kingdom

The potential of technologies when used in care work to deliver efficiencies are emphasised by both developers of these devices and systems, and within policy discourse (Greenhalgh et al, 2012; Nilsson et al, 2022; Whitfield and Hamblin, 2024). These claims neglect the mediated nature of technology, requiring users to ‘tinker’ and ‘tame’ devices to make them ‘work’ or, in this context, ‘care’ (Pols & Willems, 2011). Analysing five case studies of care providers – a mix of home care and residential care, with different business models – this paper empirically interrogates how ‘socio technical imaginaries’ (Jasanoff & Kim, 2015) relate to such mediation. Building on existing literature (Wærness, 1984; Pols and Willems, 2011), we explore how digital systems both facilitate care and create new tasks and ‘articulation work’ (Star and Strauss, 1999). All the providers had introduced ‘digital social care records’ (digitising records is an area of policy focus in England). We argue that particular previously invisible or background tasks are newly foregrounded by and through these systems in ways which centre the technology, with relationalities of care relegated to second-place. Further, with implications on the person-centred nature of the care, the design of the devices and systems often breaks care down into a series of sometimes generic or irrelevant tasks. We conclude by exploring how in practice these systems are not as straightforwardly efficient as socio-technical imaginaries of developers and

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policymakers would suggest, and analyse how the imaginaries of fast, technology-mediated care relate to ideals of ‘good’ care.

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What caring values does AI promote and downplay in nursing homes?

Niels Christian Mossfeldt Nickelsen[1], Hilde Thygesen[2]
[1]University of South-Eastern Norway (USN), Drammen, Norway, [2]University of South-Eastern Norway (USN), Drammen, Norway

This paper explores autonomy as it is imagined and enacted in care homes through AI sensor technology. AI and sensor technology is involved, on one side, in a dream of privacy and safe care, and on the other side, in excessive control, and failure on the part of staff. Drawing on ethnographic work in Denmark and Japan and inspired by Delanda (2016), the paper debates the ways in which AI, co-produce assemblages of autonomy and assemblages of dependency. Imagine that a new employee is assigned at every care home to help the staff to keep an eye on whether the individual resident is well and notify when problems arise. Imagine then, that the new "employee" is a digital assistant who, via AI sensor technology, can translate camera images from inside the home into text and animations on the staff's various devices and in that sense does not compromise privacy. In a situation like that, what is camouflaged in autonomous dreams of AI in terms of agency of staff and the residents? First, the notion of an assemblage enacting autonomy is outlined. Second, the care and footwork it takes to sustain autonomy is examined, sketching the assemblage of dependency. The article's contribution is a discussion of how AI sensor technology and its reverberations are involved in configuring ideas about good and less good elderly care systems.

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Digital exclusion and technology workarounds in care homes for the old

Hilde Thygesen[1]
[1]University Of South-eastern Norway, Norway

In Norway, as in many parts of the world, society is increasingly becoming digitalized. This is also so in care homes for older people, where smart technologies and appliances, such as automatic lighting, home/away buttons, temperature control and induction cook tops are integrated. The aim is for the technology to support the older citizens’ self-management and independence for as long as possible. Increasingly, over the past decades, municipalities have invested much money in building care homes, which are co-located small apartments with close proximity to homebased services, as a measure of meeting the needs of a growing ageing population.

This paper is based on empirical data from two research projects in two different care homes and is focused on the residents’ use of the integrated technologies. Ethnographic fieldwork and individual interviews are conducted at both settings.

The findings show that many residents don’t use the technologies installed and use a lot of (often creative) resources in working around the technologies in order to avoid having to deal with them. Also, the results show that some technologies make the residents more dependent upon assistance or services.

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The contribution of the paper is twofold: on the one hand it contributes with nuanced knowledge to the growing field of ageing and digital exclusion, and also, on the other hand, to make visible the amount of work involved in avoiding technologies that is not mastered and finding alternative pathways of solving everyday issues.

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DIGITAL CARE IMAGINARIES: AN EVOLUTION OF SOCIO-TECHNICAL TRANSFORMATION IN NORWEGIAN CARE

Gloria Ziglioli[1]
[1]University Of Agder, Norway

Welfare technology (WT), encompassing various technologies used in care work in Scandinavia, has been a flagship of the Norwegian healthcare policy for over a decade now. This has transformed care work, practices, dynamics, and relationship (Kamp, Obstfelder, Andersson, 2019; Dahl & Hansen, 2022). The presented study aims to describe and compare the socio-technical imaginaries (Jasanoff & Kim, 2015) of technologically enabled care that have emerged end evolved in Norway in the past 15 years.

The empirical context of this study combines Norwegian policy documents and interviews with care services' managers and frontline professionals from the home care department in Kristiansand (south of the country). To investigate the evolution of WT socio-technical imaginaries, the study includes and analyzes key healthcare policy documents, including those that introduced (NOU 2011:11) and launched the WT programme (Meld. St. 29 (2012-2013)); comparing them with recent policies (Meld. St. 24 (2022-2023)) and the national digitalization strategy 2024-2030. Moreover, the dataset is complemented with interviews conducted in 2017 and 2024 as part of my PhD-project.

The analysis focuses on the evolving imaginaries for different care policy and service subjects: care professionals, care users, and informal caregivers. This allows for a comprehensive examination of how WT has reshaped the conceptualization and practice of care work overtime, highlighting overemphasized or overlooked elements. Overall the findings reveal a significant shift from initial imaginaries of basic technological aid to more integrated and pervasive digital ecosystems, within which care professionals, users and informal caregivers are framed and recognized in distinct ways.

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S4: New Research on Ageing and Care: Key findings of the Centre of Excellence in Research on Ageing and Care (CoE AgeCare)

Room: F3010
Time: 14:15-15:45
Chairs: Teppo Kröger, Sirpa Wrede
Discussant: Tania Burchardt

The Centre of Excellence in Research on Ageing and Care (CoE AgeCare), which is the main organiser of the 7th Transforming Care Conference, is one of the 12 Centres of Excellence funded by the Research Council of Finland for the period 2018–2025. CoEs are large-scale research investments that are considered to be at the cutting edge of research in their fields, carving out new avenues for research, developing creative research environments and innovations, and training new talented researchers. CoE AgeCare is the first Finnish Centre of Excellence to focus its research on ageing and care.

Now that CoE AgeCare is coming to the end of its term, it is time to look at some of its key research findings. CoE AgeCare is organised around four collaborating research groups based at the Universities of Jyväskylä, Helsinki and Tampere. This symposium will present the research carried out in each group. The key feature of the work of CoE AgeCare has been to approach care as a multidimensional issue, and thus to study different forms of care in relation to national and international care policies, population ageing, the agency of older people, the increasing digitalization of societies, as well as increasing migration. Care poverty, that is, the lack of adequate care and support for older people, has been one of the key themes, together with trends in care policies, agency in decision-making about care and the living environment, health and functioning of the ageing population, the relationship between migration backgrounds and vulnerability of older people, and the digital transformation of care work and the everyday lives of older people.

The symposium will highlight key findings from this research. The speakers of the symposium are leaders of the four research groups of CoE AgeCare.

Papers:

The ageing population, health and functioning, professor Marja Jylhä, Tampere University

International trends and issues in care policy, professor Teppo Kröger, University of Jyväskylä

The relationship between migration backgrounds and vulnerability of older people, professor Sirpa Wrede, University of Helsinki

Digitalisation, ageing and care, professor Sakari Taipale, University of Jyväskylä

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S12 Strengthening supports available to long-term care workers and informal carers for improving their resilience and mental well-being through care partnerships - the EU WELL CARE project

Room: F3006
Time: 14:15-15:45
Chair: Elizabeth Hanson
Discussants: Shereen Hussein, Sari Tervonen

We address the Conference dimension on formal and informal long-term care (LTC) work within the context of the WELL CARE project. Various individual, social and structural factors have been identified that positively or negatively affect the mental well-being and resilience of LTC workers and informal carers. However, both groups have been mainly studied and addressed separately. WELL CARE treats the mental well-being of LTC workers and informal carers as interconnected. We analyse care partnerships from a multi-level approach, examining broader organisational and societal contexts that may significantly influence the dynamics of relationships. The project is conducted within five EU Member States, representing different welfare regimes, namely Germany, Italy, the Netherlands, Slovenia and Sweden.

Papers:

Paper 1 (Elizabeth Hanson) provides the contextual backdrop for the symposium by giving the rationale for and an overview of the 48-month EU Horizon Europe funded WELL CARE project.

Paper 2 (Marco Socci) presents systematic review findings of scientific and grey literature of good practices of innovative solutions supporting LTC workers' and informal carers' resilience and mental well-being, including practices that may foster care partnerships. The "state of the art" in the field will be discussed, including existing knowledge gaps and suggested ways forward.

Paper 3 (Ludo Glimmerveen) highlights a draft scientific paper that conceptualises care partnerships within the project. Also, a lay summary version which forms part of a living Guide designed to help consortium partners and stakeholders to tailor, implement and evaluate good practices targeted at strengthening the mental well- being of both LTC workers and informal carers.

Paper 4 (Lennart Magnusson, Elin-Sofie Forsgärde) features Blended Learning Networks (BLNs) in the five countries for promoting the continuous involvement of LTC workers, informal carers and multi-stakeholders in the project. This includes cross- country findings from national BLN sessions in which care partnerships within formal and informal LTC were discussed.

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Wednesday 25 June: Parallel sessions 1

S15 Ambivalent care and (non)emancipatory human rights approaches

Room: F3004
Time: 14:15-15:45
Chairs: Po-Han Lee
Discussants: Emily Nicholls, Hildegard Theobald

This symposium critically interrogates the potential, challenges, and limitations of applying a human rights-based approach to care policies and practices. As a latecomer democracy and a welfare state, Taiwan's care policies, examined against international human rights standards, show diverse, sometimes contradictory, practices across areas and populations.

In "Late Initiation of Prenatal Care in Taiwan: Why Are Rural Residents Behind?" Tung-Hsien Wu and Ching-Ching Lin analyse urban-rural disparities in prenatal care and identify factors (lower socio-demographics, higher behavioural risks, and lower specialist availability) as major causes for rural women, revealing the gap in universal health coverage.

In "The Ethics of Healthy Ageing-Centric Long-Term Care Systems: Using Taiwan as an Illustrative Case", Yu-Chun Hsieh, Chong-Min Su and Ming-Jui Yeh explore the ethical foundations of healthy ageing in long-term care systems, addressing utilitarianism, agency, self-reliance, and self-restraint, while considering objections related to intergenerational injustice, ageism, and excessive individual responsibility.

In "Seeking the Right Ways of Care: Research on Tuberculosis and its Control in Taiwan", Chen-I Kuan investigates tuberculosis patients and their families' experiences, highlighting their underrepresentation in developed nations. She employs the concept of "biocitizenship" to critique health governance's neglect and its impact on equitable care.

In "Evidence-Making Harm Reduction: Chemsex Healthcare and Community Service in Taiwan", Poyao Huang considers tensions between community-focused chemsex care and medical science-informed harm reduction. His ethnography reveals inconsistencies in care practices driven by differing epistemologies despite their alignment with human rights norms.

The symposium reflects discrepancies between diversified yet inconsistent human rights-based, person-centred approaches in care policy design and implementation across regimes.

Papers:

Tung-Hsien Wu & Ching-Ching Claire Lin (co-first author): Late Initiation of Prenatal Care in Taiwan: Why Are Rural Residents Behind?

Yu-Chun Hsieh, Chong-Min Su & Ming-Jui Yeh: The Ethics of Healthy Ageing-Centric Long-Term Care Systems: Using Taiwan as An Illustrative Case.

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Chen-I Kuan: Seeking the Right Ways of Care: Research on Tuberculosis and its Control in Taiwan.

Poyao Huang: Evidence-Making Harm Reduction: Chemsex Healthcare and Community Service in Taiwan.

Discussants:

Emily Nicholls, Senior Research Fellow, Institute for Global Health, University College London

Hildegard Theobald, Professor, Department of Organizational Gerontology, University of Vechta

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Wednesday 25 June: Parallel sessions 1

OS8 Inequalities and ambivalences of migration and care

Room: U3039
Time: 14:15-15:45
Chair: Deborah Lambotte

Presentations:

- 467 Nuno Ferreira Dias: Home care in Portugal: Where are we now?
- 204 Deborah Lambotte & Benedicte De Koker: Addressing inequalities in care: developing diversity-sensitive training for professionals supporting older persons with a migration background and their informal carers
- 45 HienThi Nguyen: Residing with Descendants: Ambivalence and Adaptive Solutions Among Older Vietnamese Migrants
- 3006 Nazlı Akay: Migrant nannies, parenting and well-being: The perspectives from the past and current research

Short presentations:

- 238 Alicia Lee: Walking A Fine Line Between Gratitude and Self-advocacy: Understanding the Experiences of Migrant Domestic Workers in Malaysia

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Home care in Portugal: Where are we now?

Jose Soeiro[1], Sara Canha[2], **Nuno Dias**[3], Sofia Cruz[4]
[1]Faculty of Arts, Institute of Sociology, University of Porto, Portugal, [2]Centre for Research in Anthropology, University Institute of Lisbon, Portugal, [3]Interdisciplinay Centre of Social Sciences (CICS.NOVA), Nova University Lisbon, Portugal, [4]Faculty of Economics, Institute of Sociology, University of Porto, Portugal

This paper analyses the role of the private home care sector in the care regime in Portugal, focusing on the fragmentation of the legal frameworks governing care professions and their implications for working conditions.

It focuses on three analytical dimensions. Firstly, it examines how the professions associated with home care are regulated, analysing how the absence of legislation on the care profession, as well as legislative fragmentation, which segments care work into different types of precarious legal categories, is a product of the historical devaluation of care work, and is at the same time a tool for reproducing this same devaluation. Secondly, it discusses how this lack of

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labour protection has facilitated the expansion of a labour market increasingly dependent on the exploitation of immigrant workers, predominantly women, who face low wages, exploitation and precariousness, in contexts of great social and economic vulnerability. Thirdly, it explores the mobilisation efforts and the agenda of demands for improved legislation and working conditions for home care workers, discussing the elements that could be part of a change in public policy and improved labour protection in the Portuguese care sector.

This paper contributes to broader discussions about the transformation of care work, highlighting how labour law, as a historical product, is marked by an androcentric deviation in the conceptual construction of the legal figure of the worker and how legal frameworks shape the precariousness of work.

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Addressing inequalities in care: developing diversity-sensitive training for professionals supporting older persons with a migration background and their informal carers

Deborah Lambotte[1], **Benedicte De Koker**[1], Emina Hadziabdic[2], DI.S.C.O.P.M.B. partners[3]
[1]HOGENT University of Applied Sciences and Arts, Belgium, [2]Linnaeus University, Sweden, [3]Linnaeus University; European Centre for Social Welfare Policy and Research; Jade yhteisö ry; HOGENT University of Applied Sciences and Arts; Anziani e non solo, Sweden; Austria, Finland; Belgium; Italy

The intersection of ageing and increasing diversity highlights critical disparities in access to health and social care services. Older adults with a migration background face numerous barriers in accessing care services, while informal carers, who often provide most of the care to this group, are rarely engaged as equal partners. These disparities underscore the need for targeted interventions to address inequalities and enhance competencies in person-centred, diversity-sensitive care and informal carer engagement among care professionals.
To address this need, the Erasmus+ DI.S.C.O.P.M.B. project developed a training package using the ‘Double Diamond’ methodology. Drawing on scientific literature, experiential knowledge, storytelling interviews, and best practices, the training equips care professionals with the tools to deliver person-centred, diversity-sensitive care to older adults with a migration background and their informal carers and to address structural inequalities. The package consists of four chapters containing reading materials and learning activities: (1) person-centred care in a context of diversity, (2) access barriers to professional health and social care services, (3) stereotypes and prejudices, and (4) diversity-sensitive communication.
The training was tested among 276 participants, including students in healthcare programs and health and social care professionals. Results indicated a positive impact on participants’ knowledge and attitudes towards person-centred, diversity-sensitive care. Developing a training focused on diversity-sensitive care is essential for addressing the unique needs of older adults with a migration background and their informal carers. It enhances care competencies, improves communication, and supports informal carers, ultimately leading to better health outcomes and a more inclusive care environment.

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Intergenerational Co-Residence: Ambivalence and Adaptive Solutions Among Vietnamese Migrants in Australia

Hien Thi Nguyen[1]

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[1]Edith Cowan University, Perth, Western Australia, Australia

Migrating later in life poses numerous challenges for older migrants, with navigating intergenerational dynamics arising from co-residence being a particularly significant hurdle. This paper draws on qualitative research conducted with 42 Vietnamese migrants (22 older parents and 20 adult children) residing in Australia, utilising fine-grained ethnographic interviews and participant observation. Framed by the concept of intergenerational ambivalence, the paper explores the complex lived experiences and intergenerational relationships within Vietnamese-speaking migrant families. It examines the diverse intergenerational expectations of older parents and adult children, the nuanced forms of ambivalence that emerge at both psychological and structural levels, and the innovative strategies they use to manage the challenges of intergenerational co-residence. By shedding light on these multifaceted dynamics, the research contributes to a deeper understanding of family relationships and living arrangements in migrant contexts, offering valuable insights for policymakers, practitioners, and communities supporting older migrants.

3006

Migrant nannies, parenting and well-being: The perspectives from the past and current research

Nazlı Akay[1]
[1]Birmingham City University, Birmingham, United Kingdom

Migration has significant implications for parents, potentially affecting their childcare practices, the dynamics of relationships with the cared children, and their psychological well-being. Having a job that parallels parenting, migrant nannies may experience the same. Based on Akay's (2013) qualitative study with migrant nannies from Turkmenistan and Uzbekistan, which identified dilemmas and sacrifices, blurred roles and boundaries, caring reciprocity, and long-distance mothering as themes, this review synthesizes literature from the past twelve years, structured around four sections: an introduction to nanny care and migration, developments in global research in the past twelve years, preliminary findings from a new study exploring adult children's perspectives on nanny care in the UK, and recommendations for further research. The background highlights how nannies, often migrants, fulfill parent-like duties, yet face loss of social support networks, acculturation challenges, and regulatory neglect. The review concludes that despite growing interest, research on migrant nannies remains limited, particularly concerning child and father voices, psychological outcomes, and the influence of crises like COVID-19. Future multidisciplinary and longitudinal studies are recommended to address these gaps, inform socially inclusive policy broadly, and enhance the well-being of migrant nannies and their employing families.

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Walking A Fine Line Between Gratitude and Self-advocacy: Understanding the Experiences of Migrant Domestic Workers in Malaysia

Alicia Lee[1], Shanthi Thambiah[2], Denise Spitzer[3], Anis Farid[1], Shazana Agha[1], Syazwani Hamzah[1]
[1]Women's Aid Organisation, Malaysia, [2]University of Malaya, Malaysia, [3]University of Alberta, Canada

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Migrant domestic workers (MDW) are an essential part of the care ecosystem in Malaysia, and their contributions in reducing the care burden of Malaysian women remains largely unrecognised and undervalued. The nature of work done by domestic workers blurs the boundary between professionalism and development of familial bonds with employers. This poses challenges for MDW when advocating for their own rights. Using an intersectional feminist lens and 5R Framework for Decent Care Work, this research – in collaboration with MDW organisations – explores the realities and well-being of Filipina and Indonesian domestic workers in Malaysia throughout the COVID-19 pandemic until now, through a quantitative survey (n=324) complemented by insights from five focus group discussions. Preliminary findings of this research show that about 87% of MDW surveyed generally feel that their employers support them, and 83% agree that their employers care for their well-being. Yet, around 41% of them reported feeling afraid to share concerns or opinions with their employers. This paper unpacks these contradictory findings by exploring how MDWs' perception of their employers' care for their well-being and support for them translates into gratitude, which appears to be an ambivalent response to their feelings of concern for their safety. This ambivalence shows that perception towards their employers contains both positively and negatively valenced components influencing their overall views on rights and well-being. This research underscores the need to create centralised spaces for knowledge-sharing and support for MDW, suggesting that bridging this gap could strengthen their collective advocacy for rights.

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OS3a Reconciling care, work, studies and well-being

Room: U3029
Time: 14:15-15:45
Chair: Susanne Langer

Presentations:

- 251 Susanne Langer & Susanne Martikke: “It is hard”: grappling with the negative emotions and everyday struggles of sandwich caring
- 224 Ana Jagodic: Self-Care and Autonomy Through the Lens of the Ethics of Care
- 418 Miriam Laschinski: Who cares about carers? Economic strain caused by taking up informal care across European care regimes
- 90 Dangeni & Marie-Pierre Moreau: Tracing student carers in higher education: A literature review

Short presentations:

- 452 Hanna Kelm: Support for women belonging to “sandwich generation” in reconciling work with providing care over dependent persons in family.

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“It is hard”: grappling with the negative emotions and everyday struggles of sandwich caring.

Susanne Langer[1], **Susanne Martikke**[2], Andrew Clark[3]
[1]School of Psychology, Manchester Metropolitan University, , United Kingdom, [2]Independent researcher, United Kingdom , [3]Institute for Lifecourse Development, University of Greenwich, United Kingdom

This paper focuses on the emotional work of caring as experienced by sandwich carers, i.e. those with multiple, often contradictory caring relationships across generations. This challenging role demands the articulation of complex networks of formal and informal, generational, and sequential care and kinship arrangements, as well as ongoing mediation between institutions, communities, and individuals. Participants in this UK-based qualitative scoping study asserted the value and benefits of caring, its centrality to living a worthwhile and righteous life, to what it means to be human, and to their own sense of self. Yet these explicitly voiced moral sentiments contrasted sharply with the ceaseless and often thankless toil of their everyday caring. Negative emotions, such as guilt, anger, and grief, as well as feeling beleaguered, helpless, and invalidated dominated their accounts. They identified the causes of their predicament, as lying both within the self, in other people, and in relationships, combining

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into a sense of all-encompassing entanglement and inescapable entrapment. Carers in general need many years to recognise themselves as carers. However, our research highlighted particular challenges for sandwich carers because of the fragmentation of their work, the invisibility of their role, and the lack of recognition they face. In this context, participants' oft-repeated sigh of 'it is hard' represented both a statement of fact and a painful realisation that they were struggling. Placing it centre-stage, enables us to shed new light on the dark side of (sandwich) caring and sketch out possible ways forward, as identified by the participants.

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Self-Care and Autonomy Through the Lens of the Ethics of Care

Ana Jagodic[1]
[1]Faculty Of Social Sciences, University Of Ljubljana, , Slovenia

This paper examines the concepts of self-care and autonomy within the theoretical framework of the ethics of care. It is based on a qualitative study of multigenerational care work of the sandwich generation in Slovenia. The study combined solicited diaries and in-depth interviews and was conducted between February 2022 and May 2022 on a sample of 30 individuals, providing care work to a younger (children, grandchildren) and older generation (parents, parents of the partner). The analysis identifies self-care as one of the key dimensions of multigenerational care work. From the perspective of the ethics of care, both self-care and autonomy are relational. Self-care is conceptualised as an integral part of collective care, in contrast to interpretations of self-care as part of neoliberal citizenship that establish self-care as a new field of productivity, self-management and consumption. In the care practices and everyday life of the sandwich generation, self-care is expressed primarily through the negotiation of autonomy and the establishment of boundaries within care and family relationships. These boundaries are negotiated both in daily interactions and in long-term decision-making. Consistent with the ethics of care, autonomy is understood in terms of self-determination and interdependence, as opposed to individual self-sufficiency. Participants' experiences show, in line with the ethics of care, that recognising and addressing one's own care needs is a fundamental prerequisite for caring for others. Acknowledging self-care within multigenerational care work is important both for the well-being of carers and for the quality of care and care relationships.

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Who cares about carers? Economic strain caused by taking up informal care across European care regimes

Miriam Laschinski[1], Fridolin Wolf
[1]University Of Bremen / SOCIUM / DIFIS, Germany

Informal caregiving can restrict caregivers' participation in the labour market, leading to income losses and risks to their social rights. Women, individuals with lower socioeconomic status, and those with prior caregiving responsibilities are more likely to provide care, leading to gendered accumulated risks over the life course. While a few studies have explored the relationship between informal caregiving and wages, there is limited research on its impact on caregivers' living standards and financial strain.

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Over the past decade, European social policies promoted affordable and accessible care services to enhance the social rights of care receivers and caregivers. As welfare states and care regimes vary in their long-term care policies with different degrees of de-familization, they impact the labour-market participation of informal caregivers and thus, their social rights and economic strain. By taking an international comparative approach this study examines how different care regimes cope with those risks. Do informal caregivers face a risk of economic strain due to limited labour-market participation? How does this risk vary by gender and across European care regimes?

A panel analysis will be conducted using fixed effects (individual slope) models on data from the Survey of Health, Ageing, and Retirement in Europe (SHARE). Preliminary findings indicate that caregiving within the household negatively impacts financial strain, with care regimes offering stronger social rights, such as Scandinavian care regimes, in France, Belgium, the Netherlands, and Switzerland, showing better coping mechanisms compared to those with weaker support, like Southern European countries and Germany, Austria and the Czech Republic.

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Tracing student carers in higher education: A literature review

- Dangeni, **Marie-Pierre Moreau**
[1]Anglia Ruskin University, United Kingdom

Over the past three years, discussions about student carers' social and human rights have gained momentum, in part as a result of the disruption to academic and family norms associated with the Covid-19 pandemic. Yet research on this group remains marginalised, possibly due to the long-lasting devaluing of care work (Hook et al., 2022; Lynch, 2010). An earlier literature review has shown that research on carers in higher education tends to focus on individuals in academic positions or with parenting responsibilities. Students and those with responsibilities other than parenting – and a fortiori students with caring responsibilities other than parenting - have attracted limited consideration (Moreau & Wheeler, 2023). This systematic review of the literature in English language seeks to generate a deeper understanding of students with caring responsibilities other than parenting, an often neglected yet critical cohort within higher education and care research. The review is part of a larger international project considering the experiences of young people in education who care for older people (InterCare, 2024-2028). Drawing on the scholarly literature, this presentation traces the representations of this group and of the multifaceted challenges they encounter in access to human and social rights. By capturing perspectives and themes that have been mobilised in relation to this group, as well as reflecting on the research silences, the presentation highlights potential new directions for research and, subsequently, policy intervention.

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Support for women belonging to “sandwich generation” in reconciling work with providing care over dependent persons in family.

Hanna Kelm[1]
[1]University of Economics in Katowice, Poland

According to the latest National Census of Population and Housing (2021) in Poland, nearly 400,000 women are inactive in the labor market due to caregiving responsibilities for children or adults, compared to about 43,000 men (GUS 2024).

The current demographic situation is unprecedented due to the phenomenon of the "sandwich generation," where working-age individuals care for both their children and their aging parents or grandparents. This results from two overlapping demographic trends: delayed parenthood and rapid aging of populations in developed countries. The convergence of these social and demographic changes increases the caregiving burden on working-age women, potentially leading to reduced or completely abandoned professional work, thus worsening the family's financial situation.

To maintain women's professional activity despite caregiving burdens, appropriate social policy tools are needed to support families. This research aims to answer whether existing tools genuinely offer women the choice between work and caregiving.

The analytical framework for this research is based on the Capability Approach (CA), a paradigm for defining and measuring social development, welfare, quality of life, poverty, and social justice and inequality (Comim et al. 2010), as developed by A. Sen (1983, 1985) and further by M. Nussbaum (1987, 2000). This approach assesses real opportunities available to society, emphasizing individual agency over resource-oriented evaluations. The CA is subjective, focusing on the individual's perspective and the ability to choose a preferred lifestyle (Kurowska 2017). Social policy's role is to enable this choice, upholding the right to self-determination.

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Wednesday 25 June: Parallel sessions 1

Meet the authors session 1

Room: Fuksi
Time: 14:15-15:45
Chair: Riitta Hänninen

- Alisoun Milne & Mary Larkin: Family Carers & Caring: What It's All About, Emerald Publishing, 2023.
- Pat Armstrong, Hugh Armstrong & Jacqueline A. Choiniere (eds.) The Labour Crisis in Long-term Care: The Right to Care, Edward Elgar, 2024. (presented by Susan Braedley)
- Catherine Needham and Patrick Hall: Social Care in the UK's Four Nations, Policy Press, 2024.
- Riitta Hänninen, Sakari Taipale & Laura Haapio-Kirk (eds.) Digital Repertoires – Embedded and Everyday Technologies in Later Life, UCL Press, 2025

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Wednesday 25 June: Parallel sessions 2

TP18a: Inequalities of care

Room: Small Hall
Time: 16:00-17:30
Chairs: Teppo Kröger, Nicola Brimblecombe, Lina Van Aerschot

Presentations:

- 287 Ricardo Rodrigues: How out-of-pocket payments for home care impact access to care and poverty risk among older users of care across Europe
- 470 Sarah Jasim: Understanding the influence of diverse cultural backgrounds and ethnicity as barriers to access and uptake of UK social care services
- 157 Ionut Foldes: Examining Elderly Vulnerabilities and Support Arrangements in Romania
- 179 Rosie Read: Social care crisis and social inequalities: moving away from ‘zero sum’ approaches

Short presentations

- 415 Gülçin Con Wright: Mapping the Gaps: An Analysis of Inequalities in Turkey's Long-Term Care Provision

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How out-of-pocket payments for home care impact access to care and poverty risk among older users of care across Europe

Ricardo Rodrigues[1]
[1]Iseg Research, Iseg, University of Lisbon, Portugal

Across different long-term care (LTC) systems, users of care services are required to contribute to the costs with care through out-of-pocket (OOP) payments. Given the socio-economic gradient in LTC needs, there are concerns that OPPs are particularly concentrated on poorer individuals and that older people face catastrophic costs when requiring LTC, thus limiting their access to care. This study estimates the prevalence of catastrophic payments for home care in different European countries for the population aged 60, as well as how the risk of poverty among users is impacted by OOP payments. It goes on to estimate characteristics associated with catastrophic payments and impoverishment. This study uses a pooled sample from the Survey on Health, Ageing and Retirement in Europe (SHARE) for the years 2013-2015 when information on OOP payments is last available. Across different thresholds of catastrophic payments, Southern European countries, as well as Austria, show the highest prevalence of such payments. In all countries, catastrophic payments are concentrated on the poorest,

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including in the Nordic countries. OOP payments exacerbate the risk of poverty among users of care by 4 p.p. on average across the sample, with this being highest in Spain and Italy. Preliminary results from the multivariate analysis suggest that individuals with greater care needs and those combining informal care with home care are most affected by catastrophic payments and impoverishment after OOP payments, suggesting that these have serious equity implications and that informal care may partially arise due to difficulties in affording care services.

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Understanding the influence of diverse cultural backgrounds and ethnicity as barriers to access and uptake of UK social care services

Sarah Jasim[1]
[1]Care Policy and Evaluation Centre, LSE, United Kingdom

Reducing social care inequalities has been a UK priority for over 20 years. Despite efforts to create a more equal society, progress has been limited, and some areas of inequality have widened for older adults (particularly during the COVID-19 pandemic). Inequality and inequity remain under researched topics in social care and gerontology. In 2021, the Department of Health and Social Care (DHSC) commissioned a rapid realist evidence review to support primary research and evaluation of ethnic differences in provision and experience of adult social care in England. Exploring the needs and barriers to access was identified as an urgent research priority, especially for the UK ageing population. This scoping study applies a realist action approach which asks 'for whom does this work, in what contexts, to what extent and how?' with a participatory action research cycle, to better understand the influence of diverse cultural backgrounds and ethnicity as barriers to access and uptake of social care services for older adults from London Boroughs of Redbridge and Newham.
Drawing on views of social care practitioners from Redbridge and Newham, and users and carers from the area, we have co-developed a preliminary conceptual framework for diverse cultural backgrounds and ethnicity in the context of the UK social care system and used this framework to systematically review international evidence. We used this evidence to guide qualitative research to understand what users and carers from diverse cultural backgrounds and ethnicity view as barriers to access and uptake of UK older adult social care services.

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Examining Elderly Vulnerabilities and Support Arrangements in Romania

Ionut Foldes[1], Mihaela Haragus[1]
[1]Babes-Bolyai University, Romania

With an emphasis on vulnerable populations, such as those with functional difficulties, those living alone, and those residing in disadvantaged areas, this study investigates the caregiving arrangements and unmet needs of older adults in Romania. This study looks at the caregiving arrangements and unmet needs of Romania's senior citizens using new data from a national survey of 800 persons 65 and older. This study adds to the body of literature by emphasising the role that informal networks and family structures play in helping vulnerable older subgroups, particularly in areas with inadequate state services. Reliance on family and friends is crucial for handling the mounting demands of an ageing population in Romania due to the country's subpar public care system. This study examines the disparities in care delivery between

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economically prosperous and impoverished regions, highlighting a persistent problem in Eastern and Central Europe. The socioeconomic situation in Romania, which is marked by youth emigration, population ageing, and a lack of official care options, makes caring for the elderly more difficult, especially in underprivileged areas. In order to better understand care inequalities in the context of socioeconomic change, this study will provide insight into how families and communities adjust to these mounting demands. The results have wider ramifications for Eastern and Central Europe, where demographic changes are placing an increasing burden on traditional family-based care systems, necessitating the development of new support arrangements.

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Social care crisis and social inequalities: moving away from ‘zero sum’ approaches

Rosie Read[1]
[1]Bournemouth University, United Kingdom

The system of long-term care provision in England (social care) is widely acknowledged to be in crisis. Demographic ageing, altered family structures, government austerity since the 2010s, and Covid-19 have all taken their toll on a fragmented, poorly governed and unsustainably funded system. Care workers in social care are poorly paid, vis-à-vis equivalent occupations in other sectors. Family (unpaid) carers are left overburdened and unsupported, with negative consequences for their health, finances and employment. Disabled, older and chronically ill people have inadequate support services that inhibit their full participation in society. As the experiences of these respective groups indicate, the social care system is shaped by wider gendered, class-based, racialised and ableist inequalities within neoliberal capitalism.
This paper examines how different academic, policy making and activist discourses make claims for improved rights and entitlements for social care workers, carers and service users. It develops a critique of the view (implicit and explicit in many of these discourses) that improving the circumstances of one group (eg, paying care workers more) requires a weakening of the entitlements of another (eg, carers or disabled people must contribute more towards their support). In place of this ‘zero sum’ perspective, this paper uses feminist social reproduction theory to argue for a conceptual approach which sees the inequalities experienced by workers, carers and service users as inherently connected, and in need of a common resolution. This approach can inform debates and campaigns for equality and social care transformation.

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Mapping the Gaps: An Analysis of Inequalities in Turkey's Long-Term Care Provision

Gülçin Con Wright[1]
[1]Assistant Professor Of Sociology, Ted University, Türkiye

The long-term care (LTC) system in Turkey relies primarily on informal care provided by family members, with a fragmented and limited provision of formal institutionalized care. National and municipal governments provide a combination of home care and social services to older people in need, with most programs being means-tested. In this paper, I examined the long-term care system in Turkey through the lens on the inequalities that underpin it. I first conducted a content analysis on the Ministry of Family and Social Services’ most recent (2020-2025) administrative data and policy documents on LTC. Second, I reviewed all online content on institutionalized care, home care services, and social services offered by private for profit and

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private non-profit institutions, as well as local governments. Not only did I map all formal care facilities around the country, but I also reviewed their guidelines for target audience and scope of their services. The preliminary findings of this research suggest that there are regional, rural-urban, gender-based and class-based inequalities. First, LTC services are predominantly located in metropolitan cities in the Western side of Turkey, leaving smaller cities and rural areas, especially in the Eastern side, in care poverty. Second, the eligibility and costs associated with many of these services exclude middle-class older people and older people with cognitive disabilities. Third, older couples were rarely targeted since priority is given to the widowed, and no provisions were made for older LGBTI+ couples. Policymaking should target elimination of this type of systematic exclusion in formal care.

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TP26a Transforming care work: changing working conditions, actors, approaches and outcomes

Room: F3003
Time: 16:00-17:30
Chairs: Costanzo Ranci, Hildegard Theobald

Presentations:

- 34 Duncan Fisher & Liam Foster: What are paid care workers' attitudes, motivations, and considerations regarding organising?
- 41 Paula Gonzalez Vila: Who pays and who provides? A quantitative cross-regime analysis on the migrantisation and marketisation of care work in Europe
- 127 Lucinda Allen: Identifying and assessing national policy options to improve care worker pay in England
- 289 Monique Lanoix: Teamwork: Lessons from the COVID-19 pandemic

Short presentations:

- 205 Ting-hsin Li: Democratic Deliberation on Home-Based Childcare Wages in Taiwan: Policy Implications and Governance Challenges

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What are paid care workers' attitudes, motivations, and considerations regarding organising?

Duncan Fisher[1], **Liam Foster**[1]
[1]The University Of Sheffield, UK, Sheffield, United Kingdom

In England, working conditions in adult social care (ASC) employment in are among the worst in the labour market. These are longstanding issues, with this work having been classed as low paid by the Low Pay Commission since 1988, for example, and high levels of vacancies and turnover persisting. There are signs of positive reform through legislation being introduced by the new Labour government, elected in July 2024, but there are several obstacles to that effecting meaningful change. With positive state-level policy slow to materialise, this paper examines a dimension of paid care workers' own efforts to bring about change, namely their orientations towards organising. Levels of unionisation are low in ASC compared with other sectors, and although small-scale effective union and non-union campaigns take place, the overall numbers and impact are limited. For organisations seeking to represent paid care workers to engage with them effectively, it is important to understand these workers' views on organising for change. This paper draws on analysis of 35 interviews with paid care workers and key actors from organisations – including unions and campaign groups – representing their interests. It presents findings in areas including care work's relational labour process, the status of paid care work, and awareness of unions and the potential of organising. The analysis engages with literature on paid care workers' wider work orientations (England, 2005; Meagher, 2006; Daly, 2023), and with the burgeoning literature on organising among paid care and domestic workers (Boris and Klein, 2006; Whitfield, 2022; Tungohan, 2023).

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Who pays and who provides? A quantitative cross-regime analysis of the migrantisation and marketisation of care work in Europe

Paula Gonzàlez Vila[1]
[1]Universitat Autònoma de Barcelona, Sociology Department and QUIT (Sociological Research Centre on Everyday Life and Work), Catalonia

Globalization and neoliberalism have led European societies to rely on migrant care workers to compensate for declining familial care. Even though global care chains have been widely studied, most research treats care regimes as fixed classifications, overlooking how regime shifts affect the migrantization and precarity of care work. This paper uses quantitative data from 19 European countries to construct mutable care clusters and employs a probit model to link care marketization with the reliance on a precarious and feminized migrant workforce. Using two-way fixed effects, results show that care regimes (social-democratic, continental, liberal, familialistic) significantly influence the likelihood of care workers being migrants, even when controlling for migration flows and labor regimes, revealing that policy shifts can reduce reliance on migrant workers in care. These findings underscore the need for stronger public care provision to avoid perpetuating precarious and gendered labor dynamics.

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Identifying and assessing national policy options to improve care worker pay in England

Lucinda Allen[1], Nina Hemmings[2], Cyril Lobont[2], Hanan Burale[3], Hugh Alderwick[1], Ruth Thorlby[1], Natasha Curry[2]
[1]The Health Foundation, , United Kingdom, [2]Nuffield Trust, United Kingdom, [3]RCGP, United Kingdom

England's adult social care sector faces persistent workforce challenges. Improving problems with insecure and low pay alone will not solve these issues, but targeted government action and funding to increase wages are essential for a more sustainable care workforce.

Our analysis sets out evidence on the implementation and potential impact of five policy options for improving care worker pay: better enforcement of the economy-wide minimum wage, uplifts to the economy-wide minimum wage, bonus payments in social care, a sector-specific minimum wage, and a national sector pay scale.

We used a mixed-methods approach, combining evidence synthesis, quantitative data analysis, and stakeholder engagement. A comprehensive literature review and scoping interviews with over 40 stakeholders in the care sector informed the identification of the policy options and existing evidence on their impact. We analysed pay using data from the Adult

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Social Care Workforce Data Set and Office for National Statistics. We also reviewed evidence on the implementation and impact of international examples of pay policies in care. We developed a framework for evaluating the options against key policy considerations and tested our conclusions through workshops with experts, policymakers, and care sector representatives.

Our research underscores the need for sector-specific government action on social care pay, including to tackle relatively high levels of underpayment. Each policy option varies in scope and ambition so has distinct benefits and risks – combining approaches could maximise impact. International evidence suggest that meaningful improvements in care worker pay are achievable with political commitment and investment.

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Teamwork: Lessons from the COVID-19 pandemic

Monique Lanoix[1]
[1]Saint Paul University, Canada

In this presentation, I discuss a novel finding from a project aimed at understanding how personal support workers (PSWs) were coping during the fifth wave of the COVID-19 pandemic (January-April 2022). Semi-structured interviews were conducted with PSWs who were providing care in non-profit nursing homes in Ottawa, Canada. The goal was to uncover which activities or regulations made workers feel more vulnerable to harm. Some of the results were predictable, as workers had to contend with multiple levels of uncertainty stemming from changing regulations to residents and staff getting sick (Upasana et al 2024). However, there was one unexpected finding. The interviews revealed how some units achieved better team cohesion. Notably, the objective of managing the COVID-19 virus encouraged all levels of personnel on the unit to problem solve together. Such a procedure is not standard practice, as problems are usually resolved in a top-down manner. To show why this finding has potential to enhance care provision, I explain how care duties are assigned on units and the problems that emerge from this structure. I follow this with a description of the way teamwork emerged through non-hierarchical communication, open discussion and exchange between registered nurses, registered practical nurses and PSWs on the unit. This way of problem-solving mirrors the approach developed by Dejours (1998; 2000), the psychodynamics of work, to address the suffering of workers. Using Dejours' insights, I argue that nursing homes would benefit from this approach as it would enhance the quality of care provision and PSW satisfaction.

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Democratic Deliberation on Home-Based Childcare Wages in Taiwan: Policy Implications and Governance Challenges

Ting-hsin Li[1], Shu-Yung Wang[1]
[1]Dept. of Social Welfare, National Chung Cheng University, Taiwan

Taiwan's declining birth rate has prompted the government to implement childcare subsidies. However, despite increased financial support for parents, the home-based childcare workforce faces severe shortages due to low wages and unfavorable working conditions. This empirical study employs a case comparison approach, analyzing government meeting records and policy frameworks to evaluate the wage determination process for home-based childcare providers. It

focuses on the role of local government-led Childcare Policy Management Committees (CPMCs), which convene stakeholders through democratic deliberation to discuss and consult matters such as personnel wages, supervision, and evaluation.

The study identifies structural barriers in participatory governance. While Taiwan's government employs democratic deliberation in wage-setting, its "ceiling pricing strategy" caps childcare fees, limiting wage growth and discouraging young professionals. Furthermore, CPMCs are dominated by officials and experts, with minimal representation of childcare providers, resulting in elite-driven decision-making.

This research also critiques the decentralized wage-setting approach, highlighting insufficient central government oversight and the excessive delegation of wage deliberation to local governments. While parental subsidies are standardized nationwide, childcare providers' wages remain subject to regional discretion, exacerbating concerns about fairness and adequacy.

The study underscores the limitations of the current governance model, emphasizing the need to enhance childcare providers' representation in deliberative processes. It also highlights the importance of stronger central government oversight to harmonize wage-setting mechanisms, ensuring fairness and sustainability in Taiwan's childcare system. These findings contribute to global discussions on fair wages in the care sector and the role of democratic governance in social welfare policies.

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TP25a Transforming early childhood education and care services

Room: F3017
Time: 16:00-17:30
Chairs: Francesca Bastagli, Emmanuele Pavolini, Stefania Sabatinelli

Presentations:

- 29 Martin Gurín: From Termination to Revival: Exploring the Dynamics of Childcare Policy Reintroduction
- 370 Stefano Neri & Stefania Sabatinelli: It's now or never? Expanding ECEC coverage and protecting quality in Italy
- 221 Kayla Benjamin: Childcare in Canada: An intersectional analysis of progress and policy gaps in access and affordability
- 80 Rebecca Gale: Child Care Policy Innovation While the World Is Burning

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From Termination to Revival: Exploring the Dynamics of Childcare Policy Reintroduction

Martin Gurín[1]
[1]University of Bremen, Germany

Childcare services are vital for promoting child well-being, gender equality, and a sustainable work-family balance. However, childcare policies are not always designed to adapt to evolving societal and parental needs. Flaws in policy design and unintended consequences can generate dissatisfaction among beneficiaries—a process known as self-undermining policy feedback. If this dissatisfaction is not effectively addressed, it can result in policy retrenchment, a shift toward familialistic measures, or even outright termination.

Reintroducing terminated childcare policies, however, is a formidable task. It requires rebuilding dismantled institutional structures, addressing competition for resources with entrenched policies like pensions or education, and overcoming the legacies of negative feedback that led to their termination. These challenges are further compounded by the emergence of replacement policies that develop their own constituencies and reinforce opposition to change.

The Czech Republic illustrates these dynamics vividly. Following the termination of state-supported childcare services in the 1990s, public provision remains limited, despite growing demand. Efforts to reintroduce childcare services have been hindered by institutional inertia, cultural resistance to state-led non-familial care, and entrenched policies favoring familialistic measures that were put forward during the interim.

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By examining the Czech case within broader welfare state and institutional change frameworks, this paper reveals how policy termination leaves a lasting legacy that actively inhibits future reintroduction of childcare services. This provides a sobering lesson for policymakers: dismantling childcare services is far easier than rebuilding them, and the costs of termination often persist for decades.

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It’s now or never? Expanding ECEC coverage and protecting quality in Italy

Stefano Neri[1], **Stefania Sabatinelli**[2]
[1]University of Milan, Italy, [2]Polytechnic of Milan, Italy

The ECEC system in Italy has historically developed based on a rigid split system. While enrollment in preschools (for ages 3-6) became quasi-universal in the 1990s, thanks to the direct role of the State in provision, the expansion of services for children under 3, whose responsibility mainly remained with local governments and Regions, has lagged behind. Unlike other European countries, the increase in coverage, including through private providers, has been slower, further hindered by the impacts of the global recession and the pandemic. The low national average conceals severe territorial disparities and socio-economic inequalities in access and participation.

In the late 2010s, however, the central State intervened in two ways: first, by introducing demand-side subsidies to reduce the impact of fees on households; second, through an institutional reform aimed at integrating the two age-based segments. The "Integrated System 0-6" is being gradually implemented through the institutionalization of national earmarked funds for both infrastructure and operations, as well as national systems for training, monitoring, and evaluation. The 2021-22 National Recovery and Resilience Plan, financed by the EU, has provided additional resources for a significant expansion in coverage. However, implementation is complex, and the objectives have been downscaled over time.
The Italian ECEC system is, therefore, at a crossroads. Ensuring coherence and effective implementation across different streams of intervention is crucial to preventing the persistence of Matthew Effects and trade-offs between service quantity and quality, particularly the hard working conditions of the ECEC workforce.

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Childcare in Canada: An intersectional analysis of progress and policy gaps in access and affordability

Kayla Benjamin[1], Anna Kuznetsov[1], Daniela Ugarte-Villalobos[1], Ito Peng[1], Erica Di Ruggiero[1]
[1]University of Toronto, Canada

Canadian federalism has previously limited opportunities for a coherent national childcare policy, resulting in a patchwork childcare infrastructure and policy across Canada and significant childcare access and quality issues. In 2021, the federal government announced its intention to address these concerns by establishing a Canada-wide Early Learning and Child Care (CWELCC) system. The CWELCC includes the ambitious aim of nationally subsidized childcare ($10/day childcare). Using data from a large, representative survey of 1000 Canadian caregivers (completed in 2022), as well as follow-up interviews with a sub-sample of 46 caregivers across Canada (completed in 2023), we identify gaps between the current childcare

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infrastructure and policy in Canada and the realities of Canadian unpaid caregivers. We find that while many caregivers have benefited from lower childcare fees under the early adoption of the CWELCC, this policy has primarily benefited caregivers who had access to regulated and licensed childcare before the implementation of the new policy. For other families, persistent issues of access to CWELCC-subsidized childcare include (1) the lack of availability and wait lists, 2) living in rural areas, 3) the lack of accommodation and support for children with mental or physical disabilities, and 4) standard operating hours. In addition, our study finds that paid childcare use varies greatly according to household income, with 70% of the highest-income households (150,000 CAD or more) using paid childcare compared to 24% of the lowest-income households (under 50,000 CAD). We conclude this paper with recommendations for improving the CWELCC system.

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Child Care Policy Innovation While the World Is Struggling

Staff Writer Rebecca Gale[1]
[1]New America, Washington D.C. , United States

The United States lacks a national child care infrastructure, even though the majority of children are raised in households where child care is essential. This is, in large part, because quality care for children and other vulnerable members of society is viewed as an individual responsibility and not part of a larger social contract about what we owe each other by virtue of our humanity. Though there have been some limited progress on subsidizing child care at the federal level, by and large, U.S. parents are on their own as they face a patchwork of expensive and often inadequate options. In the absence of the political will to care for vulnerable humans, and, more specifically, waning hope of a national childcare infrastructure in the U.S., some states are addressing the issue themselves. Vermont and New Mexico are both in the process of implementing near-universal child care systems. As many in the U.S. and around the world face growing authoritarianism and profound threats to human rights, some of the key spaces where change can squeak through will be states, regions, and localities. For many, the question is: what we can do now, where we are at, with what we have? Drawing lessons from Vermont and New Mexico, we see that there are creative and innovative policy options that can create more just and sustainable care infrastructures, even in the face of growing challenges to social and human rights.

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TP1a: Social care and the changing service pathways of older adults

Room: F3020
Time: 16:00-17:30
Chairs: Heli Valokivi, Paula Vasara, Andrea Lorenz-Wende

Presentations:

- 405 Pamela Pasian Integrated, person-centred and innovative long-term care: the questions we need to answer
- 146 Fintan Sheerin: Caring for Older Adults with Intellectual Disabilities and Emerging Complexity
- 367 Sirpa Granö: Person-centered transition to retirement for ageing people with intellectual disabilities - enabling and challenging factors in the service system
- 253 Myra Lewinter: Refusing Care - Role of Family and Public Services: Three case studies from Denmark

Short presentations:

- 69 Hilla Kiuru & Andrea Lorenz-Wende: Placing the case management of older adults
- 338 Blanca Valdivia: The socio-spatial dimension of long-term care services

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Integrated, person-centred and innovative long-term care: the questions we need to answer

Barbara Da Roit[1], Alisa Bader[2], **Iris Boot**[3], Eckhard Nagel[2], Pamela Pasian[1], **Sebastian Schmidt**[2], Bert Vrijhoef[3]
[1]Department of Philosophy and Cultural Heritage, Ca' Foscari University of Venice, Italy,
[2]Institute for Management in Medicine and Health Sciences, University of Bayreuth, Germany,
[3]Panaxea, the Netherlands

Across European countries, long-term care (LTC) is generally constituted by a complex set of measures and interventions that cut across diverse policy with different regulations, resources and organisation. Separate need assessment rules and procedures, funding, modes and places of delivery imply that people in need of care often need to identify, reach out to and combine different sources of support. These complexities may contribute to overlapping as well as unmet needs, inequalities, inefficient use of resources, and lower-than-desired quality of care and wellbeing.

International organisations and expert networks have pointed to the need to develop “integrated” and “persons-centred” LTC models, to increase care accessibility and quality,

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users' autonomy and self-determination, and formal and informal caregivers' quality of (working) life. Yet, how these models work out in practice remains uncertain, because they originate from different policy fields and disciplinary approaches, and their concrete design, implementation, and evaluation is context specific.

This paper, stemming from the collaboration among three large Horizon Europe-funded projects (BUILD, Laurel, LeTs-Care) discusses the translations and applications of "integrated" and "persons-centred" LTC in diverse individual circumstance and institutional, disciplinary and policy contexts as a necessary step to understand their potential.

Based on the analysis of policy documents, grey and scientific literature, surveys and interviews, the paper first traces the founding ideas, history, multi-disciplinary debates and policy expectations around "integrated" and "persons-centred" models. Subsequently, it reviews and discusses what is known about their design and implementation, the questions that remain open, and the methodological challenges ahead.

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Caring for Older Adults with Intellectual Disabilities and Emerging Complexity

Fintan Sheerin[1], Maureen D'Eath[2], Sandra Fleming[2]
[1]School of Nursing, Maynooth University, Ireland, [2]School of Nursing and Midwifery, Trinity College Dublin, Ireland

Aim
To identify the service options available to older people with intellectual disabilities and complex needs in Ireland. It also explored the challenges to providing service pathways that are individualised to their needs and preferences.

Methods
A descriptive mixed-methods design was employed with two phases, the first of which used focus groups with service managers, as well as surveying all major disability services providers. The second phase again used interviews/focus groups to elicit perspectives of direct care staff, family carers and people with intellectual disabilities. In all, 77 participants engaged in the study, including 45 in the interviews/focus groups. Data were analysed thematically or statistically as relevant. Ethical approval was obtained.

Findings
It is clear that service delivery for older adults with intellectual disabilities in Ireland is not underpinned by any clear model of care but is addressed through eclectic approaches which are determined by service philosophy and the underlying state funding model. This 'one-size-fits-all' funding model presents a significant challenge to the delivery of positive and person-centred ageing support. It has also resulted in the absence of integrated care and service delivery, in respect of health, accommodation and end-of-life planning. Despite this, services, direct care staff and families are doing exemplary work to achieve quality outcomes, but these are not possible for all.

Conclusion
Positive ageing is something that societies and services strive to deliver. For people with intellectual disabilities in Ireland, this is challenged by the absence of a clear service and dynamic funding model. Recommendations are provided.

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Person-centered transition to retirement for ageing people with intellectual disabilities - enabling and challenging factors in the service system

Sirpa Granö[1], Elisa Tiilikainen[2], Sonja Miettinen[3], Elina Kontu[1]
[1]Tampere University, Finland, [2]University of Eastern Finland, Finland, [3]The Finnish Association on Intellectual and Developmental Disabilities, Finland

For people with intellectual disabilities (ID) transition phases to old age challenge the service system and the person's right to appropriate support. In Finland these transitions, such as retirement, often proceeds in a person-centered or system driven way. A person-centered approach tailors services around the individual, and is a widely accepted model.

This presentation examines enabling and challenging factors for the person-centered transition process from the perspective of directors. The findings draw on focus group discussions (N=4) carried out online with directors of disability and aging services from Finnish wellbeing services counties. The data were analyzed with inductive content analysis and further deepened using a framework of 'conditions of systemic change' (Kania et al. 2018).

The findings show that, at the structural level, flexible service models, resource prioritization, and utilizing different laws enabled person-centeredness. Concurrently, age limits for day activities, staff shortages, and budget pressures posed structural challenges to the process. At the relational level, the system's siloed nature and suboptimization of costs caused challenges for person-centered transition. Increasing collaboration between professionals and service providers working in the transition process was seen as a solution to these relational challenges.

At the transformative level, knowing clients and seeing them as equal citizens supported person-centeredness, while discrimination and exclusion of disabled people outside disability services challenged the transition process.

More emphasis is needed in ensuring that people with ID are treated as equal citizens and have adequate access to healthcare and services for older adults.

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Refusing Care - Role of Family and Public Services: Three case studies from Denmark

Myra Lewinter[1]
[1](emerita) Dept. Soc. U. Copenhagen, , Denmark

In this paper I am going to take up situation that I have not seen researched in literature, of daughters who see their mothers refuse to accept the home care offered by Danish municipalities and insist on taking care of their stroke ill husbands alone.
The focus on these daughters "arose from data". In a research project focusing on family care, the first step of the project was a questionnaire sent to a sample of people 45 to 64 years of age in 2 municipalities of Denmark. The final question was, if the respondent was a caregiver, and if so, would they be interested in a personal interview. The three cases presented here were among those interviewed for the project.
The cases will be presented from the daughters' perspectives and in their words.

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Both the daughters (two working full time and one on a pension) and the home care municipal authorities accepted the mothers' refusal of help. However, they each had their own discrete ways of "keeping an eye" on the mothers, exercising both restraint and vigilance. The daughters, though, felt that their parental loyalty was stretched. Therefore, they not only helped with several practical tasks but also, in the end, were able to influence a resolution of the situation. However, this probably wouldn't have gone as smoothly as it did, without the vigilance of the home care and in particular the home nurse.

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Placing the case management of older adults

Hilla Kiuru[1], **Andrea Lorenz-Wende**[1], Heli Valokivi[1]
[1]University Of Jyväskylä, Finland

Abstract

Since the population is ageing, societies are looking for solutions concerning the care of older adults. Case management is essential in supporting ageing in place and organizing services for older adults. It is also a key method of gerontological social work. In our paper, we study case management with older adults in the context of space and place since case management occurs in a place/space and affects them. We did a scoping review covering articles about case management, social work, space, and place published during 2000 and 2024 and included twenty-one articles in the review. The following themes were identified in relation to case management, space, and place: ageing in place, placement of older adults, the place of case management/case manager within the service system, case management as navigator in the service system, and the space/place where case management is done. By theorizing case management with space and place, our paper opens new ways to conceptualize and study case management in the context of gerontological social work.

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The socio-spatial dimension of long-term care services

Blanca Valdivia[1], Sara Moreno[1]
[1]Universitat Autònoma De Barcelona, Spain

In Spain, the model of old people's homes has been strongly questioned since the COVID-19 pandemic, with very high mortality rates and where major shortcomings in day-to-day care became evident.

Given the diversity of situations in relation to dependency, it is necessary to consider heterogeneous resources that can respond to different needs, thinking about what criteria the resources must meet to guarantee optimal care and adequate working conditions.
Although the state of the art on long-term care services is abundant, very few studies analyse the spatial and temporal characteristics of institutions and their impact on care. As has been pointed out in the field of feminist urbanism (Col·lectiu Punt 6 2019; Valdivia, 2021; Davis, 2022), the spatial and urban conditions of care infrastructures and their environment directly determine the quality of care and the conditions in which it is carried out.
This paper analyses the impact of the spatial and temporal dimension of the different long-term care services, the care of dependent persons and their family or affective environment.

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The methodology is based on a case study of residential homes, day centres and sheltered housing in municipalities in the Metropolitan Area of Barcelona. An analysis is made, linking the quality of life of residents and their affective network with urban and architectural characteristics.

The work shows empirical evidence of the impact of characteristics such as proximity, accessibility, continuity and everyday life on the conditions of care and the quality of life of the users of the different long-term care resources.

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S11 The right to access and provide quality long-term care

Room: F3005
Time: 16:00-17:30
Chair and discussant: Susan Braedley

Framed around the right to access quality care and provide quality work, this symposium presented by an international team of researchers explores strategies used in Canada, Norway and Sweden to address the crisis in the long-term care labour force. The papers are based on an open-access book in press, supplemented by key informant interviews - currently underway - with people from government, unions and employer organizations. The team has identified five kinds of strategies used to varying degrees in the three countries; reduce, reorganize, replace, recruit and retain. Arguing that the conditions of work are the conditions of care and that retention must be a core concern, the papers analyse the extent to which each strategy contributes to the right to care. The conclusion, which we propose as an alternative to a discussant, proposes ways to rethink approaches to the labour force crisis in long-term care approaches that make gender a critical concern.

Papers:

Reduce- Gudmund Ågotnes, Norway

Recruit, Marta Szebehely, Sweden

Replace-Rebecka Strandell, Sweden

Retain- Christine Streeter, Canada

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Wednesday 25 June: Parallel sessions 2

TP17a Navigating entangled systems: institutional interplays in care systems

Room: F3010
Time: 16:00-17:30
Chairs: Mara Yerkes, Jana Javornik, Ester Gubert

Presentations:

- 230 Zhongyan Zhang & Wing Kit Chan: The Institutional Interaction of Long-Term Care System in Mainland China and Taiwan: A Path Dependence Perspective
- 269 Susanne Martikke & Susanne Langer: Maintaining infrastructures of caring: sandwich carers' invisible work of keeping care flowing between people, needs, and systems
- 181 Patrick Hall: Layered Ideas, Drifting Structure: institutional change in English long-term care commissioning

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The Institutional Interaction of Long-Term Care System in Mainland China and Taiwan: A Path Dependence Perspective

Zhongyan Zhang[1], **Wing Kit Chan**[2]
[1]School for Business and Society, University of York, UK, [2]School of Government, Sun Yat-sen University, China

In light of the rapidly growing demand for care by the ageing population, long-term care insurance has been introduced in welfare states to address the unprecedented social risks. Although it is a new institutional arrangement, the formulation and reform of long-term care insurance are constrained by existing policy paths, significantly limiting its development. For instance, China's long-term care insurance is hindered by the influence of health insurance in areas such as eligibility, funding, and provision mechanisms.

This article examines the interaction between various institutions, particularly how established institutional paths influence the development of long-term care insurance in Mainland China and Taiwan, and their impact on caregivers. We also analyse the reasons behind this. Firstly, influenced by the productivist welfare capitalism in East Asia, long-term care insurance in both regions still follows the model of Japan and South Korea, prioritising local economic growth. Secondly, in terms of political structure, factors such as intergovernmental relations and the official promotion system affect the reform process of long-term care insurance in both regions. Finally, institutional costs also reinforce the continued reliance on existing paths.

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Since upfront expenses have already been incurred, and the effectiveness and benefits of alternative paths remain uncertain, it is prudent to stick conservatively to the established path.

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Maintaining infrastructures of caring: sandwich carers' invisible work of keeping care flowing between people, needs, and systems

Susanne Martikke[1], **Susanne Langer**[2], Andrew Clark[3]
[1]10GM, Manchester, United Kingdom, [2]School of Psychology, Manchester Metropolitan University, , United Kingdom, [3]Institute for Lifecourse Development, University of Greenwich, United Kingdom

Sandwich carers are maintaining multiple often contradictory caring relationships across different generations. Their work is essential in connecting people, needs and systems of care, yet it remains invisible and unacknowledged in contemporary policy. Data from our UK-based qualitative scoping study showed that sandwich caring was characterised by ongoing and overlapping caring relationships and activities. Common life events such as the beginnings and endings of relationships, the arrival of new children and the departure or return of older ones, ageing parents, in-laws, and spouses necessitated constantly shifting arrangements. Furthermore, the needs sandwich carers were responding to were themselves unstable, with existing morbidities and vulnerabilities often worsening and multiplying over time. Finally, decades of under-funding, new public management, and privatisation have led to a UK welfare system that is overstretched, fragile, opaque, and constituted by services focused on narrow and inflexible parameters of often time-limited provision. In this challenging context, sandwich carers took on the daunting task of connecting loose ends, preventing disruptions, and keeping it all together. Ironically, their success at engineering the smooth flow of care came at the expense of erasing the traces of the resources and skills necessary to achieve it and of making themselves and their work invisible in the process. By highlighting the dilemmas and contradictions that sandwich caring poses to contemporary conceptions of care, we want to draw attention to the pivotal role of sandwich carers and begin the process of them gaining greater recognition in social policy.

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Layered Ideas, Drifting Structure: institutional change in English long-term care commissioning.

Patrick Hall[1]
[1]University Of Birmingham, United Kingdom

This study explores the relationship between ideas and structures of long-term care 'commissioning' in English local government. Combining institutionalist concepts of gradual change (Hacker, Pierson and Thelen, 2015) with Morphogenetic Cultural Theory (Archer, 1996), it constructs an 'Ideas System', iterated with data from interviews with 30 commissioners across England. 'Commissioning' emerged in English social care in the 1990s-2000s as public services adapted to increased non-state provision (Bovaird, Briggs and Willis, 2014). Three key narratives can be identified in historical commissioning discourse:

- 'Personalised' Commissioning: 'Empowering Disabled People to Co-Commission Independent Lives'.

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- 'Partnership' Commissioning: 'Partnership with our community and providers to commission wellbeing' · '
- ‘Evidence-Based' Commissioning: "Meeting population care need through evidence-based commissioning"

This created a 'layered' set of ideas with different, sometimes conflicting interpretations that coexist (Allen et al., 2023), impacting commissioners’ work. While there is ideational 'syncretism'(Archer, 2005) present in commissioners' values and goals, this mechanism is absent when practical tasks are conceptualised. Two key dynamics emerge: Commissioners control abstract ideas but lack control over service procurement and monitoring. These aspects are influenced by stakeholders whose 'drifting' NPM-style approaches (McCray and Palmer, 2014) limit ideational and institutional change in commissioning. The findings contribute to empirical evidence of ideas' impact on practice in Long-Term Care and suggests a theoretical framework to help explain the 'direction' of gradual institutional change (Béland, 2007) by incorporating Archer's analytical dualism.

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TP8 Caring beyond cure in the narratives from the Global South

Room: F3006
Time: 16:00-17:30
Chairs: Pragya Dev, Binod Mishra

Presentations:

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Negotiating Care: Contestations of Psychiatric Treatment and Healing Practices in Indian Autopathographies of Psychiatric Patients

Sree Lekshmi M S[1], Aratrika Das[2]
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Care in mental health treatment, particularly within the Indian context, emerges as a contested and multifaceted process. This paper examines the interplay between institutionalised frameworks of allopathic psychiatry and the enduring presence of indigenous and ritualistic healing practices in India. Drawing upon autopathographies of bipolar patients—Swadesh Deepak's I Have Not Seen Mandu: A Fractured Soul-Memoir (2021), Shreevatsa Nevatia's How to Travel Light: My Memories of Madness and Melancholia (2017), Vijay Nallawala's A Bipolar's Journey: From Torment to Fulfillment (2015), and K.S. Ram's Warrior: The Bipolar Battle (2015)—this paper explores the dynamic landscape of care for psychiatric patients in India. Helene Basu (2014) notes that in South Asia, psychiatric institutions coexist with Hindu temples, Christian churches, and Sufi shrines, all of which are committed to healing madness and negative possession. This coexistence reflects a widely shared and culturally embedded ideology of health across diverse communities. Building on this perspective, the paper investigates how care is provided to psychiatric patients within a therapeutic environment where allopathic psychiatric practices are continually negotiated alongside indigenous healing traditions. The study interrogates the ethical, relational, and practical dimensions of care and the contestations that arise when biomedical psychiatry intersects with culturally embedded healing practices. This exploration contributes to a nuanced understanding of care as a

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relational, situated, and context-sensitive process, particularly within the pluralistic therapeutic landscape of the Global South.

Keywords: Care, India, Indigenous, Autopathographies, Psychiatry, Indigenous Healing Practices

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How Female Architects Care: A reflection on the design of housing and their authors

Rose-ann Mishio[1], **António Carvalho**[1]
[1]Politecnico Di Milano, Milan, Italy

The idea of care in architecture connotes an empathetic dimension in design where the discourse shifts from the traditional views of form and function into the role it plays in supporting and shaping well-being through spaces that are suitable for individual and communal needs (Bertolino 2024), particularly the vulnerable and marginalized for a resilient and sustainable future. But how do these architectures of care come about, who instigates it, and how does it materialize? Using four attributes of care identified in Joan Tronto's definition of care (1) as a theoretical background, three housing projects are analyzed and reflected upon: Tosin Oshinowo's homes for Ngannaram project in Borno, Nigeria completed in 2022, Mariam Issoufou's Niamey 2000 project completed in 2016 and 2020 in Niamey, Niger and Yasmeen Lari's Lari Octa Green (LOG) housing in Pono, Pakistan in 2022. In this contribution, the lens is shifted back and forth from the building to the designer, the design thinking behind their architectures of care and how they come about through first-hand reflections considering "who", "for whom", "why" and 'how'. Personal reflections driven by these questions reflect the architects' identities, what drives the 'empathy' instigating the structures and spaces of care, and their design approaches that demonstrate care beyond rules and regulations.

(1) The concept of care by Joan Tronto can be split into principles: 1. care leading to action, 2. care as an activity to maintain, continue, and repair our "world", 3. care as is culturally defined 4. care as an ongoing activity

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Eyes of Understanding: Ophthalmologists' Attitudes Toward Caring for People with Intellectual Disability

Chiun-Ho Hou[2], Yueh-Ching Chou[1], **Christy Pu**[1]
[1]National Yang Ming Chiao Tung University, Taiwan, [2]National Taiwan University Hospital, Taiwan

Background
Healthcare disparities often stem from the attitudes of physicians toward individuals with disabilities. Despite their pivotal role, little research exists on ophthalmologists' attitudes toward people with intellectual disability (ID).

Objective
This study evaluates ophthalmologists' attitudes toward people with ID in both clinical and nonclinical settings, emphasizing the importance of empathy in care.

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Methods
A cross-sectional survey was conducted from January 2022 to October 2023, involving members of the Ophthalmological Society of Taiwan and the Taiwan Optometry Education Association. The study used a 14-item general attitude scale for nonclinical settings and an 8-item scale for clinical contexts. Participants were also asked about their experiences caring for people with ID and their involvement in related vision care training.

Results
The study received responses from 127 physicians, 100 optometrists/opticians, and 86 other healthcare professionals. Ophthalmologists expressed generally positive attitudes in nonclinical settings (average score = 55.9/70) but displayed more negative attitudes in clinical settings (average score = 23.5/40). Interestingly, ophthalmologists' attitudes were more positive than those of other healthcare professionals. However, prior experience or training in caring for people with ID was linked to more negative attitudes in clinical settings.

Conclusion
Attitudes toward people with ID in clinical settings differ significantly from nonclinical interactions. This suggests that traditional training for ophthalmologists may fall short in fostering empathy and understanding, emphasizing the need for innovative approaches to cultivate a culture of care beyond cure for this challenged population.

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S3: Talking about rights in LTC: a polysemic pool of terms and ideas

Room: F3004
Time: 16:00-17:30
Chair: Bernhard Weicht
Discussant: Claude Martin

Multiple voices call for developing integrated, empowering and inclusive LTC policies and interventions to secure the right to affordable and good quality LTC services for all persons, as stated in Principle 18 of the European Pillar of Social Rights. The recent EU Care Strategy establishes furthermore the aim that high-quality care services should benefit the wellbeing, health and social inclusion of people in need of care and in/formal caregivers, while providing good employment opportunities and making the care system more efficient and sustainable through increased fiscal revenues and social contributions.

These aims and principles are fostering new debates within national LTC systems with ideas travelling and practices diffusing in search of promising ways to tackle the main challenges while safeguarding and promoting fundamental rights and freedoms of citizens. Yet, the formulation of EU policies and guidelines is broad and might be open to diverse interpretations and definitions of LTC-related rights.

Diversity of trajectories and timing of policy developments are likely to amend otherwise consensually agreed terms and ideas. This can be challenging for meeting policy goals under a common EU strategy.

In this symposium, we start from the polysemic nature of policy ideas and terms and discuss the meanings of taken-for-granted LTC concepts that frame how different stakeholders deal with LTC challenges. We take a comparative, cross-national approach and investigate how these variations and differentiations might relate to the European Pillar of Social Rights. The proposed symposia will share work developed by the Horizon Europe Consortium LeTs-Care – Learning from Long-Term care practices for the EU Care strategy - and present the results of research carried out in seven countries (Italy, Denmark, The Netherlands, Austria, Lithuania, Portugal and Spain) on five different thematic areas related to meanings of needs and quality of care, care work and quality of care work, (in)equalities in LTC, and sustainability of LTC. The symposium will gather five presentations, each tackling one of the afore- mentioned thematic areas of meanings. Research findings are based on extensive literature reviews, policy analyses and interviews with key-stakeholders held in all seven countries, following a common methodological framework. The discussion will not only highlight the relevance of understanding what ideas mean for different stakeholders and in different contexts, but it will also reflect on how different meanings involve different levels of integration of a human-rights based approach to LTC provision.

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Papers:

“’Good care’ and good care jobs. A comparison of 7 EU countries", Barbara Da Roit, Ca’ Foscari University of Venice, and Siënna Hernandez

“Priorities in LTC needs assessment in different European countries”, Virginija Posküte, ISM University of Management and Economics

“Human rights and the sustainability of LTC: an analysis of (conflictive) meanings and challenges in seven EU countries”, Roberta Perna, Agencia Estatal Consejo Superior deIinvestigaciones Cientificas (CSIC)

“Inequalities in LTC in seven EU countries: does human rights’ approach make a difference?" Alexandra Lopes, University of Porto

Discussant:

Claude Martin, University of Rennes, France

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OS4 Technology-assisted care

Room: U3039
Time: 16:00-17:30
Chairs: Erika Takahashi

Presentations:

- 92 Yu-Hsiang Chou: Technology and Well-Being: A Capability Approach Analysis of Pepper Robots in Long-Term Care Facilities
- 5 Yea-Ing Shyu: A smart-clothes assisted home care for family caregivers of persons living with dementia
- 82 Erika Takahashi: Digitalisation and managerial technologies in Finnish home care: socio-technical articulation of care labour and the quality of care
- 432 Sara Skardelly & Leonie Winterpacht: Who cares? Contesting anticipations about the future of "healthy ageing" through Communicative AI

Short presentations:

- 237 Riitta Hänninen: Rethinking warm experts – challenges of informal digital support

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Technology and Well-Being: A Capability Approach Analysis of Pepper Robots in Long-Term Care Facilities

Yu-Hsiang Chou[1], YI-TING LIN[2]
[1]Chinese Culture University, Taiwan, [2]Providence University, Taiwan

This study aims to explore the role and impact of Pepper robots in two day-care centers and four residential long-term care facilities using the capability approach. Data sources include surveys conducted with older adults and qualitative interviews with both older adults and care workers. The findings reveal that Pepper robots possess both generative and transformative dimensions. The generative aspect is reflected in their provision of entertainment, companionship, and exercise demonstrations, which enhance older adults' well-being and capabilities in physical health, emotional connection, interpersonal relationships, and leisure. The transformative aspect lies in Pepper's ability to augment the value of other inputs, such as serving as an interactive medium to facilitate communication among older adults and between them and care staff. However, Pepper's effectiveness is influenced by multilevel conversion factors, including individual technological literacy, staff acceptance, and organizational infrastructure like WiFi coverage. Through a capability lens, this study demonstrates that technology is not merely a neutral tool for achieving capabilities but a dynamic factor embedded in sociotechnical contexts, interacting with individuals and environments. By

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transforming and enhancing well-being capabilities and care service values, Pepper robots underscore the significant role and profound impact of technology in capability practice.

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A smart-clothes assisted home care for family caregivers of persons living with dementia

Yea-Ing Shyu[1], Ya-Li Sung[2], Huei-Ling Huang[2]
[1]Chang Gung University, Taiwan, [2]Chang Gung University of Science and Technology, Taiwan

Caring for older adults with dementia at home can place a significant burden on family caregivers, often leading to increased stress and depression. Interventions that incorporate smart clothing technology for monitoring the care recipient have the potential to reduce caregiver strain and enhance care quality. This study explores the impact of a homecare program supported by smart clothes technology on family caregivers of individuals with dementia in Taiwan.The program utilized a smart-clothes vest equipped with sensors that, along with additional home-based sensors, transmitted activity data to a nurse via a smartphone app. The nurse provided caregivers with real-time feedback and used the data to develop personalized care strategies. Participants in the intervention group (n = 30) had their care recipients wear the smart-clothes vest continuously for six months, while the control group (n = 30) received standard care. Results indicated that the smart clothes-assisted nursing program improved caregiving balance, enhanced preparedness, and positively affected caregivers' mental health over the six-month period. These outcomes suggest that wearable technology can be a valuable component in designing support interventions for family caregivers of individuals with dementia.

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Digitalisation and managerial technologies in Finnish home care: socio-technical articulation of care labour and the quality of care

Erika Takahashi[1]
[1]Chiba University, Japan

This paper explores the impact of digitalisation and managerial technologies on the reform of home care services in Finland, where public long-term care systems face significant pressures from workforce shortages and increasing social security expenditures. In response, Finnish municipalities have increasingly turned to a managerial technology called the enterprise resource planning (ERP) system to enhance the efficiency of home care provision by applying corporate practices to public services. This system includes the patient information platform, its mobile extensions, and the optimization program that streamlines scheduling for home care workers.

Drawing on ethnographic research conducted in four areas of a rural/suburban municipality in southwestern Finland, this study examines how managerial practices are implemented within the specific geographical, social, and organizational contexts of home care. Participative observations reveal how digital tools structure the care work and how care workers frequently deviate from pre-set plans to meet their clients' complex and fluid needs. These deviations highlight the inherent tension between managerial efficiency and the situated, relational nature of care in practice, shedding light on the resulting deterioration in labour conditions and the quality of care.

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By examining these transformations, this paper contributes to the broader discussion of how digitalisation and platformisation are reshaping the home care market at a regional level. This Finnish case offers critical insights into the intersections between care work, digital infrastructures, and labour rights. Ultimately, this paper explores the future of social justice and care workers' rights within the rapidly changing landscape of long-term care.

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Who cares? Contesting anticipations about the future of “healthy ageing” through Communicative AI

Sara Skardelly[1], **Leonie Winterpacht**[1], Juliane Jarke[1]
[1]University of Graz, Austria

How we feel, think and approach “societal problems” is strongly influenced by anticipations about technoscientific progress (Adams et al. 2009; Markham 2021). In the context of this panel, this is particularly relevant with respect to anticipations about new and emerging technologies for health and social care, such as communicative AI applications (ComAI) like social bots and voice assistants. These anticipations are not neutral but define what futures seem thinkable and desirable (Poli 2017). They are based on the “socio-technical imaginaries” that powerful actors such as policy makers or technology developers articulate (Jarke & Manchester 2025). This raises critical questions: What kinds of anticipations are articulated about the care responsibilities of health-related ComAI? How are societal imaginaries of care negotiated and contested through the development and implementation of ComAI? In our paper, we address these questions by focusing on health-related ComAI for older adults. We draw on text mining analysis, conducted as part of a larger project, to explore the anticipations of different stakeholders, including healthcare professionals, policymakers, and developers within policy documents and ageing reports in the UK, US, Germany and Austria. By bridging these empirical findings with critical reflections, as well as theoretical insights from critical studies of ageing and technology, this research contributes to debates on the sociotechnical futures of care, demonstrating how anticipations about health-related ComAI contribute to the ongoing reconfiguration of “ageing well”, “healthy ageing” and “good care”.

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Rethinking warm experts – challenges of informal digital support

Riitta Hänninen[1], Sakari Taipale[1]
[1]University Of Jyväskylä, Finland

This critical conceptual analysis explores the key challenges associated with the notion of warm experts, such as family members and friends, in providing informal digital support in later life. In the first part of this analysis, we examine the challenges arising from the individual characteristics of a warm expert as an intergenerational agent with varying levels of resources to provide digital support to older adults. Secondly, we address the issue of unequal access to digital support among older adults, which highlights the social aspects of the warm expert role. Finally, we discuss the societal significance of warm experts as primary providers of digital support. In conclusion, while the contribution of warm experts to digital support in later life is evident, from an individual perspective they may lack the necessary resources to meet the heterogeneous needs of older adults. From a societal perspective, the primary limitation of warm experts as providers of informal support is the inequitable distribution of the informal

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digital support they provide. Futhermore, we argue that warm experts should not be seen as the sole solution to the challenges of digital inclusion and digital inequalities associated with ageing. Rather, all forms of digital support in later life are needed to increase digital inclusion and avoid exclusion.

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OS3b Reconciling care, work, studies and well-being

Room: U3029
Time: 16:00-17:30
Chairs: Shao-fen Lee

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- 280 Allison Williams: Standards: An Innovative Solution for Creating Caregiver-friendly Workplaces that makes Employers State Actors in Care Provision as a Human Right
- 295 Thomas Geisen & Karl Krajic: New Social Rights for Employees in the Making? The Company's Role in Combining Employment and Caring for Older Relatives
- 268 Ke-Hsien Lai: The Debate Between Work and Care During the COVID-19 Pandemic: Working Mothers' New Challenge in Taiwan
- 266 Shao-fen Lee: The "Second Shift" of the Home Care Workers in Taiwan through the prism of Capability Approach

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Standards: An Innovative Solution for Creating Caregiver-friendly Workplaces that makes Employers State Actors in Care Provision as a Human Right

Allison Williams[1], Jeanne Bank[2], Bharati Sethi[3]
[1]McMaster University , Canada, [2]Jeanne Bank, Care Partner, [3]Trent University, Political Studies, Peterborough, ON, Canada

As the world's population ages, more unpaid care provision is required from family, friends and neighbours. The vast majority of unpaid carers are simultaneously employed, and most are female. Building carer-friendly workplace policies (CFWPs) are needed to help carer-employees/working carers to better balance their work and care responsibilities, help reduce carer distress, and prevent carers from exiting the workforce altogether. Voluntary standards are an innovation solution to assist employers in the creation and maintenance of CFWPs.

The "International Organization for Standardization (ISO) 25551:2021 Ageing societies – general requirements and guidelines for carer-inclusive organizations standard" used, as its seed document, the "Canadian Standards Association B701-17 Carer-inclusive and accommodating organizations standard", the latter which serves the 1 in 4 Canadians who are carer-employees. These voluntary standards provide a set of guidelines for employers to best support carer-employees, via a step-by-step approach to create CFWPs.

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These standards align with eight of the United Nations (UN) Sustainable Development Goals (SDGs) and the International Labour Organization's mandate. In addition, these standards were written as gender-responsive, with the international standard being recognized by the ISO and highlighted in a recent ISO guidance document.

This paper outlines the process of the development of these Canadian and international standards, while reviewing the alignment with the UN SDGs. It highlights the challenges of promotion, adoption, and implementation, while reflecting on how to best move these standards from voluntary to required and, in so doing, placing employers as state actors in the provision of unpaid care as a human right.

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New Social Rights for Employees in the Making? The Company's Role in Combining Employment and Caring for Older Relatives

Thomas Geisen[1], **Karl Krajic**[2]
[1]University Of Applied Sciences And Arts Northwestern Switzerland, Switzerland, [2]University of Vienna, Austria

Due to demographic change, aging workforces, and shortages of labour force, many employers are seeking to strengthen their retention activities. This includes activities to improve possibilities to combine employment and caring for older relatives. So far, there is little knowledge on the amount of awareness and the specific forms and impact of these changes in everyday work life. A comparative international study conducted company case studies in Switzerland and Austria, allowing to social practices that have been developed to combine employment and caring for older relatives (COMBECA project 2021-2025, funded by the Swiss National Research Foundation and the Austrian Science Fund FWF4840-G).
Workplace case studies (n=15) were conducted in Switzerland and Austria. In each organization open interviews (management=3, workers=4) were conducted and analysed according to a Grounded Theory framework (Strauss/Corbin). Additionally, an online questionnaire was offered to the employees.

The case studies show that support for combining employment and caring for older relatives is considered a complex issue not to be solved by general measures. Procedural practices are the dominant feature, based on the key-category "negotiating employment and care obligations" ori-ented at finding solutions with good connectivity to processes and structures of the companies. Solutions focus on adapting the time dimensions of employees' roles, but include also adapta-tions concerning the place of work, work content, involved persons and management responsibili-ties. Overall, there seems a strong need to raise awareness of companies of issues and solutions in combining employment and caring for older relatives as a new social right for employees.

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The Debate Between Work and Care During the COVID-19 Pandemic: Working Mothers' New Challenge in Taiwan

Ke-Hsien Lai[1], Shu-Yung Wang[2]
[1]PhD Student of Social Welfare, National Chung Cheng University, Taiwan, [2]Associate Professor of Social Welfare, National Chung Cheng University, Taiwan

The COVID-19 pandemic has been a global phenomenon since December 2019. Governments have been implementing prevention policies, and businesses have been adapting their working models to reduce the risk of person-to-person transmission. With childcare services and school resources forcibly halted due to the pandemic, the caregiving and educational needs of children are redirected back to the family.

Influenced by Taiwan's traditional gender norms of "male breadwinner/female homemaker," despite both genders participating in the labor market, mothers are still perceived as bearing more household chores and childcare responsibilities. This societal expectation forces them to revert to traditional gender roles during the pandemic, striving to fulfill the family's caregiving needs. Working mothers have to take on the responsibilities of being "caregivers" and a "breadwinner", they have to deal with the psychological stress that comes with these changes. The research takes Taiwan's pandemic context as a backdrop and investigates the working and caregiving situations of 13 dual-income families with children under 12 through in-depth interviews.

The research reveals the phenomenon of a "pink-collar recession" among working mothers in Taiwan during the pandemic. This not only exposes them to economic risks but also leads them to revert to traditional gender caregiving roles when unable to balance work and family. Working mothers contribute significantly more time to household chores and childcare during the pandemic than fathers, highlighting the exacerbation of caregiving inequality in Taiwan under the influence of the COVID-19 pandemic.

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The "Second Shift" of the Home Care Workers in Taiwan through the prism of Capability Approach

Shao-fen Lee[1]
[1]National Yang Ming Chiao Tung University, Taiwan

Taiwan has implemented the Long-Term Care 2.0 policy since 2017, driving the thriving development of the labor market for community home care service, which is highly gendered (90% female workers). While most Taiwanese people look forward to being able to break free from the heavy burden of caregiving and gain more freedom, home care workers have to expose themselves to risk in order to ensure the continuous provision of care. Drawing on interviews with 24 home care workers (women and men in northern, eastern, western, and southwestern Taiwan) conducted during 2022–2023 and 2024–2025, my study delves into understanding how these care workers coped with the work-care conflicts posed by the unique work nature of home care.

The study points out that despite the booming development of home care work (HCW), it was not necessarily a good job but rather a ‘‘sheltered job’’ for these workers, most of whom were

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precarious workers. The high flexibility offered by this occupation met their need to balance work and their own reproductive labor. However, the hourly wage system motivated them to extend working hours in exchange for more income to the extent of sacrificing their own time and the quality of their own unpaid care. This study will analyze, through the prism of the Capability Approach, how these care workers employed various strategies to take on their ‘‘Second Shift’’ (Hochschild). It aims also to explore the hidden inequalities within the social arrangements of home care.

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OS6 Policies of long-term care

Room: U3040
Time: 16:00-17:30
Chairs: Astrid Pennerstorfer

Presentations:

- 40 Viktoria Szenkurök: The 'Care Penalty' in the Portuguese Labour Market: Examining Pay Differentials in Long-Term Care
- 23 Varvara Lalioti: Delving into the Institutional Setting of Long-Term Care in Greece: Challenges for Quality Service Pathways and Rights
- 319 Julia Radlherr & Astrid Pennerstorfer: Entering Entangled Formal Long-term Care Systems: The Case of a Universal Care Allowance Program
- 176 Anna Elomäki & Hanne Marlene Dahl: Development of long-term care as an EU policy field: framings, boundaries and knowledge

Short presentations:

- 136 Maëlle Meigniez & Katja Haunreiter: Care Work in Swiss Social Policy: Exploring Autonomy through the Personal Assistance Allowance
- 369 Maria Cheshire-Allen: Welfare Mix in Practice: Social Enterprise Organisations, Unpaid Carer Rights, and Co-production in Wales

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The 'Care Penalty' in the Portuguese Labour Market: Examining Pay Differentials in Long-Term Care

Viktoria Szenkurök[1], Ricardo Rodrigues[2]
[1]Vienna University of Economics and Business, Austria, [2]Lisbon School of Economics and Management, Portugal

Focusing on long-term care (LTC) and sectoral disparities within caring sectors, we use a multilevel model based on linked employer-employee data covering Portugal's manufacturing and service sectors to analyse wages and earnings in and within female-dominated sectors. Exploring competing theories of gender-based devaluation, ageism and compensating wage differentials, our findings provide evidence for the existence of a financial devaluation of care work, with occupational penalties extending to sectoral penalties. The 'care penalty' yet only partially extends to male workers in the field, implying that a gender pay gap persists but

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remains significantly smaller. Notably, sectoral segregation between the highly gendered LTC and other health and social care sectors exists, with results demonstrating a remunerational premium for LTC. This premium, despite lower average pay, likely reflects financial recognition of the emotional demands associated with caring for older adults. Revealing these pay differentials provides valuable insights for researchers and policymakers aiming to improve working conditions, which is essential for meeting LTC workforce needs in aging societies.

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Delving into the Institutional Setting of Long-Term Care in Greece: Challenges for Quality Service Pathways and Rights

Varvara (Berry) Lalioti[1]
[1]National and Kapodistrian University of Athens, Greece

This paper examines the institutional framework of the long-term care (LTC) system in Greece, focusing on the challenges that hinder efforts to improve service quality and strengthen the rights of the LTC recipients and the relevant workforce. Drawing on findings from semi-structured interviews with members of the LTC workforce, policymakers and administrators, the paper highlights key barriers within the overall underdeveloped social care system in the Greek welfare state. Set against the backdrop of supranational influences—such as the 2017 European Pillar of Social Rights and the 2022 European Care Strategy—and the increasing pressures of population ageing at both macro- and micro-levels, the paper addresses an under-researched yet critical topic. It sheds light on the fragmented institutional landscape of Greek LTC, characterized by a 'mixed' model, which combines a strong reliance on informal family caregiving, with a growing, albeit uneven, trend towards the diversification of formal LTC providers. The research identifies significant deficiencies in quality-related aspects of Greek LTC, including the absence of standardized quality benchmarks, a dedicated quality assurance body, and even a comprehensive definition of 'quality' that incorporates crucial dimensions such as safety, person-centredness, needs-based care, effectiveness and efficiency. The paper argues that these shortcomings undermine the rights of both LTC users and members of the LTC workforce, informal caregivers included, whilst creating significant barriers to equitable and effective service pathways for older adults. The concluding discussion includes recommendations for addressing these systemic gaps to promote a more inclusive and sustainable LTC framework in Greece.

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Entering Formal Long-term Care Systems: The Case of a Universal Care Allowance Program

August Österle[1], **Julia Radlherr**[1], **Astrid Pennerstorfer**[1]
[1]WU Vienna University of Economics and Business, Austria

The long-term care allowance in Austria represents a key pillar of the national long-term care system. For many in need of long-term care, the allowance represents the first contact with the formal care system. Although it is a universal and well-established benefit that is regulated on a federal level, in a recent study, we identified regional inequalities in the take-up of the long-term care allowance (Pennerstorfer & Österle, 2023), which exist independently of differences in the age structure or the health status of the population. The variation in take up might thus be

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attributable to differences in (not) applying for the benefit and discrepancies in the process of granting the benefit.
Against this background, this paper explores the pathways of potential recipients into the system of care allowances, from considering (or not considering) an application, to the processing of the application and the final benefit decision. To do so, we first present regional differences in the (non-)take up of the benefit, outline the associated application procedure in detail and map relevant actors involved. Expert interviews are then used to study the legal and institutional framework as well as the interplay of actors that can both help and hinder application processes and impact the behavior of potential recipients (or informal carers).
The study adds to existing knowledge on inequalities in long-term care by providing quantitative and qualitative evidence on the take-up of cash benefits and argues that institutional complexities and barriers might reinforce existing socio-economic inequalities in accessing individual social rights.

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Long-term care as an EU policy field: Framings, boundaries and knowledge

Anna Elomäki[1], **Hanne Marlene Dahl**[2], Mary Daly[3]
[1]Tampere University, Finland, [2]Roskilde University, Denmark , [3]University of Oxford, UK

Long-term care (LTC) has become a visible topic on the European Union’s agenda, despite the EU’s limited competences in this field. Most recently, the European Care Strategy adopted in 2022 emphasised the need to improve accessible, affordable and high-quality LTC. Scholars too have begun to pay attention to the EU’s LTC policies and discourses (Caracciola di Torella and Masselot 2024; Dahl and Litvina 2023; Daly 2023; Zacharenko 2023). This research has pointed out the contradictory and competing problem representations and inadequate and soft policy responses but also noted the holistic approach of the Care Strategy that connects childcare and long-term care and the needs of care recipients and carers.

This paper increases understanding of long-term care as an EU policy field through tracing its emergence and development. The paper asks: How has the EU’s understanding of long-term care as a policy field and policy problem developed over time? The paper analyses rationales, actors, struggles and modes of knowledge production behind the EU’s growing interest in how member states organise care for older people. We pay particular attention to the problems and fields with which LTC has been coupled or decoupled and how the shifting boundaries between policy fields have affected the EU position on LTC policy. The paper utilises discourse tracing (LeGreco and Tracy 2009) and a genealogical approach focused on how power operates through the construction of particular knowledges (Crowley 2009) and draws on extensive document data from 1980 until 2024.

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Care Work in Swiss Social Policy: Exploring Autonomy through the Personal Assistance Allowance

Maëlle Meigniez[1], **Katja Haunreiter**[1]
[1]University Of Applied Sciences Western Switzerland - Faculty of Social Work, Switzerland

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This contribution explores the complex relationship between autonomy and long-term care (LTC) in Swiss social policy through the lens of the Personal Assistance Allowance. Introduced in 2012 under the Federal Law on Invalidity Insurance, the Personal Assistance Allowance aims to promote independent living for disabled persons requiring daily assistance. By contracting personal care assistants through a formal employment relationship, the Personal Assistance Allowance reflects a policy shift towards individual empowerment and self-determination, echoing broader European trends in LTC policy reforms. However, the model introduces significant tensions: while emphasizing autonomy, it imposes administrative and legal burdens on beneficiaries, who must assume the role of employers. This contribution, based on socio-legal research, including legal analysis and ethnographic observations and interviews in the Canton of Vaud, examines how the formalization of care work affects both care recipients and their support networks. Specifically, we explore the paradox where autonomy is encouraged through employment relationships, yet caregiving by close relatives remains excluded from financial support. This exclusion contrasts with other European cash-for-care models. We argue that the Swiss approach, emphasizing "defamilialization by the market," not only redefines the care relationship but also raises critical questions about the boundaries between professional and informal care. This analysis contributes to the broader debate on how LTC policies frame autonomy, care responsibilities, and the recognition of care work in modern welfare states.

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Welfare Mix in Practice: Social Enterprise Organisations, Unpaid Carer Rights, and Co-production in Wales

Maria Cheshire-Allen[1]
[1]Swansea University, United Kingdom

The critical role of civil society organisations in social care is widely acknowledged, with these organisations often assumed to be better placed than statutory or private providers to deliver co-produced care and support. This paper presents findings from a mixed-methods study investigating the collaborative arrangements between social enterprise organisations (SEOs), a specific type of civil society organisation, and statutory commissioning bodies. The study aims to identify factors that enhance unpaid carer involvement in support services. Focusing on Wales as a case study, where care policy reform is deeply rooted in co-production and collaboration, this study draws on 13 in-depth interviews with national and local social enterprise leaders, statutory commissioners, and providers to explore how Wales's policy landscape shapes co-produced carer support services.

Findings highlight that complex commissioning processes and varying organisational capacities create regional disparities in the effectiveness of SEOs in facilitating co-production with carers. While some SEOs successfully integrate carers' lived experiences into service design, evidence for widespread, effective co-production remains limited. Additionally, regional inflexions lead to ambiguous definitions of SEOs, compounded by insufficient impact measurement frameworks, making it difficult to assess how co-productive approaches improve carers' rights and wellbeing outcomes.

This paper contributes to debates on social enterprises' role in realising social care rights and underscores the importance of place-based policy responses. The findings have implications for policy development in devolved administrations and commissioning practices that strengthen unpaid carer voice.

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Wednesday 25 June: Parallel sessions 2

Meet the authors session 2

Room: Fuksi
Time: 16:00-17:30
Chair: Lea Graff

- Andries Baart & Guus Timmerman: Relational Caring and Presence Theory in Health Care and Social Work - A Care-Ethical Perspective, Policy Press, 2024.
- Robinson, Sally & Fisher, Karen (eds.) Research Handbook on Disability Policy, Edward Elgar, 2023.
- Sung, Sirin (ed.) Gender, Family and Policy: International Perspectives, Edward Elgar, 2025.
- Teppo Kröger, Nicola Brimblecombe, Ricardo Rodrigues & Kirstein Rummery (eds.) Care Poverty and Unmet Needs: Inequalities in Theory and Practice, Policy Press, 2025.

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Thursday 26 June: Parallel sessions 3

TP26b Transforming care work: changing working conditions, actors, approaches and outcomes

Room: Small Hall
Time: 8:45-10:15
Chairs: Costanzo Ranci, Hildegard Theobald

Presentations:

- 323 Jiby Mathew Puthenparambil: Workforce Conditions in Finnish Long-Term Care: Analyzing the Impact of the 2023 SOTE Reform
- 453 Annie Dussuet: Autonomy vs. independence for home care workers: what transformations in employment and work organization models
- 378 Michaela Evans-Borchers & Denise Becka: 'Fair Wage Clauses' in Long-Term Care: Prospects and limits of a new governance between collective bargaining policy and welfare state
- 310 Nobu Ishiguro: A Workforce Divided: The Polarization of Full-Time and Registered Home Care Workers in Japan's Marketized Long-Term Care

Short presentations:

- 119 Kelly Hall: The Social Care Workforce Crisis: Could Social Enterprise offer a Solution?

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Workforce Conditions in Finnish Long-Term Care: Analyzing the Impact of the 2023 SOTE Reform

Jiby Mathew Puthenparambil[1]
[1]University of Jyväskylä, Finland

Like many Western societies, Finland is also experiencing an ageing population. Workers in the long-term care sector have been struggling with many existing and emerging challenges, including working conditions, staffing shortages, and organisational issues.

In this study, I examine how the 2023 social and healthcare reform (SOTE) affected workers, analyzing the significant changes before and after its implementation. The SOTE reform transformed Finland's health and social care system by centralizing care services, transferring responsibility from 311 municipalities to 21 newly created wellbeing service counties. This

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restructuring aimed to enhance service efficiency and ensure more equitable access to care across the country.

The impact of the SOTE reform's centralization and organizational changes on working conditions remains unclear, with the potential for both positive and negative effects. Therefore, this study investigates the working conditions faced by Finnish workers who care for older people, examining factors such as workload, physical demands, supervisory support, and workplace autonomy. Following Vellani et al.'s (2022) framework, the analysis covers four distinct categories of LTC workers: (1) personal and support care workers, (2) nursing professionals, (3) rehabilitation and recreational care providers, and (4) related healthcare professionals.

This study analyzes panel data collected through online surveys (using the 1ka platform) from various types of workers caring for older adults in two waves, 2019 and 2024. The findings will reveal how workforce work environments and conditions have evolved after the SOTE reform.

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Autonomy vs. independence for home care workers: what transformations in employment and work organization models

Annie Dussuet[1], Nicole Teke, Lorena Poblete
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Demographic ageing is causing a growing demand for home care services in France and elsewhere in Europe. However, all national and international research converges to highlight the poor quality of jobs in this sector. Beyond the very low wages, the working conditions appear to be unsustainable, with significant repercussions on the health of workers. Field surveys show a risk of isolation for workers who most often work alone in private homes, but also an intensification of work through the division and timing of interventions which leads to heteronomy and loss of work meaning.

However, since the mid-2000s in France, public policies have been challenging the employment model of home care providers by supporting other models, promising freedom and autonomy, first through the promotion of the Universal Employment Service Voucher (CESU), then more recently through the encouragement of the creation of digital platforms offering home care. These models can attract some employees looking for the autonomy in work that they have been deprived of by the industrialization of home care organizations, at the cost of increasing their isolation. Furthermore, the experimentation of “autonomous teams” by some associative home care providers can also appear as a response to this demand for autonomy and meaning in work.

We seek to analyze the effects of these models of employment and work organization using the results of two qualitative surveys, conducted between 2020 and 2025, among workers and managers of both associative home care providers experimenting with autonomous teams, and of digital home care platforms.

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‘Fair Wage Clauses’ in Long-Term Care: Prospects and limits of a new governance between collective bargaining policy and welfare state

Michaela Evans-Borchers[1], Julia Lenzen[1], **Denise Becka**[1]
[1]Institut Arbeit und Technik, Westfälische Hochschule Gelsenkirchen Bocholt Recklinghausen, Germany

Labour market institutions are particularly weak in female-dominated sectors (ILO 2023). Acute shortages of skilled workers in long-term care and persistent wage disparities have significantly increased the pressure on politicians to improve wages and working conditions in Germany. In 2018 the Concerted Action on Care (Konzertierte Aktion Pflege, KAP) was initiated. The aim was to implement measures to improve pay and working conditions in long-term care. Following the failure of a generally binding collective agreement for long-term care in Germany (2021), a ‘Fair Wage Clauses’ law was implemented (2022). This regulation marks a new governance between collective bargaining policy and the welfare state (Evans 2023). The authorisation of care facilities to provide care is now directly linked to the payment of employees in nursing and care. Care facilities now have three options: They can conclude a collective agreement, apply a collective agreement or pay their employees according to the standard regional wage level. The ‘Fair Wage Clauses’ as a case study shows how the state can actively intervene to improve pay conditions in addition to minimum wages. The intended and unintended implications of the ‘Fair Wage Clauses’ on the remuneration and working conditions of employees in long-term care will be discussed (Lenzen & Evans-Borchers 2024). With regard to the care profession's attractiveness, we additionally focus on results of the nationwide survey “I would care again if…” (Auffenberg et al. 2022) to analyse how legal regulations correspond with preferences of nursing and care staff and which aspects were overlooked.

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A Workforce Divided: The Polarization of Full-Time and Registered Home Care Workers in Japan’s Marketized Long-Term Care

Nobu Ishiguro[1], Yayoi Saito[1], Momoko Sato[1], Angela-Miku Cherry[2], Rei Kubota[1]
[1]Osaka University, Japan, [2]Nihon Fukushi University, Japan

As Japan faces a rapidly aging population, the demand for home-based long-term care has grown. However, its delivery remains structurally fragile. This study investigates the polarization between full-time and registered (part-time) home care workers under Japan’s marketized long-term care system. Drawing on the institutional logic of New Public Management (NPM) and the gendered organization of care work, it analyzes how institutional structures, labor segmentation, and workforce shortages interact to produce unequal burdens. Quantitative data from the 2022 NORDCARE Japan survey are complemented by qualitative interviews with 15 home care workers conducted in January 2025. Findings reveal that full-time staff are tasked with disproportionate administrative duties, coordination roles, and emotional labor, including supporting part-time colleagues and maintaining service continuity.

Registered workers, paid per visit, face financial precarity—cancelled visits mean lost income, and travel and documentation time remain unpaid. Their low wages, instability, and limited contact with colleagues often lead to isolation and uncertainty in care delivery.

This study highlights how the polarized labor structure produces distinct forms of burden: economic precarity for part-time workers and psychological and emotional strain for full-time

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workers. These contradictions underscore the limits of marketized home care and call for urgent policy reforms to create a more sustainable workforce and responsive care service.

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The Social Care Workforce Crisis: Could Social Enterprise offer a Solution?

Kelly Hall[1], Janelle Kerlin[2], Meng Ye[2]
[1]University Of Birmingham, United Kingdom, [2]Georgia State University, USA

In England, the social care sector faces major workforce challenges. Poor pay and working conditions can lead to staff shortages and poor-quality care. Most adult services are delivered by for-profit organisations, leading to concerns of profit being prioritised over quality of care and working conditions. Alternatively, non-profit charities that might prioritise quality and social goals can lack financial resilience, also creating insecurity for workers.

There is, however, another organisational model that combines business and social goals, the social enterprise. There are an estimated 5000 social enterprises operating in the English social care sector, but little is known about them, especially in relation to the workforce; a gap this paper seeks to fill. We explore and compare the characteristics, conditions and experiences of the care workforce in social enterprises and other organisational models.

We draw on Skills for Care data to quantitatively compare staffing outcomes across for-profit, non-profit, government and Community Interest Company social enterprises. We also compare staffing outcomes against quality of care across different organisational models using Care Quality Commission (CQC) data to understand how variance in workforce metrics plays a mediating role in explaining any differences in quality. Our preliminary quantitative analysis suggests that social enterprises perform better than most other organisational models in relation to staffing level and turnover, with further analysis to be competed in the next two months on a wider set of workforce characteristics, conditions and experiences.

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Thursday 26 June: Parallel sessions 3

TP18b: Inequalities of care

Room: F3003
Time: 8:45-10:15
Chairs: Teppo Kröger, Nicola Brimblecombe, Lina Van Aerschot

Presentations:

- 211 Barbara Da Roit & Marta Pancheva: Gender and Regional Inequalities in Transitions to Informal Caregiving: Evidence from ITA.LI
- 19 Tania Burchardt: Re-framing long-term care policy: from services to social determinants
- 27 Seonwoo Yoon: Care Needs Interpretation on the Ground: Why Older People in Poverty and Elderly Females are More Likely to be Excluded
- 112 Shu-Man Pan: Navigating Multiple Layers of Exclusion: The Experience of PLWHAs and LGBTQ+ Individuals Facing Intimate Partner Violence in Social Care Systems

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Gender and Regional Inequalities in Transitions to Informal Caregiving: Evidence from ITA.LI

Barbara Da Roit[1], **Marta Pancheva**[2]
[1]Ca' Foscari University of Venice, Venezia, Italy, [2]Sophia University Institute, Figline e Incisa Valdarno, Italy

Informal caregiving remains a cornerstone of Italy's welfare model. However, the determinants of transitioning into care-giving roles and the associated inequalities remain underexplored. This study investigates the socio-demographic, regional, and familial factors influencing transitions into caregiving, focusing on gender inequalities and regional disparities.
Using data from the first wave of ITA.LI – Italian Lives (N=8,777), a nationally representative panel study collected between June 2019 and January 2021, we employ discrete-time event history analysis to examine the likelihood of transitioning into caregiving episodes. A total of 896 respondents (10.2%) reported at least one caregiving episode, and 166 of them experienced multiple episodes, resulting in 1,080 caregiving transitions analysed. Covariates include age, gender, employment status, education, union status, region of residence, number of cohabiting children, and contextual indicators of long-term care provision. The analysis is conducted separately for men and women, and accounts for unobserved heterogeneity at the individual, household, and regional levels.
The findings underscore the interplay of social, demographic, and structural factors shaping inequalities in informal caregiving in Italy. Women disproportionately bear the burden of caregiving, particularly during midlife, reflecting entrenched gendered responsibilities. Higher

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education is associated with a lower likelihood of caregiving entry among women but not among men, indicating gendered SES effects. Moreover, men in union are less likely to become caregivers, suggesting a gendered delegation of care responsibilities within couples. Regional disparities highlight the unequal distribution of caregiving across the country, even after accounting for differences in formal care provision.

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Re-framing long-term care policy: from services to social determinants

Tania Burchardt[1]
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The organisation and financing of services dominates long-term care policy and research. This article argues for reorientation towards the social determinants of long-term care and the inequalities they generate. Building on Dahlgren and Whitehead’s influential equivalent for health, the article offers a framework for understanding how inequalities in long-term care need, access and experience are shaped by social networks, living and working conditions, services and policies, social norms, and political, economic and environmental conditions. International evidence on inequalities in need, access and experience is reviewed and new analysis is presented for England, based on analysis of the Health Survey for England and the Adult Social Care Survey. Socio-economic inequalities are associated with steep gradients in need. Combined with unequal access to formal services, this results in more unmet need among disadvantaged people and a greater weight of responsibility on their family and friends. The final section explores the implications of a social determinants’ perspective for long-term care: addressing ‘upstream’ drivers of need (including social protection, housing and neighbourhood regeneration and child and adolescent well-being); inclusion and empowerment agendas; and ensuring that services compensate for, rather than re-enforce, inequalities.

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The Politics of Care Need Interpretation in the City: Stratified and Gendered Care Needs Across Differential Neighbourhoods in Seoul

Seonwoo Yoon[1]
[1]University of Oxford, Oxford, United Kingdom

Welfare professionals encounter the multidimensional care needs of older people that are revealed at the local level; however, the public resources they can provide address only some of these needs due to the conditionality of benefits. Then why are some care needs considered ‘public’, resulting in preferential allocation of state resources, while others are not? In advancing the notion that care needs are culturally and politically constructed, this paper draws on Nancy Fraser’s concept of ‘politics of need interpretation’ and investigates discourses around care needs across different neighbourhoods where diverse care needs and the conditionality of formal care provisions coexist.

This paper focuses on two policies in Seoul, the capital city of South Korea: The Community Support Program and Seoul’s Outreach Community Project. Both emphasised the role of welfare professionals in addressing the care needs of residents at the local level, as well as facilitating the creation of village communities by residents themselves based on their needs. In analysing how care needs on the ground and public constraints intersect across

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neighbourhoods, the paper employs a cross-case qualitative causal inference by utilising a novel dataset comprising twenty-seven public documents and fifty-one interviews with welfare professionals.
The study shows that discourses around ‘chronic dependency’ emerged during the process when one-sided supports from welfare professionals are regarded as a last resort, and the way they are addressed across neighbourhoods leads to differential interpretation of care needs. Moreover, discourses around ‘family dissolution’ are highly gendered, resulting in the overrepresentation of older males’ care needs.

Keywords: care needs, politics of need interpretation, neighbourhood dimension of care, welfare professionals, gender

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Navigating Multiple Layers of Exclusion: The Experiences of People Living with HIV/AIDS in the Social Care System

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This study applies the theory of intersectionality to analyze how Taiwan’s long-term care system marginalizes people living with HIV/AIDS (PLWHA). Drawing on interviews with 19 PLWHAs and focus groups with 34 service providers (2018–2022), the research reveals that care systems, designed from a supposedly universal perspective, systematically overlook the intersecting identities and compounded vulnerabilities of PLWHAs. These include HIV status, socioeconomic class, gender, and sexual orientation, which together intensify barriers to accessing equitable medical and long-term care.

The concept of “dual aging” further highlights the psychosocial and physical challenges PLWHAs face as they grow older in a stigmatizing society. Structural stigma is found to be embedded in institutional practices, including discriminatory care policies, lack of provider training, and ethical dilemmas surrounding privacy and disclosure. These factors contribute to the exclusion of PLWHAs from dignified and timely healthcare services.

Despite these challenges, community-based organizations such as the Harmony Home Association offer alternative care models grounded in empowerment and human dignity. These grassroots strategies embody "subjugated knowledge" and challenge dominant paradigms by responding more effectively to the needs of marginalized groups.

The study concludes with policy recommendations advocating for intersectional and rights-based reforms: mandatory anti-stigma training for care staff, revised care protocols that balance patient rights and staff safety, and formal partnerships with NGOs. Without systemic change, long-term care in Taiwan will continue to reproduce health inequities for PLWHAs. This research underscores the urgent need to reform care systems to ensure inclusivity, cultural competence, and social justice in an aging society.

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Thursday 26 June: Parallel sessions 3

TP22 Changing policies and cultures of motherhood and fatherhood

Room: F3017
Time: 8:45-10:15
Chairs: Birgit Pfau-Effinger

Presentations:

- 122 Merita Mesiäislehto: The complex interplay between changing gender role attitudes and family policies: case Finland
- 250 Adi Sadeh: Changing the cultural ideal of fatherhood? How High-Tech Companies are redefining fatherhood for Israeli men
- 333 Sandra Obiol-Francés: School, Time and Parenting: How does the Compacted School Schedule Impact on the Caring Arrangements?
- 364 Johanna Närvi: Finnish parents' time use in childcare – who cares, how much and in which tasks is the time spent?

Short presentations:

- 326 Anis Farid: Renegotiating Gender Roles: Examining shifts in care redistribution amongst Malaysian COVID-19 Essential Care Workers
- 154 Sirin Sung: Changing Fatherhood?: Gender Norms, Culture and Policies in South Korea

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The complex interplay between changing gender role attitudes and family policies: case Finland

Merita Mesiäislehto[1], Johanna Lammi-Taskula[1], Johanna Närvi[1]
[1]Finnish Institute for Health and Welfare, Finland

This paper explores the evolving attitudes towards gender roles and different earner-carer models in Finland since the 2000s, focusing on the interplay between cultural norms, societal attitudes, and public care policies. Alongside other Nordic countries, Finland is often viewed as a forerunner in gender equality, with notable increases in paternal involvement in childcare; however, structural issues such as labour market segregation, wage disparities, and an unequal distribution of care responsibilities persist. Finland's comprehensive parental leave system, including several reforms throughout the 2000s and most recently in 2022 to extend leave entitlements for fathers and offer greater flexibility, exemplifies how policies adapt to promote gender equality and support diverse family structures.

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Drawing on data from the International Social Survey Programme (ISSP) for 2002, 2012, and 2022, we empirically investigate shifts in attitudes towards gender roles and different earner-carer models and examine through quantitative multivariate analysis associations with sociodemographic factors, including gender, age, and education. Additionally, we review the parental leave schemes in 2000-2022 and evaluate how the developments in parental leave policies correspond with shifting social attitudes. Against the backdrop of Finland's historically low birth rate and evolving perspectives on family and life goals among younger generations, this analysis contributes to current debates regarding the role of care policy and societal norms in shaping gendered expectations and family life. Offering a timely empirical case, this paper illuminates the complex interdependence between cultural gender norms and policy in challenging or reinforcing traditional family ideals.

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Changing the cultural ideal of fatherhood? How High-Tech Companies are redefining fatherhood for Israeli men

Adi Sadeh, **Anat Herbst-Debby**
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In 2016, Israel initially implemented by law, a week of paternity leave reserved exclusively for fathers, consisting of two sick days and three annual vacation days. Couples are permitted to share the mandatory maternity leave, which totals 15 paid weeks, with the first six weeks reserved exclusively for mothers. Due to the short duration of the leave, the uptake rates remain relatively low.

Simultaneously, the past decade has witnessed a rise in the number of high-tech companies implementing company-provided paternity leave, which are diverse in length and terms of access, while some have also been extended throughout the years. Following COVID-19, remote and hybrid work practices have become widespread in these companies. These two factors—paternity leave and hybrid work practices—contributed to a significant shift in the culture of fatherhood within the sector, enhancing the visibility of fatherhood in the workplace and fostering a newfound sense of agency.

In-depth interviews with 20 men working in the High-Tech industry highlight how changes in workplace practices following COVID-19, particularly the adoption of hybrid work, enable employees to reposition themselves in relation to childcare, with workplace culture and supervisor support playing a crucial role in facilitating this shift. A notable example involves blocking early afternoon hours on calendars to prevent meetings from being scheduled, some even referring to these hours as "children's time." Moreover, they view their ability to take an active role in childcare responsibilities as both a workplace privilege and a nonnegotiable commitment, considering it an integral aspect of their working conditions.

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School, Time and Parenting: How does the School Compacted Schedule Impact Caring Arrangements?

Sandra Obiol-Francés[1], Elisabet Almeda-Samaranch[2], Catalina Arteaga Aguirre[3], M. Elena Casquel del Campo[1], Daniel Gabaldón-Estevan[1]
[1]University of Valencia, Spain, [2]University of Barcelona, Spain, [3]University of Chile, Chile

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In Spain, the school schedule has been concentrated in the morning since the 1990s. Today, more than 80% of the public schools and 23% in the case of private schools in Spain follow this type of schedule. One of the main reasons for this change has been the idea that freeing up school time allows children to spend more time with their families and engage in extracurricular activities. In fact, this is an educational policy that directly affects families. Consequently, the aim of this study is to present the first results of our analysis on the impact of the compacted school day on family and care arrangements, and by extension, on women's time availability. Through discussion groups with mothers and teachers, as well as in-depth interviews with mothers, we have observed the different family strategies for managing care when the school schedule is compacted. These arrangements are primarily carried out by women. At the same time, we have identified the widespread notion in our sample of good parenting as an endless investment of time, financial and emotional resources. This aligns with what Hays (1998) termed the ideology of the intensive mothering. In this sense, the school itself has played a key role in reinforcing this ideology, legitimising the compacted school schedule.

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Finnish parents' time use in childcare – who cares, how much and in which tasks is the time spent?

Johanna Närvi[1], Anneli Miettinen[2], Johanna Lammi-Taskula[1]
[1]Finnish Institute For Health And Welfare, Finland, [2]Social Insurance Institution of Finland, Finland

This study focuses on Finnish parents' time use in childcare, and gender and socioeconomic differences in different childcare activities. Both mothers' and fathers' time devoted to childcare has increased in Western countries, related to an ideology of intensive parenting and the idea of caring fatherhood (Miller, 2017; Dermott, 2008; Johansson & Klinth, 2008; Sullivan et al., 2014). The Nordic countries have been forerunners in policies promoting fathers' care and gender equality in work and family life. Yet, gender inequalities in time use persist (Grunow & Evertsson, 2016) and parents also often adopt gender specific tasks in childcare (Attila et al., 2019). Research also shows that highly educated parents devote more time to childcare, especially to developmental activities (Monna & Gauthier, 2008; Sullivan et al., 2014; Schneider et al., 2018).

We use the Finnish Time Use Surveys 2009–2010 and 2020–2021 to study parents' (N=1,704) childcare time from a gender perspective. We ask how much time parents use in childcare as total, and in different tasks of childcare (basic care, developmental activities, transportation). Furthermore, we use regression analysis to investigate socioeconomic factors related to parents' time use. The preliminary results show both gender and socioeconomic differences – although not always consistent – in the total childcare time as well as in different tasks. Based on the results, we discuss how different types of childcare time and the differences among parents reflect the aims of family policies and today's (intensive) parenthood in Finland.

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Renegotiating Gender Roles: Examining shifts in care redistribution amongst Malaysian COVID-19 Essential Care Workers

Anis Farid[1], Shanthi Thambiah[2], Denise Spitzer[3], Sharifah Shazana Agha[1]
[1]Women's Aid Organisation (WAO), Malaysia, [2]University of Malaya, Malaysia, [3]University of Alberta, Malaysia

Traditional gender roles still permeate Malaysian society amid lagging family-friendly policies. Childcare is insufficiently provided by the state, and women are also dropping out of the labour force to care for the elderly.

This paper examines how Malaysian care workers from healthcare and social care negotiate and manage unpaid care work, including parenthood, during the COVID-19 pandemic and beyond. Formal care work in Malaysia is highly feminised, with women comprising approximately 80% of various health, social, and domestic care sectors. Using an intersectional feminist approach, we analyse the experiences of Malaysian essential care workers, with data from a quantitative survey with over 600 respondents, coupled with insights from 19 focus group discussions with women employed across a range of care work settings, and consider which factors are most relevant to creating equitable shifts in their unpaid care and domestic responsibilities.

Preliminary findings reveal that, at times of crisis, a shift in gender roles can occur when women are positioned as essential care workers, becoming primary income earners and thereby initiating a more equitable redistribution of care responsibilities. This proposition is supported by data from the labour force survey, indicating men undertook more care and domestic responsibilities during the pandemic. These changes can occur despite strong gender role norms, with over a quarter of respondents viewing household duties as a woman's responsibility. Reconciling these tensions necessitates re-examining the asynchronicity between care realities and support provided by the state, where policy lags behind the needs of Malaysian families.

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Changing Fatherhood?: Gender Norms, Culture and Policies in South Korea

Sirin Sung[1]
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Abstract

Interest in the concept of “good fatherhood” has been growing in Korea since the 1990s. The norms of good fatherhood have also been shifting, in line with ongoing socio-economic, demographic, cultural and policy changes. For example, women’s participation in the labour market has increased, attitudes towards gender roles have become more egalitarian, and policies have been introduced to support gender equality, including the promotion of father’s involvement in childcare (e.g. daddy leave). Despite these notable improvements, however, mothers remain more likely to make use of parental leave, and although it has been rising gradually, uptake by Korean fathers remains low. This paper explores the parenting and childcare experiences of both fathers and mothers, with particular focus on how they share/negotiate childcare responsibilities as couples, and how they perceive the norms of good fatherhood. It also critically evaluates work-family balance policies such as maternity/paternity/parental leave and flexible working arrangements from a gender perspective. Drawing on findings from qualitative semi-structured interviews with 30 dual-earner couples (60 individuals) in Seoul, Korea, in 2023, it suggests that while fathers’ involvement in childcare has improved, reflecting the recent changes in Korea, the traditional, gendered expectations of childcare as mothers’ responsibility persist, even when both parents are working. It concludes that a cultural shift is as necessary as policy development to encourage fathers’ involvement in childcare and to promote equal sharing of paid and unpaid work between men and women.

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TP1b: Social care and the changing service pathways of older adults

Room: F3020
Time: 8:45-10:15
Chairs: Heli Valokivi, Paula Vasara, Andrea Lorenz-Wende

Presentations:

- 188 Sara Wittzell: Making sense of a denied application for residential eldercare: experiences of older people and family carers
- 457 Petra Ulmanen: Further development of a conceptual model of family members' managerial caregiving: three types of processes differing in tasks and experiences
- 156 Karen Christensen & Oddvar Førland: Representations of early intervention in long-term care pathways in the Nordics
- 75 Paula Vasara & Tiina Hautamäki: Discretion as Resistance – Case Management with Older Adults in New Wellbeing Services Counties in Finland

Short presentations:

- 442 Tianqin Chen: The impact of public spaces in elderly living communities on daily activities and social interactions

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Making sense of a denied application for residential eldercare: experiences of older people and family carers

Sara Wittzell[1]
[1]Department Of Social Work, Stockholm University , Sweden

With policy emphasis on 'ageing in place' and reduced provision of residential care in Sweden, older people, who previously would have been granted residential care, now increasingly have their application denied. This study aims to add knowledge about the consequences of this development by examining older people's and family carer's experiences of having an application for residential care denied, particularly focusing on how they make sense of the decision to deny. Semi-structured interviews were carried out with people aged 65+ and family carers who experienced a denied application for residential care in the City of Stockholm, Sweden, during 2023 or 2024. Interviews were carried out either separately or together, resulting in 17 interviews including 12 older people aged 72-93 and 10 family carers aged 55-88. The material was analysed from a sensemaking perspective, which highlights the contextually dependent understandings older people and family carers rely on to make sense of the decision to deny, and how these understandings open up for different plausible actions following the decision. Preliminary results show three main paths of sensemaking, all questioning the legitimacy of the decision, but leading to different courses of action: appeal, resign or strategise. How different understandings lead to each perceived possible action is further developed in the paper and discussed in relation to the institutional context of Swedish eldercare.

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Further development of a conceptual model of family members' managerial caregiving: four processes differing in tasks and experiences

Petra Ulmanen[1]
[1]Stockholm University, Department of Social Work, Stockholm, Sweden

Due to strong marketisation and de-institutionalisation trends in Sweden, long-term care services have become less accessible and more fragmented. This development heightens the need for family members of older individuals with extensive care needs to provide managerial care. This implies functioning as informal case managers to ease access and delivery of services to ensure that they meet the older person's needs.

In previous work, the author developed a conceptual model of family members' managerial caregiving as a process comprising a sequence of four tasks, often repeated due to changes in needs or service delivery: 1. Identifying service needs, entitlements, and availability; 2. Gaining access to and mobilising services; 3. Monitoring and evaluating services; and 4. Making complaints and coordinating services. Thus, managerial caregiving entails navigation, advocacy, motivation, monitoring, and coordination work.

Based on a longitudinal interview study with 32 family members of home-dwelling older persons with extensive care needs in Stockholm County, this paper explores differences among family members in the managerial care tasks performed and the extent and experiences of managerial caregiving. Using the previously developed conceptual model, the analysis aims to identify various sub-processes of managerial caregiving and further develop the model.

Results show that family members' managerial caregiving differed regarding its extent, the tasks they performed, and how they experienced it. In this way, they experienced four different managerial caregiving processes within the overarching model: The smooth process, The stalled process, and two versions of The reiterated process.

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Representations of early intervention in long-term care pathways in the Nordics

Karen Christensen[1], **Oddvar Førland**[2], Annette Fagertun[2], Ingrid Ramsøy[2], Katarina Andersson[3], Lina Van Aershot[4]
[1]Roskilde University, Denmark, [2]Western Norway University of Applied Sciences, Norway, [3]Umeå University, Sweden, [4]University of Jyväskylä, Finland

Currently, there is an increasing pressure on long-term care (LTC) services due to the ageing population combined with a shrinking care workforce. In the Nordic countries, this has led to rising attention to timely assessments of needs, access to LTC and the legal base of such rights. Driving this development is the scrutiny of the first entrance to LTC service pathways, related to ideas of early intervention. Governments try in different ways to turn the focus of LTC politics from 'repairing', towards 'preparing' individuals and families for ageing and frailty, emphasising the potential for self-care and/or help from informal carers. Potentiality, in this regard, appears as a highly political and moral concept.

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While the Nordic welfare states have many similarities, there are important differences regarding models of early intervention and the legislation regulating rights to public care services. This study uses a comparative historical approach and a Bacchi-inspired policy analysis of central national policy documents in Norway, Denmark, Sweden and Finland to point at Nordic similarities, differences and mutual inspirations regarding articulation of early intervention. The analyses mirror a West-East dichotomy with Norway and Denmark having a longer history of early intervention approaches and inspiring each other's systems, while Sweden and Finland are latecomers, following their own ideas about LTC and its legislation. Overall, this paper contributes to the understanding of redirecting LTC-pathways in different Nordic contexts, by showing how the notion of potentiality changes how we think about care for older people, how we imagine ageing and future care.

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Between a rock and a hard place – Use of discretion in case managers' work in services for older adults

Paula Vasara[1], **Tiina Hautamäki**[2], Katja Valkama[2], Heli Valokivi[1]
[1]University of Jyväskylä, Finland, [2]Seinäjoki University of Applied Sciences, Finland

Case management aims to ensure that those in need of support receive the necessary services in a timely and appropriate manner. While the work of case managers is regulated by laws related to social care, there is some room for exercising individual discretion within the guidelines. Yet, with the recent social and health care reform in Finland, there has been a push to conform with the guidelines and instructions concerning the allocation of services within the new wellbeing services counties. This has affected individual case managers' ability to consider individual circumstances. Employing narrative analysis, this study explored the views of case managers regarding the exercise of discretion. The findings indicate that case managers engage in almost constant ethics work with the need to interpret ambiguous instructions to safeguard their clients' interests.

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The impact of public spaces in elderly living communities on daily activities and social interactions

Tianqin Chen[1]
[1]Politecnico Di Milano, Italy

With the intensification of the problem of population ageing, healthy ageing has received more and more attention from society. Especially during the Covid-19, strict home quarantine policy has caused severe physical and mental isolation to older adults, which has caused many social and health issues. This situation has become the starting point of this study. The participation of older people in community public spaces directly affects their daily activities and social interactions.
This paper takes elderly living communities in Milan, Italy as an example, using space syntax analysis along with convex space, axis and view grid models to interpret the accessibility, visibility and comprehensibility of community public space. In addition to the qualitative analysis, interviews and field surveys are implemented for the qualitative approach. By integrating both quantitative and qualitative methods, the study analyses the relationship between the configuration of community public spaces and the daily activities and social

interaction of older people, explore the mechanism of action between the two, identify specific spatial elements that affect the daily activities and social interactions of older people, and clarify the specific impact path of community public spaces on the daily activities and social interactions of older people.

The study proposes a community public space intervention design strategy guided by behavioral activities and emotional needs, aiming to improve the community participation and comfort of daily activities of older people, and promote the social interaction and their physical and mental health.

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OS1 Methodological and ethical approaches in care research

Room: F3005
Time: 8:45-10:15
Chairs: Tove Harnett

Presentations:

- 22 Rachel Crossdale: Carers' research: Who is it for? A critical evaluation of carers' research since the start of the Carers' Movement
- 360 Tove Harnett & Glen Möllergren: Balancing Past and Present: Using Life Stories in Dementia Care
- 455 Julia Lawrence: Navigating Ethical Challenges in Co-Production: Lessons from the Intersectional Stigma of Place-Based Ageing (ISPA) Project
- 248 Martina Smith & Francesca Ribenfors: Inviting Kindness and Curiosity into English Health and Social Care Systems

Short presentations:

- 214 Chantal Hillebregt: Co-creating the future of transforming carepartnership in nursing homes: a participatory research approach
- 294 Ferhana Hashem & Sophie Fournel: Using communities of practice to strengthen caregivers and care receivers' participation in co-producing knowledge, defining territory and inventing new practice

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Carers' research: Who is it for? A critical evaluation of carers' research since the start of the Carers' Movement

Rachel Crossdale[1], Lisa Buckner[2]
[1]The University Of Sheffield, United Kingdom, [2]The University of Leeds, United Kingdom

Since the start of the Carers' Movement research into unpaid care and carers has been used to advocate for policy change. This research addresses the changes in research into unpaid care and carers since the start of the Carers' Movement and explores the relationship between these changes and social policy. Based on a qualitative study of documents within the Carers UK archive, the research finds that research into unpaid care and carers has changed focus from caregiving as an identity and lifestyle to an interruption to "normal" life and employment. Changes in research are intertwined with changes in policy, with research evidencing advocation for policy change and policy change fuelling further research. Changes in the methodology of this research exposes transition points in the Carers' Movement and in social research more broadly, highlighting the aspects of 'carer' that are deemed (un)important.

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This paper contributes to critical understandings of the relationship between research into unpaid care and caring and policy as well as debates on methodology, exploring how the methodological zeitgeist presents in archived research. It is original in developing a critical analysis of the relationship between research into unpaid care and carers and social policy, understanding how current research into unpaid care and carers has been developed and acknowledging the role of policy in research development brings available data on unpaid care and caring under scrutiny for regulating what we know and understand about the carer population.

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Balancing Past and Present: Using Life Stories in Dementia Care

Tove Harnett[1], **Glenn Möllergren**[1]
[1]Lund University, Sverige

This study explores the challenges faced by dementia care staff in using life stories to provide personalized care as dementia progresses and alters an individual's preferences and personality. Life stories are often employed in dementia care to encourage staff to recognize the "person behind the dementia," supporting a more person-centered approach. However, as dementia advances, discrepancies between documented life story information and the present behaviors of individuals can complicate this practice. Data were collected from six focus group interviews across dementia care settings in five Swedish cities, and analyzed through Atchley's continuity theory. The results revealed that external continuity established through life stories was frequently perceived as invalid and ineffective in maintaining the individual's internal continuity. Staff described life stories as a way for families to preserve a version of the person that no longer existed, with comments like "The family writes from before they got dementia" and "we focus on the person who is here." In some instances, preferences documented in life stories, such as avoiding alcohol or enjoying church music, were disregarded when they conflicted with the person's current behaviors. The study highlights the need for dementia care practices that prioritize the present needs and desires of individuals, while still respecting their personal history. This research contributes to the ongoing conversation on social and human rights in dementia care, advocating for care approaches that balance both a person's past and evolving wishes.

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Navigating Ethical Challenges in Co-Production: Lessons from the Intersectional Stigma of Place-Based Ageing (ISPA) Project

Julia Lawrence[1], Vikki McCall[1]
[1]University Of Stirling, United Kingdom

The Intersectional Stigma of Place-Based Ageing (ISPA) project is a five-year participatory mixed-methods study, running from September 2022 to September 2027. Funded by the Economic and Social Research Council (ESRC), it aims to investigate how stigma related to where people live intersects with the lived experiences of disability and ageing. The project is a collaboration between the University of Stirling, University of St Andrews, Newcastle University, and University of Bristol, in association with the Housing Learning and Improvement Network (Housing LIN) and the Scottish Federation of Housing Associations (SFHA).

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At the heart of the ISPA project are 140 disabled Community Peer-Researchers (CPRs), aged 45+, from across Scotland, England and Wales. These CPRs play a central role in co-producing research on the lived experiences of disabled people. This co-production approach, while highly rewarding, also raises critical ethical challenges, particularly in managing relationships within a large and diverse group of CPRs. These challenges include overseeing interactions among CPRs, facilitating the formation of subgroups, and addressing sensitive situations such as when an established subgroup seeks to exclude a member. Additionally, the death of a CPR presents unique ethical dilemmas, requiring careful communication with the CPR's family and informing the wider group of CPRs.

This presentation will share key lessons learned from both the successes and challenges faced during the project. It will also offer reflections on the importance of navigating these complexities to create a supportive and inclusive research environment, providing valuable insights and guidance for future coproduction research projects involving CPRs.

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Inviting Kindness and Curiosity into English Health and Social Care Systems

Martina Smith[2], **Francesca Ribenfors**[1], Katherine Runswick-Cole[2], Sara Ryan[1]
[1]Manchester Metropolitan University, United Kingdom, [2]The University of Sheffield, United Kingdom

Background

Health and social care systems and services within England are under pressure following years of economic austerity. Nevertheless, they are affective spaces in which acts of kindness and unkindness are deeply felt. Kindness itself remains under-theorised and there is no duty on health and social care professionals to act with kindness.

Methods

This paper engages with interview data from 12 parent carers of adults with learning disabilities. The interviews formed part of a wider project, Tired of Spinning Plates, exploring how family carers of adults with learning disabilities conceptualise and experience mental health, services, and support.

Results

Despite searching for kindness within the interview transcripts, we found stories of unkindness and cruelty and experiences of disinterest and disconnection embedded within family carers' encounters with health and social care. Drawing on feminist and critical disability scholarship, we understand these experiences as the result of an absence of curiosity and kinship on the part of health and social care systems, services, and professionals leading to the continued othering and harm of family carers and adults with learning disabilities.

Conclusions

We invoke a repatterning of kinship that pays attention to all ties of kinship, expanding beyond familial ties. In doing so, we call for a strengthening of connections with carers as kin and the

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responsibility and curiosity that comes with this and we demonstrate the need for embedding a socially just, cultural politics of kindness in health and social care services and systems.

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Co-creating the future of transforming carepartnership in nursing homes: a participatory research approach

Chantal Hillebregt[1], Marian Zegwaard[1], **Hennie Boeije**[1]
[1]Vilans, The National Centre Of Expertise For Long-term Care, Netherlands

The long-term care (LTC) sector for frail elderly residents in nursing homes faces critical challenges, including workforce shortages and high caregiver burden. Formal care workers and informal caregivers (family members, relatives, and volunteers) often operate in parallel rather than in genuine partnership, limiting care quality and efficiency. Transforming care work requires innovative approaches to enhance collaboration.

This participatory action research (PAR) analyses how care partnerships between informal caregivers and formal care workers can be reimagined to enhance care quality in Dutch nursing homes. The study, conducted in three nursing homes, engaged three interdisciplinary teams of family caregivers, volunteers, and formal care workers, treating all participants as equal partners with unique contributions.

Through over 30 participatory meetings and semi-structured interviews, the research facilitated a co-creative process where participants explored their roles and relationships within this dynamic care triangle. They identified successes, challenges, and institutional changes needed to improve collaboration.

Key findings highlight the importance of clearly defining roles, tasks, and responsibilities to reduce tensions and strengthen collaboration. Practical tools and strategies were developed to address communication gaps, role clarity, and mutual understanding. However, systemic barriers, including insufficient institutional support, poor information sharing, and the lack of a unified adopted vision, continue to hinder effective collaboration.

This research offers valuable insights for improving the LTC sector by offering practical recommendations to foster stronger care partnerships between informal and formal caregivers. It underscores the importance of both relational and structural changes to redefine care work and enhance collaboration.

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Using communities of practice to strengthen caregivers and care receivers' participation in co-producing knowledge, defining territory and inventing new practice

Ferhana Hashem[1], **Sophie Fournel**[1,2], Vanessa Abrahamson[1]
[1]University of Kent, United Kingdom, [2]Disability Assist, United Kingdom

Since their inception, Communities of Practice (COP) are recognised as a shared learning tool aimed at situating learning, deepening knowledge and interacting to exchange expertise in a specific area. Despite their organic origins, COPs have found several practical applications in business, government, education, professional associations and development projects, yet their civic purposes have almost been overlooked, particularly how these social learning spaces help caregivers and care receivers to educate, support and coach social care practitioners to shape practice or change process.

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This paper reports on the findings of a study based in South-East England of two COPs co-designed with experts by experience supporting adult social care practice. The overarching topics (‘Complex needs’ and ‘Workforce’) were co-developed by a prioritisation exercise. Both COPs had monthly online sessions with invited speakers and a discussion forum. Attendees included experts by experience, social care practitioners, managers, and researchers. We interviewed 21 attendees to explore: how the COPs shaped learning (co-producing knowledge); how learning was transferred beyond the COP (defining territory); and how this learning influenced new ways of working (inventing new practice).

Thematic analysis identified that participants valued an inclusive and safe learning environment, enabling them to share learning and reflect on each other’s experiences. Relationships developed across roles/settings, providing opportunities to bridge silo thinking, validate research ideas and take learning beyond the COP. Time pressures and the prevailing organisational culture inhibited attendance by frontline staff, set against the need to learn and innovate. Networking was a frequently cited outcome, leading to knowledge-exchange collaborations.

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TP17b Navigating entangled systems: institutional interplays in care systems

Room: F3010
Time: 8:45-10:15
Chairs: Mara Yerkes, Jana Javornik, Ester Gubert

Presentations:

- 219 Håkan Jönson: Navigating the support system: Older adults as the bricoleurs of Swedish home care
- 306 Macgregor Goodman: Filling the gaps: How do family carers reveal and resist systemic failures in healthcare?
- 78 Chieh-hsiu Liu : Navigating Care Poverty: Unmet Care Needs during Health and Social Care Transitions under Taiwan's Long-Term Care 2.0 Reform

Short presentations:

- 31 Chiara Giordano: The public, the private and “the hidden”: undeclared work in home care for older people in Belgium

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Navigating the support system: Older adults as the bricoleurs of Swedish home care

Håkan Jönson[1], Glenn Möllergren[1], Marianne Granbom[2]
[1]Lund University, School of Social Work, Sweden, [2]Lund University, Department of Health Sciences, Sweden

Challenging conventional provider-oriented perspectives on older adults’ spatial realities, this study explores how community-dwelling care users in Sweden manage and adapt their home environments. It investigates how they utilize the welfare system and coordinate many disparate resources to achieve a spatially sustainable approach to aging-in-place. Research on domiciliary care for older adults has largely focused on providers, overlooking the skills and strategies older care users themselves employ to make things work; this study uses a fresh lens by examining the active engagement of older adults in shaping their own home arrangements. The data comprised twelve qualitative interviews with older care users, along with accompanied home walk-alongs, focusing on how different areas of the home were used in everyday life. The concepts of bricoleur, bricolage, and tinkering were employed to analyze the activities and arrangements respondents implemented to utilize services in managing their daily lives. The findings revealed that participants had been prompted to develop sophisticated procedures and competencies, leveraging supportive networks and combining housing adaptations, assistive devices, and innovative uses of household items to make services useful. The study highlights the importance of recognizing the active coordination efforts of older care users and underscores the need to focus on their expertise and adaptive learning

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within supportive systems. An eldercare system such as Sweden's, offering a variety of services, can be perceived as fragmented and challenging to navigate, necessitating a user-centered approach to improve accessibility and effectiveness.

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Filling the gaps: How do family carers reveal and resist systemic failures in healthcare?

Macgregor Goodman[1]
[1]York University, Canada

Families face increasing, multifaceted pressures to take on responsibilities of care for aging family members. In doing so, many carers encounter significant bureaucratic and structural violence while navigating an underfunded, unsustainable, and siloed healthcare system. This paper outlines how social networks of care respond to hostilities, inadequacies, and failures of the healthcare system to meet the needs of our aging population and their family members.

Drawing from interview data from 36 diverse family caregivers including those from LGBTQ, racialized and immigrant communities, we posit that the ways in which carers explain how they "fill the gaps" of the healthcare system not only illuminate these gaps and failures but illustrate potential solutions and interventions that can be implemented on a systemic level. This holds the potential to inform systemic transformation that can both reduce caregiver burden and to improve quality of care for all service users, many of whom do not have family members who are able and willing to perform extensive advocacy work and supplement care. Indeed, participants repeatedly stated that if they had not intervened to provide informal care, the person they are caring for likely would have died. We conclude by calling for structural improvements in the provision of family medicine, including support in system navigation upon diagnosis with dementia, and transformational change to embed principles of social justice and anti-racism within institutions of care.

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Navigating Care Poverty: Unmet Care Needs during Health and Social Care Transitions under Taiwan's Long-Term Care 2.0 Reform

Chieh-hsiu Liu[1]
[1]Department of Geriatrics and Gerontology, College of Medicine, National Cheng Kung University, Taiwan

Since the late 2000s, Taiwan, characterized as an East Asian familialist welfare regime, has sought to expand its long-term care (LTC) system to address demographic and familial changes. The LTC 2.0 reform, launched in 2017, broadened service eligibility and packages, while introducing new mechanisms for service assessments and care management. Despite these advancements, concerns remain regarding whether the reform substantially addresses the care needs of older adults and family caregivers, as well as the institutional barriers that hinder the development of the public care services within the familialist regime. This study examines unmet care needs of older adults and caregivers during transitions between health and social care, a critical period marked by heightened vulnerability and complex arrangements, under the LTC 2.0 reform. Drawing on 20 semi-structured interviews with older adults and caregivers navigating transitions between hospitals, communities, and homes, the analysis employs the "care poverty" framework and the Consolidated Framework for

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Implementation Research. Findings reveal persistent unmet care needs spanning personal, practical, and socio-emotional domains, shaped by both individual complexities and systemic constraints. The fragmented integration of health and social care systems—rooted in not only technical and administrative challenges but also normative and institutional divides, including conflicting professional cultures and norms as well as tensions between Taiwan's established social insurance-based National Health Insurance and its emerging tax-funded LTC services—further limits accessibility, effectiveness, and inclusivity. These findings underscore the structural challenges of adapting Taiwan's LTC system to evolving societal needs within its familialist welfare regime.

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The public, the private and "the hidden": undeclared work in home care for older people in Belgium

Chiara Giordano[1]

[1]Université Libre de Bruxelles, Belgium

In many European countries, families often employ home care workers without regular contracts as part of their strategies to meet the growing needs for older care. In Belgium, such undeclared work does not exist in isolation but is frequently combined with public, private, and community services, forming a complex and dynamic care matrix. This paper examines the interplay between undeclared work and formal care arrangements in Brussels, challenging the binary view that separates these two forms of employment.

Drawing on fieldwork conducted between 2019 and 2022 – including interviews with public and private care providers, older care recipients, families, and migrant care workers, as well as a survey across three Brussels neighbourhoods – this study reveals the fluidity and interconnectedness of undeclared and formal work. Families often integrate undeclared care into broader care strategies, using it alongside public or private services. From the perspective of care workers, undeclared work frequently complements regular employment and ranges from sporadic to sustained off-the-books arrangements.

The findings highlight that undeclared work evolves over time, with care workers often participating in multiple employment types simultaneously. This coexistence of formal and informal arrangements, both within families and individual care workers' practices, underscores the adaptability of care systems in response to resource constraints. By exploring these dynamics, the paper contributes to the discussion on the future of elder care in Europe and the evolving boundaries of care work.

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S9 Routes out of the care crisis: exploring care system innovations in comparative perspective

Room: F3006
Time: 8:45-10:15
Chairs: Catherine Needham, Anette Fagertun, Emily Burn
Discussant: Kate Hamblin

Long-term care systems are in crisis in many countries, due to common issues such as population ageing and workforce shortages. This is evident in many countries despite different welfare histories and care regimes – for example in Nordic countries (Hansen and Dahl, 2021) and in the UK (Needham and Hall, 2023). This symposium will explore the care crisis and routes out of it.

In her paper Dahl explores the care crisis in a social-democratic welfare state and how it differs from the crisis experienced in liberal and continental European welfare regimes. Dahl outlines Danish policy about the recruitment of care workers and care professionals from the Global South and other possible routes to reduce the care crisis.

Jacobsen et al's paper looks at the concept of innovation as a policy solution for welfare state crisis. The paper includes a discussion of potential consequences of the present Norwegian discourse on innovation, including attending to a seemingly "technologification" of care and care planning.

Ramsøy et als's paper explores innovation within Norway's municipal home care services. While substantial changes to work-organization, burden-sharing with relatives, implementation of welfare technology, and synergies with the third sector were all planned as part of the project, the extent of their implementation was largely curtailed by economic turmoil.

In their paper, Burn and Needham, look at health and care integration in the UK as a route out of crisis through potentially saving money and providing joined-up care. In particular they focus on institutional layering, and the problems created when innovative structures are incoherently layered on top of reforms from previous eras.

The symposium is particularly oriented to two of the conference themes:

The institutional setting of care systems and care policy

Social and policy innovation on care services and care arrangements, and its impact

Papers:

Hanne Marlene Dahl, The Care crisis in the Nordics: Characteristics, Consequences and some policy options.

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Frode F. Jacobsen, Laila Nordstrand Berg, Anette Fagertun, Ingrid Jerve Ramsøy, The travel of a concept: Innovation as a panacea for the Norwegian public sector

Ingrid Jerve Ramsøy, Anette Fagertun, and Frode Fadnes Jacobsen, Cost-saving as innovation? Betterment in municipal home-care services in Norway.

Emily Burn and Catherine Needham, Integration of health and care as a route out of the care crisis: freeing up innovation or silting up the system?

Discussant: Kate Hamblin, University of Sheffield

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TP7 A human rights approach to dementia care: actors, policies, and provisions

Room: F3004
Time: 8:45-10:15
Chair: Gülçin Con Wright

Presentations:

- 243 Anže Štrancar: Characteristics and Challenges of Informal Care for People with Dementia in Slovenia
- 292 Guus Timmerman: Advanced Dementia from Within: Ambiguous for Both
- 88 Edward Tolhurst: How can the personhood of dementia care workers be supported?

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Characteristics and Challenges of Informal Care for People with Dementia in Slovenia

Anže Štrancar[1]
[1]Faculty Of Social Work, University Of Ljubljana, Slovenia

As the population ages and dementia becomes increasingly prevalent, informal caregiving is gaining greater attention from researchers and policymakers. This term refers to relatives, friends, and neighbors who provide unpaid support to individuals with dementia. This paper draws on data from a study conducted in Slovenia between 2020 and 2024, exploring the challenges faced by informal caregivers. It examines key aspects of informal caregiving in Slovenia and compares them to findings from international research, with a particular focus on human rights and the active inclusion of people with dementia. A notable aspect of this study is the direct involvement of individuals living with dementia, who are often excluded from research. Ten interviews were used in the paper—five with individuals with dementia and five with their informal caregivers—conducted across various regions of Slovenia. The findings align with those observed in other countries. In Slovenia, caregiving responsibilities primarily fall on wives and daughters, highlighting a pronounced gender dimension. Participants reported similar challenges to those faced by informal caregivers elsewhere, particularly difficulties in balancing caregiving with employment and household responsibilities. They also emphasized the emotional toll of caregiving, noting that its demanding nature often leaves little room for self-care. An explanation is also provided about the new Slovenian Long-Term Care Act, which grants family caregivers the right to employment as caregivers of a family member.

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Advanced Dementia from Within: Ambiguous for Both

Guus Timmerman[1], Judith Leest[2]
[1]Presence Foundation, Utrecht, the Netherlands, [2]HKU University of the Arts Utrecht, Utrecht, the Netherlands

This paper presents the results of a phenomenological study into the lived experience of people with advanced dementia and living in nursing homes. The study was commissioned by an older persons care organisation that wanted to improve its understanding of the inner perspective of people with advanced dementia and dependent on residential care, especially those who are not so verbally coherent as before, both to inform relational caring and to give voice to people with advanced dementia. The researchers closely observed several residents in nursing homes, in a self-critical variant of shadowing called ‘spect-acting’. They found seven themes that are relevant for what it is like to be someone with advanced dementia. In more than one way, these themes are not simple and not always unambiguous in their meaning for the person with advanced dementia. These themes are also relevant to what it is like to live with and care for someone with advanced dementia. The overarching conclusion was that it may be helpful to view living with advanced dementia as living with heightened ambiguity for both: the person with dementia and the persons who live with and care for this person. A human rights-based approach in dementia care needs to acknowledge the heightened ambiguity of being someone with dementia and take into account the relationality of living with and caring for persons with dementia. Human rights can then safeguard a space in which relational caring and thus people with dementia can flourish.

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How can the personhood of dementia care workers be supported?

Edward Tolhurst[1]
[1]Staffordshire University, United Kingdom

This UK-based qualitative research evaluated the experience of paid care workers who support people with dementia. It set out to investigate how care workers themselves can be assisted in their working roles. Discourses on personhood typically focus on the person with dementia, with the basis and maintenance of personhood for paid carers being underexplored. A transformation is thus required to ensure personhood is viewed in a genuinely relational manner, encompassing other key actors who sustain care arrangements. Semi-structured interviews were undertaken with 9 employees within a daycare organisation: 6 support workers, and 3 members of management/administration staff. Two interviews were undertaken with the support workers, approximately three months apart, with them asked to reflect on their care practice between these interviews. Interpretative Phenomenological Analysis was applied to the dataset, and four principal themes were identified: establishing care needs; negotiating family dynamics; aligning work with personal values; and positioning care within wider societal understandings. These highlight that a positive sense of status can bolster an occupational identity that helps support workers to negotiate care situations with people with dementia, and informal carers also, undergirded by a strong commitment to values of caring. This can be reinforced through a helpful organisational context. However, a wider challenge is to establish a clearer societal focus on the significance of care work via greater cultural awareness and appreciation. It is only by supporting relational contexts, which include the care workers situated within them, that the personhood of people with dementia can be positively sustained.

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S14 The FAMCARE project: Care and wellbeing in Dutch families in different policy contexts

Room: U3039
Time: 8:45-10:15
Chairs: Marjolein Broese van Groenou
Discussant: Tine Rostgaard

The increased demand for long-term care (LTC) and the drastic reforms of the LTC systems in western societies create uncertainty among families. It raises the question whether and how families can provide appropriate LTC for their older relatives and maintain wellbeing of the care recipient, the partner and their adult children. One solution is to share the care in a care network in which partner and children cooperate with publicly and privately paid caregivers. The Dutch FAMCARE project aims to add more insight in how families organize care and how this impacts on their level of wellbeing. Our work shows that care networks are associated with wellbeing of the care recipient. This symposium adds 1) the perspective of the caregiver, and 2) the robustness of the theoretical models over time. Data are derived from the Longitudinal Aging Study Amsterdam (1992-2022) and the two ancillary studies on Family Caregiving in 2002 and 2023. Project leader Marjolein Broese van Groenou will first present a short overview of the FAMCARE project. In the second contribution of the symposium Silvia Klokgieters presents how loneliness and care sufficiency impact the association between care network types and wellbeing of the care recipient in different LTC contexts (1992-2002-2012-2022). Jens Abbing takes a family perspective and shows the interdependence amongst siblings in their considerations to provide care to their parent, comparing findings in 2002 with 2023. In the fourth contribution Joukje Swinkels examines how sharing the care adds to the wellbeing of adult children in the year 2002 and in 2023. Discussion focuses on the empirical variation over historic time and how decreasing generosity of publicly provided care and increasing expectations regarding informal care in the past decades may have impacted our findings.

Papers:

Marjolein Broese van Groenou (VU), Objectives and design of the FAMCARE project (2023-2025) on care networks and wellbeing in families of older adults in the Netherlands

Silvia Klokgieters (VU), How are care networks associated with wellbeing of older care recipients – a comparison over historic time in the Netherlands

Jens Abbing (VU) Sibling influence on adult children’s caregiving to older parents in different time periods in the Netherlands

Joukje Swinkels (VU) Sharing the care: how help from formal and informal caregivers impacts on caregiver’s burden within families in 2001 and in 2023

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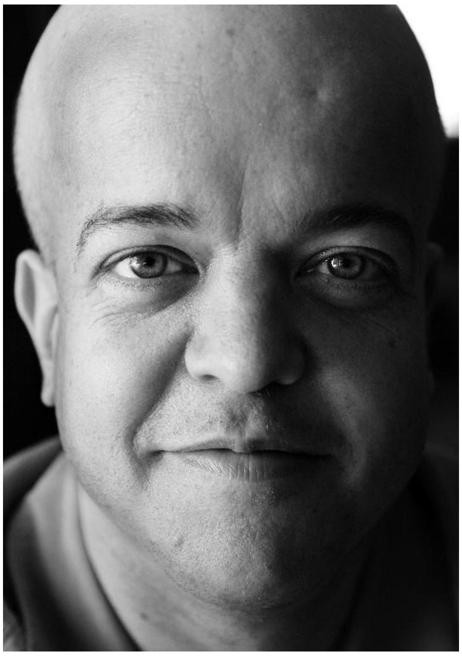
Thursday 26 June: Keynote 2, Professor Tom Shakespeare

London School of Hygiene & Tropical Medicine, United Kingdom

Room: Porthania, PI

Time: 10:45-11:45

Chair: Dr. Lina Van Aerschot, University of Jyväskylä/Tampere University



Tom Shakespeare is Professor of Disability Research at London School of Hygiene and Tropical Medicine. He was formerly at UEA Medical School, and before that at WHO, where he was part of the team who wrote the World Report on Disability (2011). His books include Disability Rights and Wrongs (2006) and The Sexual Politics of Disability (1996).

Title: Who cares? Disability rights and other rights

First, I will outline key features of what I take to be a disability rights approach: for example, we need to shift understanding from medical to social; social dependency is not physical dependency. In addition, disabled people have same needs as everyone else. And finally, of course, nothing about us without us.

But I will argue that disability rights is not enough: identity politics is not sufficient because many people are not in organisations of people with disabilities, there are multiple differences/identities at play, and as Nancy Fraser says, identity politics can be dangerous. Disability is not one thing, and people who are affected by cognitive difference – for example, people who have dementia - may need a different approach. People are often disabled by their bodies/minds.

Then I will use the research we have done on personal assistance to argue that care always involves emotions & relationships. Moreover, other people have a stake in disability, such as unpaid carers, assistants and other workers: all are involved, all are vulnerable. Finally, I will talk about how we move forward. For me, we do need more ideology. We need to recognise complexity, materiality and relationality.

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Thursday 26 June, Round Table

Room: Porthania, PI

Time: 12:00–13:00

Chair: Professor Teppo Kröger, University of Jyväskylä

Participants:

Expert Sanna Ahola, Human Rights Centre

Lawyer Pirkko Mahlamäki, active in European Disability Forum & European Women's Lobby

Professor Marja Jylhä, Tampere University

Professor Kirstein Rummery, University of Stirling

Four representatives from human rights and disability organisations, as well as academia, will identify and discuss the most relevant and topical issues in Finnish long-term care and disability policy from the perspective of social and human rights. The discussion will also place Finnish experiences in an international context.

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TP16 Children’s role as unpaid carers and its social consequences from human and social rights perspectives

Room: U3029
Time: 14:00-15:30
Chair: Başak Akkan

Presentations:

- 21 Rebecca Lacey: Young Carers and Inequalities in School Performance: Insights from the UK Household Longitudinal Study and National Pupil Database
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Young Carers and Inequalities in Educational Attainment and School Engagement: the UK Household Longitudinal Study and National Pupil Database

Rebecca Lacey[1,2], Alejandra Letelier[1], Anne McMunn[2], Andy McGowan[3], Krista Cartlidge[4]
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Background & Objectives
Young carers (individuals under 18 providing care to family members) experience significant disadvantages. While prior research suggests caring negatively impacts education, evidence is limited by methodological constraints and lacks national-level representation. This study aimed to assess associations between young caring and official educational attainment and school engagement at primary and secondary school levels in England, and to identify potential inequalities by gender, ethnicity, socioeconomic factors, household composition, and special educational needs.

Methods
We used data from Understanding Society: UK Household Longitudinal Study (UKHLS) linked with the National Pupil Database. We used cross-sectional pooled data covering 2009–2018, focusing on two educational stages in England: Key Stage 2 (KS2, end of primary school) and Key Stage4 (KS4, end of secondary school). Regression models assessed associations between self-reported young caring and educational outcomes (attainment and absenteeism), adjusting for sociodemographic covariates.

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Results
Young carers made up 12.8% of the KS2 sample (n=1,740) and 10.6% of the KS4 sample (n=2,091). They had significantly lower attainment at KS2 (reading, mathematics, writing) and at KS4 (fewer and lower-grade GCSEs). Persistent absenteeism was substantially higher among young carers compared to non-carers (KS2: 5.8% vs 3.7%; KS4: 24.5% vs 19.1%). Socioeconomic disadvantage explained part, but not all, of the educational gaps. No additional inequalities were observed.

Conclusion
Young carers face early and persistent educational disadvantages, with lower attainment and higher absence rates partially linked to socioeconomic inequality. Targeted support is urgently needed to help young carers manage responsibilities and mitigate negative impacts on education.

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Young carers in Finland: First reflections from a qualitative longitudinal participatory study

Susanna Haverinen[1], **Sini Järnström**[1], Tiina Sihto[1]
[1]University Of Eastern Finland, Finland

In September 2024, we started a research project focusing on young carers in Finland. Young carers are defined here as adolescents and young adults aged 15–24 who provide care, support, help, and/or assistance to (a) family member(s) or kin on a regular basis. The aims of the project are to 1) develop an in-depth understanding of how young carers' caring role shapes their life course transitions during adolescence and emerging adulthood, 2) produce empirical knowledge regarding young carers' family care chains and to reflect how being a young carer (re)configures the family care chains and the flow of care within families and kin networks, and what this means for the young carers themselves, and 3) analyse the formal and informal forms of support young carers have for caring. The data set will consist of qualitative longitudinal participatory data from young carers, with the aim of addressing in depth how their caregiving experiences are shaped in and through time.

We will present our first, preliminary findings from the first wave of data gathering, focusing on the three main aims of the project. We will also reflect on the perspective of human and social rights in relation to young carers in Finland – how the existence of young carers challenges the ideals of equalizing, universalistic Nordic welfare state.

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Navigating Conceptual Challenges: Advancing Support and Rights for Young Carers in Finland

Kirsi Hokkila[1]
[1]University of Turku, Finland

According to Leu and Becker’s classification, Finland moved from the 'awakening' phase in 2017 to the 'emerging' phase by 2021 in recognizing and supporting young caregivers. Advocacy by NGOs led to a milestone of inclusion of care responsibilities in Finland’s School Health Promotion study, revealing that 6.3% of 8th–9th graders provide regular care for a family

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member. Despite this progress, practical measures remain insufficient, partly due to conceptual ambiguity between lapsiomaiset (children as next of kin, later CANOK) and nuoret hoivaajat (young carers, later YC).

While CANOK traditionally describes children impacted by parental illness, YC emphasizes caregiving responsibilities. In reality, Finnish practitioners and NGOs either reject the phenomenon of young caregiving or misunderstand or treat these terms as synonymous. The term hoiva (care) in Finnish implies formal or physical care, contrasting with the broader English term encompassing emotional and self-care. Additionally, Finland's strong welfare state may obscure the caregiving roles of young carers, assuming such needs are addressed by public services.

Leaning on conceptual analysis method, this presentation investigates the contextual and conceptual nuances of these terms, analyzing why Nordic countries prioritize the concept of CANOK, while other Western nations focus on YC. It examines the attributes, conditions, and consequences of these concepts, emphasizing the importance of conceptual clarity for policy development. By identifying conceptual and related cultural and systemic challenges, the research seeks to enhance Finland’s support system and provide targeted recommendations to bridge gaps in ensuring wellbeing and rights of all children affected by parental illness.

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I Care too little or too much ? An Account on Experiences of Children with Disabilities in Uluberia

Anusuya Moitra[1]
[1]Ph.d Research Scholar, Jadavpur University, Kolkata, India

Children with disabilities are conventionally perceived, as a group in need of care. Consequently, caring in relationships of disabled children and their able-bodied carers is understood as a binary form of exchange between care-receivers and care-givers. This results in emergence of an uni-dimensional dependency dynamic that espouses an overwhelming narrative of ‘burden’ of care, imposed on kins, by the existence of these children especially, in the wake of absence of strong social security networks in rural India. Such conceptions are essentially ablest, that simplify the complex nature of disabled embodiment eventually stripping disabled children's personhood by not recognizing their agency specifically in relation to the process of care-giving. This paper, attempts to explore perceptions, aspirations and negotiations of disabled children with respect to their role as carers within their families. It tries to understand how children with disabilities comprehend and practice caring? how such comprehensions are mediated alongside the material reality of their bodies? and how their experiences as carers shape their sense of self(s)? Intersectional lens has been used to unearth the suppressed reality of caring experiences of disabled children, residing in Uluberia district of India. Primary data was collected through qualitative interviews with 15 children with loco-motor disabilities belonging to the age group of 14-17 years. Participants mostly felt, despite their best efforts, they are not considered appropriate and adept care-givers by their family members. However, they resisted such narratives,by negotiating their bodily abilities and participating in activities of un-paid carework, particularly household chores and caring for siblings.

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TP26c Transforming care work: changing working conditions, actors, approaches and outcomes

Room: Small Hall
Time: 14:00-15:30
Chairs: Costanzo Ranci, Hildegard Theobald

Presentations:

- 60 Hildegard Theobald: Reforms in long-term care work in Germany: Policies and inequality dynamics
- 61 Shereen Hussein: Shaping Social Care: Predictable and Unpredictable Policy Impacts on the UK's Care Workforce and Future Directions
- 283 Marco Arlotti & Barbara Da Roit: Long-term care and employment regulation, and labour shortages: an Italian case study
- 135 Marianne Giske Holvik: Task shifting and transformations of care work and care

Short presentations:

- 462 Tamara Daly: Super-Invisibility: 'Older' Care Workers in Home Care and Long-term Care

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Reforms in long-term care work in Germany: Policies and inequality dynamics

Hildegard Theobald[1]
[1]University of Vechta, Germany

The expansion and marketization of long-term care services in Germany were followed by a worsening of working conditions. In response to the poor working conditions and related staff shortage, reform policies were instituted on the national level with the aim at ensuring a socially sustainable long-term care infrastructure. This paper seeks to analyse whether the reforms contribute to a reduction of inequalities among care workers as a decisive element of a socially sustainable long-term care infrastructure. To this end, it selects the implementation of two key reforms in nursing home facilities – policies for increasing staffing levels based on a re-definition of the skill-based division of care tasks and policies for promoting international recruitment of care staff. Both reforms assume inequality dynamics on the basis of skill levels – as a central component of class – and migration status and their intersection.

Conceptually, the paper draws on the paradigm of multi-level intersectionality for an analysis of the intersection of inequalities based on class and migration status in the female-connotated sector. The research assumes that dynamics of inequalities are the product of an interplay of the reform policies on the macro-level, their implementation in nursing home facilities on the

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meso-level and related changes in daily practices and social interactions on the micro-level. Empirically, it is based on findings of a research project including a nationwide questionnaire study and interview studies in selected nursing homes, which examine the implementation and outcomes of the reforms.

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Shaping Social Care: Predictable and Unpredictable Policy Impacts on the UK's Care Workforce and Future Directions

Shereen Hussein[1], Erika Kispeter[2]
[1]London School of Hygiene & Tropical Medicine, , United Kingdom, [2]London School of Hygiene & Tropical Medicine, United Kingdom

This study explores how national policy drivers impact changes in the social care workforce in the UK, focusing on both expected and unexpected outcomes. Key drivers include professionalisation, integration of health and social care, funding reforms, commissioning, digitalisation, and migration policies. Employing a mixed-methods approach—comprising a literature review, stakeholder consultations, and foresight exercises— the research identifies tensions and synergies between these policies. For instance, efforts to professionalise the workforce may conflict with personalisation goals, while integration highlights systemic misalignments. Post-Brexit migration policies have exacerbated recruitment challenges in a sector reliant on migrant workers. The study presents three scenarios for the future of social care by 2035: one focused on achieving pay parity with NHS staff through workforce professionalisation, another emphasising innovative commissioning for personalised care, and a third considering the implications of legalising assisted dying for end-of-life care. In all scenarios, support for care workers is vital, requiring career progression, mental health resources, and training in new care models. Recommendations for workforce sustainability include aligning migration and development policies, promoting ethical commissioning, and ensuring fair pay, which can help create a resilient and equitable social care system. This work is part of the Care Workforce Change research group at the ESRC Centre for Care.

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Long-term care and employment regulation, and labour shortages: an Italian case study

Marco Arlotti[1], **Barbara Da Roit**[2], Stefano Neri[3]
[1]Department of Economics and Social Science, Marche Polytechnic University, Italy,
[2]Department of Philosophy and Cultural Heritage, Ca' Foscari University of Venice, Italy,
[3]Department of Social and Political Sciences, University of Milan, Italy

The shortage of care workers in the long-term care (LTC) sector has become a key concern across Europe. This is the case also in countries with relatively small LTC sector, as in the case of Italy, where shortages exist and are expected to increase.
Multiple factors may explain the insufficiency of care personnel: (a) employment and working conditions; (b) increasing service demand; (c) competition from other sectors of the labour market; (d) social devaluation of care work. The working hypothesis of the paper is that LTC and employment regulations play a significant role in mitigating or exacerbating labour shortages. The paper proposes an in-depth comparative study of the residential LTC sector (the main area of employment of LTC workers) in three Italian regions, Lombardy, Emilia Romagna and Veneto, which encompass approximately 50% of the countries' residential care beds. These cases

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allow the comparison of sub-national residential LTC systems that are unified by national employment regulation, but display different LTC policies and service regulations (supply infrastructure, forms and degree of marketization, controls and funding). Empirically the comparison relies in the analysis of existing survey- and institutional data, policy documents and interviews with key informants collected in the framework of the Prin Pnrr 2022 research project - QWoRe - Quality of Work in Residential long-term care services in Italy: determinants and strategies.
The analysis disentangles the contribution of a highly fragmented national and regional employment and service regulations to the shortages in and within the LTC sector.

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Task shifting and transformations of care work and care

Marianne Giske Holvik[1]
[1]Vid Specialized University, Bergen, Norway

This paper explores a possible connection and tension between desires for medical specialization within welfare professional groups/healthcare groups (nurses and nursing assistants) and current governmental regulation that seeks to implement “task-shifting and task delegation” as a clear division of labor between these categories/groups of healthcare workers. The connection is conceived as representing a tension between actions driven by a medical logic and actions driven by an economic and bureaucratic state logic. The exploration is theoretical and draws upon research on welfare professions and welfare states and operationalizes theoretical concept from Pierre Bourdieu (2007; 2011) in particular the logic of practice, and the left and right hand of the state. In my PhD thesis I found that nurses and nursing assistants have a habitual orientation towards the medical field that position them as vulnerable to accept task shifting practices in state regulated home care in Norway. Theoretically task shifting is here understood as a stately economic strategy through which care tasks with low prestige are handed over to unskilled workers that are socially dominated within the workplace. The paper will thus explore if changes within the workplace can be explained by this possible connection between a state logic and a medical logic, and what the tension between the two may represent for care work.

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Super-Invisibility: ‘Older’ Care Workers in Home Care and Long-term Care

Tamara Daly[1], Sara Charlesworth[2], F. F Jacobsen[3]
[1]York University, Canada, [2]RMIT, Australia, [3]Centre for Care Research, Western Norway, Norway

In advanced welfare states, most paid care for older adults is provided by ‘care assistants’ or nurses. With the pervasive under-valuing of care work, low pay, high turnover among new care workers, and poor working conditions, we ask: how are older care workers (50+) faring? We argue that poor working conditions produce worse health, safety and financial security outcomes for older care workers, who are the least visible group. The overarching invisibility of older care workers’ working and retiring conditions -- in policy, planning and practice -- positions them as ‘super-invisible”. With examples drawn from comparative analysis of Australia, Canada and Norway, we outline four ‘invisibility traps’ that produce ‘super-invisibility’ for older care workers:

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1. Precarious work, from poor pay and job insecurity leaving too little for retirement, which leads to pension precarity, making older workers, in particular older women, vulnerable in their own older age and subject to working too late for too little;

2. Work overload, as signaled by weak retention or too early retirement that push people out of jobs before they would otherwise stop working;

3. Unacceptable health and safety protections that produce sickness, injury and disability; and

4. Weak national datasets that preclude proper workforce analysis, prohibit planning and leave unchecked this overly feminized and increasingly racialized work.

We discuss health and safety, skills recognition, retention strategies, improving working conditions, and financial security for retirement as important interventions that improve conditions for all care workers, and which especially make visible older workers' needs.

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TP13b Dark side of care

Room: F3003
Time: 14:00-15:30
Chairs: Tiina Sihto, Paula Vasara

Presentations:

- 344 Antero Olakivi: Rejecting care workers’ action proposals in older people care: a dramaturgical perspective to psychological safety in workplace interactions
- 431 Maria Teresa Ferazzoli: Mental illness, resources constraint, and human rights: reflections from a scoping visit in Ghana
- 328 Elisa Tiilikainen: Home as a place of exclusion – visiting the dark side of current ageing-in-place policies
- 324 Iiris Lehto: The dark side of mundane data care work

Short presentations:

- 56 Chunhua Chen: Facing reality and then coping – Recognising the complex dynamics of care relationships in reablement in the UK

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Rejecting care workers’ action proposals in older people care: a dramaturgical perspective to psychological safety in workplace interactions

Antero Olakivi[1,2,3], Vilhelmiina Lehto-Niskala[1,3]
[1]University of Helsinki, Finland, [2]Finnish Institute of Occupational Health, Finland, [3]Centre for Excellence in Research on Ageing and Care, Finland

As most Western societies experience population ageing, the demand for professional care workers to support the oldest old is increasing. While care work for older individuals can be rewarding, it is also physically and emotionally demanding. This paper examines the dark side of care by analysing workplace interactions—specifically, those between care workers and their supervisors—where care workers voice action proposals aimed at improving work practices within their care unit.

By action proposals, we refer to care workers’ explicit and implicit suggestions for improving work practices, typically accompanied by explicit or implicit critiques of existing practices. The paper focuses on action proposals that are ultimately rejected by supervisors. It sheds light on the dark side of care by first exploring the topics that prompt criticism from care workers and, second, analysing the workplace interactions surrounding such topics—some of which may be sensitive, hidden, or associated with taboo or stigma.

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Drawing on dramaturgical sociology, the study investigates the interactional practices employed by care workers and their supervisors to foster psychological safety in the context of older people care, even in the face of the above challenges. By psychological safety, we refer to the shared belief among team members that it is safe to take interpersonal risks, voice new ideas, admit mistakes, and raise criticisms of work practices—whether explicitly or implicitly.

The article presents novel findings based on video-recorded, authentic workplace interactions from Finland.

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Mental illness, resources constraint, and human rights: reflections from a scoping visit in Ghana

Maria Teresa Ferazzoli[1]
[1]University Of Sheffield, United Kingdom

In 2012, Ghana implemented an innovative mental health legislation which has started a process of implementation of mental health services in the community (Kpobi et al., 2014). Mental health nurses in the North region of the country work to empower the whole community to address the lack of resources in rural areas and a community-strength approach is applied to reduce the cases of people affected by mental distress in institutions (Ferazzoli and Kpobi, 2023). This presentation will highlight the challenges faced by mental health professionals from the North East Region to deliver support due to the lack of infrastructure, and how this results in important human rights violations.

The main purpose of this paper is not to highlight the limitations of the mental health provisions in some areas of Ghana but to critically reflect on how lack of resources, stigma, and human rights violations are often intertwined. Furthermore, this paper seeks to reflect on the limitations of a researcher's ability to effect meaningful change within a complex socio-political context. It will explore the ethical considerations, practical constraints, and potential unintended consequences of research collaborations and engagement with professionals when there is the need for humanitarian aid.

By sharing these experiences and reflections, this presentation seeks to raise awareness about the human rights dimensions of mental illness, not only in Ghana, but more widely and stimulate discussion on the role of research in advocating for policy changes and rights-based approaches to mental health care.

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Home as a place of exclusion – visiting the dark side of current ageing-in-place policies

Elisa Tiilikainen[1], Hanna Ristolainen[1], Leena Forma[1], Marjo Ring[1], Anna Mäki-Petäjä-Leinonen[1]
[1]University Of Eastern Finland, Finland

Living independently has been an attainable goal of ageing policies worldwide. In Finland, this has been evident in the eldercare services, which have undergone a drastic turn of deinstitutionalization during the past decades. Concurrently, fewer resources have been allocated to care for older adults, and accessing adequate services has become increasingly difficult in later life. These changes have led to a situation in which older adults' ability to live meaningfully at home is more often compromised.

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This presentation scrutinizes the pitfalls of current ageing-in-place policies by visiting the dark side of older adults' home care and asking what happens when home becomes a place of exclusion. The presentation draws on empirical findings from Old-age Social Exclusion – prevalence, meanings & intervention (SOLDEX) -project conducted in Finland between 2022–2025. The data include merged survey responses (N=553) and individual interviews (N=20) collected among older (65+) adults receiving formal home care services on a regular basis.

The findings show that many older adults receiving formal home care experience different forms of social exclusion, particularly regarding financial resources, social relations and services. For some, home has become a place of multidimensional exclusion, reflecting challenges and unmet needs in multiple spheres of life despite receiving care services. The findings highlight the need to evaluate the adequacy of home care from the perspective of social exclusion. It is important to acknowledge that current ageing policies may in fact create and maintain exclusion among older people with multiple care needs.

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The dark side of mundane data care work

Iiris Lehto[1]
[1]University Of Eastern Finland, Finland

Datafication of healthcare and social welfare services has increased the need for data care work. Drawing on ethnographic data from an all-female Data team, this presentation focuses on the mundane data care work, particularly its darker sides, within a wellbeing services county in Finland. I examine how the data team manages the complexities of data care.

The term data care work highlights the labour and practical, day-to-day aspects of maintaining data and the specific actions taken by actors. Like human care work, data care work has been described as invisible or hidden work in the sense that it is often taken for granted or even not included in rationalised models of how IT systems influence work tasks or measurements of hospital productivity.

The findings indicate that the dark sides are concentrated on the difficulties in maintaining data quality. High-quality healthcare and social welfare data are crucial since the data is used to allocate funding to welfare services counties. This underscores the need to recognise the often hidden value of data care work. As a relatively new approach in care research, data care work offers a comprehensive perspective on the impact of datafication on healthcare and social welfare services.

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Facing reality and then coping – Recognising the complex dynamics of care relationships in reablement in the UK

Chunhua Chen[1]
[1]University Of York, United Kingdom

My immediate motivation for participating in the 'Dark Side of Caregiving' discussion is a rejection letter from a high-profile social policy journal: "One of my main concerns is that some of the ways that staff talked about people and families (not co-operating, low-potential for

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rehab, 'sabotaging' reablement plans etc) felt really disrespectful and sometimes really offensive ... how could we expect reablement to be effective if this is how some staff see and talk about the people they're meant to be supporting?".

Values are important in developing better care for people, but I'm surprised that some researchers can be so naïve and expect caregivers (i.e. service providers or families) to be saints. Only with a realistic perspective that recognises the dark side of care can we identify the real challenges and then find effective solutions.

This paper explores a significant and unpleasant dilemma in reablement - family sabotage or even resistance. Data was collected in 2022 from five local authorities in England and Wales, primarily through focus groups with reablement staff, supplemented by interviews with service users and their families.

It argues that, rather than the collaboration that is essential for reablement to achieve the goal of independence, reablement in the UK has involved complex interactions between service users and their families and service providers, with conflicting priorities and different goals. The paper highlights the complex dynamics and difficult emotions in care relationships, suggesting training needs for workforce development and wider policy debates, e.g. policy coherence.

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Thursday 26 June: Parallel sessions 4

TP19a Disability and human rights: Addressing support gaps across

Room: F3017
Time: 14:00-15:30
Chairs: Teppo Kröger, Yueh-Ching Chou, Salla Era

Presentations:

- 461 Benoît Eyraud: A Human Rights Approach to Disability? Applying the Spiral Model to the French Adoption of the CRPD
- 375 Gabor Petri: Are human rights-based care reforms possible in backsliding democracies? - Lessons from Central and Eastern Europe
- 229 Xin-yu Zhang: Lived Experiences and Agency of Younger Disabled Persons Living in Institutions for Older Adults
- 32 Denise Tyler: Association Between Self-Directed Models and Personal Care Assistant Wages

Short presentations:

- 215 Richard Brunner & Aisha Macgregor: Understanding and improving the wellbeing of Personal Assistants employed by disabled people: What do we know? What should be done?

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A Human Rights Approach to Disability? Applying the Spiral Model to the French Adoption of the CRPD

Benoît Eyraud[1]
[1]Université Lyon 2, France

Fifteen years after its adoption by the General Assembly of the United Nations and a decade after its ratification, France’s adoption of the Convention on the Rights of Persons with Disabilities (CRPD) has been met with harsh criticism by UN bodies. The Human Rights Committee of the International Convention on the Rights of Persons with Disabilities (CRPD) has pointed out inadequacies of French public policies regarding the implementation of the convention. Examples cited by the Human Rights Committee rapporteur concern "the non-harmonization of the 2005 law with the convention," its “roadmap on psychiatry and mental health" and the fact that "700,000 people in France remain deprived of their legal capacity." Criticism of the French system by extranational bodies has called into question both the application of international standards and the human rights approach to disability. This severity is based not so much on the question of the application of an international standard as on that of the “human rights model of disabil- ity.” Through the notion of domestication to analyze the influence of CRPD article 12 in the French context, this article seeks to shed light on the social and institutional conditions of changes in representing the rights of people with disabilities. It will show the scope and the limits of the domestication of article 12 based on the example of the universalization of the right to vote for all disabled people and the reluctance to transform legal norms such as those of guardianship and treatment without consent.

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Are human rights-based care reforms possible in backsliding democracies? - Lessons from Central and Eastern Europe

Gabor Petri[1]
[1]Central European University Democracy Institute, Inequalities and Democracy Workgroup, Hungary

In the context of developing new, progressive care systems, the role of participatory policymaking often gets superficial attention. The CRPD makes it mandatory for governments to include representative organisations of disabled people in the development and monitoring of policies. Today, disability movements participate regularly in forms of government consultations and monitoring. However, data is scarce about how these consultations (statutory and ad hoc committees, and other platforms of participatory policymaking) happen in practice, and if they ensure meaningful involvement for disability movements.
I will appraise the intricate relationship between disability movement participation in policymaking on the one hand, and policy progress on the other. I will build on a recent study that explored the position of disability movements in policymaking in Central and Eastern Europe (CEE; Bulgaria, Hungary, Romania and Serbia). I will also use monitoring data about deinstitutionalisation in CEE. I will argue that the planning and implementation of transformative care policies – including deinstitutionalisation reforms under Article 19 of the CRPD – depend on broader disability politics, and the state of country-level democracies. Findings suggest that CEE disability movements, even when formally join government consultations and monitoring, are only able to exert little influence over policy reforms and outcomes. Inclusion in policymaking remains tokenistic and superficial across CEE. In the second part of my presentation, I will focus on Hungary, a known example of de-democratisation, to show how parallel trends of democratic backsliding and the shrinking space for disability advocacy can contribute to a halt in policy reform.

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Lived Experiences and Agency of Younger Disabled Persons Living in Institutions for Older Adults

Xin-yu Zhang[1], Yueh-Ching Chou[1]
[1]National Yang Ming Chiao Tung University, Taiwan

Background and Aims:
In Taiwan, as in many countries, some younger disabled people remain institutionalized, often in facilities designed for older adults. However, their experiences are rarely acknowledged. This study adopts an emancipatory research paradigm to explore the subjective experiences of disabled persons under 65 in such institutions. It focuses on their accounts of support and care

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poverty leading to placement, their lived experiences and sense of agency within the institution, and their aspirations for transitioning to independent community living.
Methods:
Qualitative in-depth interviews were conducted with 14 younger disabled people residing in institutions for older adults, recruited through purposive and snowball sampling. Data, collected between December 2022 and May 2023, were analyzed through thematic analysis.
Findings:
Four themes emerged: (1) No Choice but to Enter: Young disabled persons are often placed in institutions for older adults by their families due to insufficient support; (2) Helpless Living: They feel isolated, like caged birds, surrounded by older residents with little peer interaction; (3) Life Remains Remarkable: Despite challenges, they adopt strategies to connect with the outside world and achieve self-realization; and (4) Hopes for Independence: Many dream of independent community living but face resource constraints.
Conclusions:
Strengthening formal support systems is crucial to prevent the institutionalization of younger disabled persons when informal care falls short. Institutions must address their social, emotional, and independence needs, including support for employment. Deinstitutionalization policies should facilitate their transition to community living with adequate resources, prioritizing their voices under the principle "Nothing about us without us."

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Association Between Self-Directed Models and Personal Care Assistant Wages

Denise Tyler[1], Miku Fujita[2], Susan Chapman[3]
[1]Scripps Gerontology Center, Miami University, United States, [2]Johns Hopkins Bloomberg School of Public Health, United States, [3]University of California San Francisco School of Nursing, United States

Most U.S. states offer self-directed models in their long-term services and supports programs. These models are a version of the “cash for care” models found in many countries. In self-directed models, clients, including older adults and people with disabilities, control how available funds are used to purchase services, including direct hiring of personal care assistants (PCAs) who provide assistance in the home and community. Self-directed programs vary by state. In most states, consumers have flexibility to set the hourly wage of PCAs and may choose to pay wages that differ from those paid to workers hired by care management organizations. Some advocates contend that PCAs working in self-direction programs can earn higher wages because overhead costs to care management organizations are eliminated in these models. The purpose of this study was to determine if state implementation of self-direction improves PCA wages. We used wage data from the U.S. Bureau of Labor Statistics to examine the association between self-direction and the wages of PCAs in comparison to the wages of other entry-level workers. We found PCAs have lower wages than other entry-level workers in all U.S. states and implementation of self-direction in a state did not have consistent associations with wages. In some states, the difference in wages between PCAs and other entry-level workers decreased after implementation and in some states the wage difference increased. There were no states where the difference in wages was eliminated indicating that self-direction is not a solution to the problem of low wages among PCAs.

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Understanding and improving the wellbeing of Personal Assistants employed by disabled people: What do we know? What should be done?

Richard Brunner[1], **Aisha Macgregor**[1], Rhiann McLean[1], Obert Tawodzera[2]
[1]University Of Stirling, United Kingdom, [2]University of Birmingham, United Kingdom

The UK-wide IMPACT social care programme, led by University of Birmingham, seeks to support social care partners to work better with evidence. This particular IMPACT project, based at University of Stirling, was focused on supporting partners in Scotland to use evidence to improve the wellbeing of Personal Assistants (PA) employed by disabled people. Improving PA wellbeing should enhance PA recruitment and retention, and boost choice, control and independent living outcomes for disabled people by giving more disabled people the confidence to choose a Direct Payment to directly employ a PA. IMPACT conducted a systematic review of international evidence on PA wellbeing and devised a novel approach to ‘sense-check’ this evidence with two Scotland-wide expert groups of PA employers and PAs. This paper will, firstly, report the systematic review analysis of the six factors that influence PA wellbeing, namely: job satisfaction and perceptions of PA work, isolation, employment conditions, training, and the nature of the work itself. Second, it will describe the resultant policy and practice recommendations to improve PA wellbeing in Scotland, coproduced with PA/PA employer partners. These empirical findings are interpreted using an ethics of care lens, drawing on Tronto’s (1993 and 2013) integrity of care framework, foregrounding three elements: attentiveness to the needs of all of those in the caring nexus; relational dynamics between PAs/PA employers, and how this intersects with wider systems and structures; and care being a social good and a fundamental component of what makes us human.

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TP25b Transforming early childhood education and care services

Room: F3020
Time: 14:00-15:30
Chairs: Francesca Bastagli, Emmanuele Pavolini, Stefania Sabatinelli

Presentations:

- 39 Adriana Offredi Rodriguez: Comparing the Inclusiveness of Social Policy in-Kind Benefits: Using the Family Model Method across Six Cases
- 65 Calum Webb: Did cutting spending on preventative services for children and families increase rates of child welfare interventions in England?
- 261 Antonio Carvalho & Alarico Ruffino: Education and Inclusion: on the importance of spaces for intergenerational bonding

Short presentations:

- 249 Doreen Gutewort: Early childhood experiences of participation as foundation for democratic socialisation

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Comparing the Inclusiveness of Social Policy in-Kind Benefits: Using the Family Model Method across Six Cases

Gabriela De Carvalho[1], Margarita Leon[1], **Adriana Offredi**[1], Ivan Cerrillo[1]
[1]Autonomous University Of Barcelona, Spain

Achieving a comprehensive, comparative cross-national understanding of the inclusiveness of social policies aimed at addressing social inequalities has proven notoriously difficult. These difficulties stem from both conceptual and methodological challenges. While there is broad agreement that more universal policies—those with fewer eligibility criteria—tend to be more inclusive, there is no consensus on the definition of social policy inclusiveness. Further, although prior research has successfully compared the inclusiveness of cash benefits across countries by calculating net disposable income, the cross-sectional analysis of in-kind benefits has proven much more challenging. We argue that the family model method is a valuable tool for comparing and measuring the inclusiveness of social services, as it provides a standardised unit of analysis that allows for clear identification of both cross-national and within-national differences in the inclusiveness of in-kind benefits. We create various family types, differing in key aspects such as the number and age of children, employment status, number of earners, administrative status, and the incidence of disability, to address the common question in social policies: 'who gets what?'. More specifically, this article compares how right to access to childcare benefits changes in Belgium, Croatia, Poland, Spain, Sweden, and the UK when contrasting the 'traditional' nuclear dual-earner cohabiting family with two children to other

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family types, such as families with migratory status or single-parent households. We anticipate that our contribution will pave the way for future researchers to explore comparative aspects of a range of social policies using this tool.

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Did cutting spending on preventative services for children and families increase rates of child welfare interventions in England?

Calum Webb[1]
[1]The University Of Sheffield, United Kingdom

By 2021-22, the average local authority in England was spending less than half of what it had spent in 2009-10 on preventative services for children and families, such as family support services, youth centres and youth clubs, and children's centres. Statements made by the children's social care regulator and by the National Audit Office have previously implied that the levels of spending on these services were not related to the quality of services, nor the rates of children entering care. This paper presents the findings from an analysis of the data from 2009-10 to 2021-22 using within-between regression models with lagged effects which found that cuts to these services were, in fact, associated with substantial increases in rates of children in care or placed on child protection plans. However, the impact of spending on these services on the rates of children entering care in England has been far from consistent across the time period studied. During this time, the UK also saw a dramatic shift away from community-based provision of preventative support and towards individualised and targeted provision. This was part of both a cost-saving drive, but also represented a significant epistemological shift towards "gold-standard evidence" at the expense of wider population- and community-level thinking around prevention. The paper will also consider the potential consequences of this policy shift at a systemic level.

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Education and Inclusion: on the importance of spaces for intergenerational bonding

Antonio Carvalho[1], **Alarico Ruffino**[1]
[1]Polytechnic University of Milan / Politecnico Di Milano, Milan, Italy

When both parents work and children's facilities are lacking or too expensive, Early Childhood Education and Care (ECEC) becomes increasingly urgent (Archambault et al, 2019). Then, creating spaces for intergenerational relationships between children and older people, promoting the emotional and social well-being of both social groups and fighting Ageism (WHO, 2021) could be an answer, also because children who regularly interact with the elderly tend to develop greater social skills and ability to face relational challenges (Gualano et al, 2018). We propose presenting and discussing these spaces.

Since the early 2000s numerous programs in schools, nursing homes and neighborhoods, have been implemented in Europe to promote spaces that bring together elderly and children through mentoring activities, lectures and games. Regulations, such as Law 328/2000 in Italy, promoting social well-being, provide a framework for intergenerational policies.

However, Covid-19 pandemic increased hyper-protective attitudes towards the most fragile. Children were further limited in open-air activities when compared to all previous generations (Gill, 2007) while the elderly were forced to reduced external social interactions. Nevertheless,

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studies have shown that a greater isolation, especially from children, has led to worsening mental conditions in older people (Patel et al, 2022).
Besides environmental benefits, urban green areas can also promote safe intergenerational gathering places (Vogler et al, 2023) as seen in Galway and South Dublin (Kerrings et al, 2011), Switzerland and Germany, where in some neighborhoods and buildings, older people became key figures in younger children's care, or in after-school programs while parents are at work.

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Early childhood experiences of participation as foundation for democratic socialization

Doreen Gutewort[1]
[1]Department Of Educational Science/ Bielefeld University, Germany

This article examines how early childhood experiences of participation influence the development of a child's self and serve as a foundation for democratic experiences, based on Kálló's statement, "At peace with myself, at peace with others" (2015). It particularly focuses on the implications of care theory in early childhood acts of care. Traditionally, these acts have been marginalized and viewed merely as hygienic tasks (Gutewort 2025), unexplored left their potential as unique body dialogues. The Loczy research on care (Appell and David 1995; Pikler 2001; Pikler and Tardos 2002) highlights the significance of relational care in the development of a child's self. Caring acts contribute to physical well-being and promote self-development and relational abilities. In addition to parents, this requires professionals in an institutional context who are also able to respond to the child's need to merge in a compensatory way and who offer and facilitate the transitional space between subject and object, between self and other, between fantasy and reality, between play and seriousness. In such participatory dialogues, moments of self-determination become intersubjective experiences of recognition (Honneth 2000), which can be seen as the initiation and reinforcement of democracy, aligning with Tronto's ideas (2000, 2013). Recognizing the importance of responsive professional action (Gutknecht 2010) allows to explore participatory professional and practical actions at various levels, highlighting their significance for children, professionals, and processes in institutional context. Participation processes in early childhood development can be viewed as initial developmental tasks and needs, representing an early initiation into democratic experiences.

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TP3b New technologies in care work: imaginaries, phantasms and new practices of care

Room: F3005
Time: 14:00-15:30
Chairs: Annette Kamp, Hanne Marlene Dahl, Agnete Meldgaard Hansen

Presentations:

- 140 Leif Sundberg: Frames of Participation in the use of Welfare Technology in Elderly Care
- 174 Antti Hämäläinen: Transforming the Nordic Welfare Regime – Policies and Frictions in Introducing Welfare Technology
- 317 Romi Mikulinsky: Designing Inclusive Phygital Spaces: A Speculative Workshop for Elder Care
- 244 Annette Kamp & Agnete Meldgaard Hansen: Welfare technology as a ‘solution’ to the care crisis: Socio-technical imaginaries and transformations of care in the Danish welfare state.

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Exploring Patterns of Inclusion in the Use of Digital Technology in Elder Care

Leif Sundberg[1], Sheila Zimic[2], Katarina Andersson[1], Magnus Bergmark[1], Björn Blom[1]
[1]Umeå University, Sweden, [2]Kommunförbundet Västernorrland, Sweden

Digital technologies are increasingly used in various sectors of society, including welfare services and social work. Technology is not a “neutral” phenomenon, but subject to the norms and values of the people engaged in its design and use. Thus, it is important to gain knowledge of the relevant social groups involved in shaping technology, to understand the its development and trajectory. To do so in this paper, we explore survey data from staff engaged in home care services for older people in two Swedish municipalities. We investigate staff’s perception of being included in the use of technology (i.e., deciding how and when digital technology should be used) in these organizations. Our findings demonstrate two main patterns. First, relatively low levels of inclusion throughout all staff groups. Second, how factors such as demographics and technology views affect variations in perceptions of inclusion. Taken together, the results suggest that there is an untapped potential for implementing more participatory processes to include care receivers and care staff in to a larger extent, but also that this might require larger shifts in how welfare technology is developed and used. Through these results, we contribute both empirically and methodologically to research on using digital technology in elder care.

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Transforming the Nordic Welfare Regime – Policies and Frictions in Introducing Welfare Technology

Antti Hämäläinen[1], **Joni Jaakola**[1], Doris Lydahl[2], Hilde Thygesen[3], Kristín Bjornsdottir[4], Niels Christian Mossfeldt Nickelsen[3]
[1]University Of Jyväskylä, Finland, [2]University of Gothenburg, Sweden, [3]University of South-Eastern Norway, Norway, [4]University of Iceland, Iceland

Based on a data driven thematic analysis of 57 key policy papers and reports from each of the five Nordic countries, we discuss national strategies on introducing welfare technology to care of older persons. We argue that the Nordic care regime is central as background for understanding and comparing welfare technology policy in two senses: 1) the tradition of strong states and extensive social rights are to the point of developing welfare technology policy, and 2) the ongoing transformation of welfare states through marketisation and digitalisation affects, promotes and pushes welfare technology policy. It appears from our analysis that Denmark and Norway have been the forerunners of utilising the concept of welfare technology in strategy papers and in practice, whereas Sweden, Iceland and Finland have followed their example. We point at several frictions emerging nationally as well as across the Nordic countries when welfare technology is introduced, that is, hype and too optimistic expectations; the issue of contested national rollouts; and the fact that there is often financial cover of acquisition, but not of maintenance cost. Our study contributes to research on care policy by contrasting different Nordic national welfare technology strategies and definitions as well as experienced frictions. We argue that the analytic notion of frictions may support inter-stakeholder communication by providing cues to and making sense of the complexity of welfare technology innovation.

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Designing Inclusive Phygital Spaces: A Speculative Workshop for Elder Care

Romi Mikulinsky[1,2], Tehilla Shwartz Altshuler,[3]
[1]Aalto University, Finland, [2]Bezalel Academy of Arts and Design, Jerusalem, Israel, [3]The Israel Democracy Institute, Israel

Previous research in Science and Technology Studies has highlighted the growing gap between technological development and policymaking (Berardi et. al, 2024; Hameed et. al., 2024), especially regarding technologies for aging populations. While scholars have examined technology adoption among older adults (Berkowsky, Sharit, & Czaja, 2018; Gambo et al., 2023), less attention has been paid to participatory approaches in designing future phygital spaces, where physical and digital realities converge through technologies like smart glasses. These technologies raise critical questions regarding privacy, autonomy, equality, and sociability in public spaces.

Our research employs speculative design methodology to investigate how emerging phygital technologies impact three key interaction types: person-to-person, person-to-space, and person-to-reality (P2P, P2S, P2R). Building on Pink's (2022) conceptualization of futures as experiential and contingent, we developed a participatory board game as our primary research tool. This game facilitates structured interactions between elderly individuals, families, caretakers, technologists, policymakers, and designers through role-play scenarios addressing ethical challenges in technology adoption.

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Our methodology combines future thinking, participatory design workshops, stakeholder interviews, and comparative analysis of policy frameworks. Results reveal that the game-based approach bridges communication gaps, enabling nuanced discussions about elderly care. We identified friction points between stakeholders' needs and values, particularly regarding surveillance and agency. Our methodology exposes blind spots in current policy approaches and highlights where regulatory frameworks need adjustment.

Our research demonstrates how speculative design offers practical tools for democratic technology governance. This approach enables consideration of diverse needs and perceptions of older people, leading to more inclusive and equitable digital futures.

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Welfare technology as a ‘solution’ to the care crisis: Socio-technical imaginaries and transformations of care in the Danish welfare state.

Annette Kamp[1], **Agnete Meldgaard Hansen**[1]
[1]Roskilde Universitet, Denmark

For more than a decade, ’Welfare technologies’ have appeared as a key ‘solution’ in Danish debates and policies addressing the crisis of care in the eldercare sector (Kamp et al., 2019). Expectations from national and local policymakers are high, forming a very optimistic ‘sociotechnical imaginary’ (Jasanoff and Kim, 2015) of a digitalized eldercare sector providing both better and more efficient care for a growing population of older persons.
Drawing on key policy documents, this paper will firstly analyse the central tenets of this sociotechnical imaginary, illustrating both its ideational dimensions, emphasizing care ideals of self-sufficiency, empowerment, freedom and dignity, and dimensions concerning the operation of the welfare state such as improved efficiency, financial sustainability, and recruitment and retention of care workers.
Secondly, drawing on promotional material, public debates, and our own previous research about two widely used welfare technologies – robot vacuum cleaners and virtual homecare visits – we will analyse how these different technological interventions enact the imaginary of digitalized eldercare quite differently, leading to respectively widespread controversy (robot vacuum cleaners) and to more ‘quiet’, yet profound, transformations of care practices (virtual homecare visits).
The paper concludes by discussing the different future avenues that the introduction of digital technologies may take us.

References
Jasanoff, S. and Kim, S.-H. (2015), Dreamscapes of Modernity, Sociotechnical Imaginaries and the Fabrication of Power. University of Chicago Press.
Kamp, A., Obstfelder, A. and Andersson, K. (2019), “Welfare Technologies in Care Work”, Nordic Journal of Working Life Studies, Vol. 9 No. S5, doi: 10.18291/njwls.v9iS5.112692.

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TP21b Autonomy in long-term care: ideas, discourses, regulations, and practices

Room: F3010
Time: 14:00-15:30
Chairs: Ralf Och, Olivier Giraud

Presentations:

- 404 Eléonore Segard: Roles of professionals in considering older people's autonomy in the context of support : a scoping review
- 409 Virginia Mellado & Arnaud Trenta: Housing arrangements and the autonomy of elderly and disabled people
- 316 Angela Perone: Safety versus Autonomy in Long-Term Care Facilities in the United States

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Roles of professionals in considering older people's autonomy in the context of support : a scoping review

Eléonore Segard[1], David Faure[2], Olivia Gross[1]
[1]Laboratoire Educations et Promotion de la Santé - LEPS UR 3412 - Université Sorbonne Paris Nord, Bobigny, France, [2]Centre de recherches en éducation et formation. Equipe "savoir, rapport au savoir et processus de transmission" (EA 1589 CREF), Université Paris Nanterre, Nanterre, France

Background. The importance of autonomy is revealed when conditions for autonomy are not met anymore. There is limited understanding of how staff address matters of autonomy in the support of older people. The aim of the review was to synthesize how older people's autonomy is understood in the literature in the context of support and how this is handled by professionals.   Methods. Four electronic databases were systematically searched in order to perform a scoping review on professionals practices in regards to people's autonomy. .
Results: 57 studies were finally included. Articles deal with a vast range of situations which have been analysed in terms of setting, life dimension and outcomes of autonomy. Three key challenges for professionals to address autonomy have been identified : building a personalized relationship, dealing with the vagueness of the professional's mandates, resolving conflicts between different values. Three main actions mobilize specific know-how from professionals: A) supporting aspirations and expression; B) supporting decision making; C) supporting actions. Professionals also need specifics know-how to adapt daily to any situation that comes their way in order to maintain a dynamic relationship with the older people and to use every opportunity possible to consider their autonomy.
Conclusion. Recognising the multifaceted nature of autonomy, understanding the nuance of its multiplicity the article proposes a framework for thinking autonomy and consider autonomy as

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a dynamic process that must be navigated through a relation between older people and professionals.

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Housing arrangements and the autonomy of elderly and disabled people

Virginia Mellado[1], **Arnaud Trenta**[1]
[1]Ires, France

For several decades, the issue of autonomy for the elderly and people with disabilities has been a major public problem in France. Policies of deinstitutionalisation in the field of disability and home care in the field of old age, in the name of the freedom of choice of the people concerned, have gone hand in hand with the professionalisation of home care services and the recognition of family carers, limiting institutional care to the most advanced situations of dependency. These last years, policy-makers and private market and non-market stakeholders have developed various forms of intermediary housing that lie between ordinary housing and nursing homes. The aim of this paper is to analyse the relationship between housing arrangements and the autonomy of the elderly and people with disabilities. By comparing situations in ordinary housing, in assisted living residences and in inclusive housing, the analysis explores the residential trajectories of people and the determinants of their choice of housing, the social relationships that these types of housing give rise to or limit (family solidarity, community links, service provision), access to rights in and through these different homes, and the way in which these housings relate to the different dimensions of autonomy (acts of daily living, sociability, citizenship, etc.). The analysis is based on interviews with elderly and disabled people, family carers and professional carers in urban and rural areas of two departments in France.

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Safety versus Autonomy in Long-Term Care Facilities in the United States

Angela Perone[1]
[1]University of California, Berkeley, United States

Long-term care poses significant conflicting rights between safety and autonomy for nursing home residents in the United States. This study uses a multi-method qualitative research design to examine how long-term care facility staff at various levels (floor staff, mid-level managers, top management) exercise discretion to resolve conflicting rights regarding resident safety and autonomy. This paper focuses on three situations: fall prevention, food intake/refusal, and medication management. Staff at various levels employed unique tools to exercise discretion, including via interpersonal conversations, documentation, and organizational lenses / resources. Staff understood and responded to conflicting rights by invoking interprofessional team approaches across staff hierarchies, especially among floor staff and mid-managers. Even when upper-managers sought external guidance (e.g. attorneys/risk managers) to resolve conflicting rights, they deferred to the discretion of floor staff and mid-managers to communicate and implement decisions on the ground, which still left room for discretion. Team approaches across staff hierarchy were less common when conflicting rights arose in medication management. Differences in organizational structure became relevant only when conflicting rights regarding autonomy and safety arose in the context of food intake. This study underscores the ubiquity and importance of team collaboration for resolving conflicting rights, particularly in a healthcare context where interprofessional teams are common. However, structural limitations that preclude some front-

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line workers from participating in formal meetings constrain their capacity to contribute beyond informal conversations with their colleagues.

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OS9 Vulnerabilities and care

Room: F3006
Time: 14:00-15:30
Chairs: Christine Kelly

Presentations:

- 190 Christine Kelly: Effective Interventions to Strengthen the Care Workforce: A Realist Synthesis Review
- 271 Shu-Er Wei: Change in the Cause of Death Structure in Taiwan and its Social Care Implications: the Analysis from 1972 to 2023
- 263 Huifen Hung: The isolated single-mother carers of children with disabilities under precarious employment
- 207 Sarah Åkerman: The alieniating experiences of caring for a spouse with dementia in a neoliberal society

Short presentations:

- 117 Yu Yinting: Addressing Loneliness, Depression, and Enhancing Quality of Life Among Care Home Residents: An Intervention Study

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Effective Interventions to Strengthen the Care Workforce: A Realist Synthesis Review

Christine Kelly[1], Lisette Dansereau[1], Ellie Jack[1], Salina Pirzada[1], Yuns Oh[1], Pranav Bhushan[1], Lorine Pelly[1], Janice Linton[1], Carey McCarthy[2], Giorgio Cometto[2]
[1]University of Manitoba, Canada, [2]World Health Organization, Switzerland

Care workers are in high demand to support growing populations who need help in daily life due to disability, aging, acute or chronic health issues, inaccessible environments, and/or socioeconomic vulnerabilities. Paid care work is predominantly carried out by women, tends to be un- or underregulated, and associated with low pay, high turnover, and precarious working conditions. Strengthening the care workforce is thus an urgent priority for health workforce planners. This realist synthesis review asks: Which interventions effectively strengthen the care workforce? Guided by an international advisory group and following RAMESES I and PRISMA-S publication standards, we systematically identified 7396 peer-reviewed sources and 481 grey literature sources, with 151 included in the review. The sources document a variety of effective interventions across the working lifespan, with an emphasis on pre-service and ongoing training for care workers. We found ambitious and effective interventions that aim to support the care workforce on multiple fronts. We encourage policy makers and researchers to pilot complex interventions that cover the entire working lifespan focusing on legislative structures,

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educational oversight, and material working conditions such as scheduling and pay as effective avenues for strengthening the care workforce.

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Change in the Cause of Death Structure in Taiwan and its Social Care Implications: the Analysis from 1972 to 2023

Shu-Er Wei[1], Ding-Yi Lai[2]
[1]Dept of Life-and Death Studies, Nanhua University, Taiwan, [2]Institute of Political Science, Academia Sinica, Taiwan

This paper aims to articulate the social fact which is constructed by varied items of death behaviors, and to analyze their proportion allocations since 1970s in Taiwan. It is found that with the development of compression of disease, larger number of people than before die in their late old age, therefore, the proportion of death age is significantly getting older. Female, aged (esp. over 85 year), married and widowed and natural death, who probably can die at home. Based on this transformation of death structure, the development of care relations and places of death has been correspondently changed. That could challenges meaning of good death, which is advocated by modern hospice movement.

According to the promotion of home care and community care policy, the proportion of die at home gradually increased, whereas the proportion of die at hospital oppositely decreased in European, American or Japan societies. On the contrary, the proportion of Taiwan people dies at home gradually decreased, whereas the proportion of them dies at hospital increased from 1972 to 2023.

This paper therefore articulates that place of death can not only be an indicator of good death in aspect of clinic practices, but also could be an index of care relationship. As given research literatures noticed, that marriage still supports older Taiwanese people’s choice. Consequently, this paper suggests, that place of death as an indicator of good death and the type of care relation can be meaningful to long-term care policy, which concerns to build reasonable care arrangements.

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The Isolated Mother-carers of People with Disabilities under Neoliberal Ableism: The Intractable Outsourcing of Parenting Children with Disabilities

Huifen Hung[1]
[1]Department of Social Work, Soochow University, Taiwan

This article discusses the isolation experienced by single mothers who care for children with disabilities, based on in-depth interviews with 18 mothers of children with disabilities and two sessions of focus group interviews with supportive social workers. The findings indicate that this isolation stems from a dual disadvantage: the marginalization of caregivers in the labor market and the societal exclusion faced by people with disabilities. As the labor market grows more competitive, working mothers often attempt to outsource parenting responsibilities. However, finding professional caregivers who understand the specific needs of children with disabilities is challenging, as these caregivers may lack experience due to the historical isolation of individuals with disabilities from mainstream society. When outsourcing caregiving is difficult, it limits the mother’s opportunities for respite and disrupts her ability to work, increasing her economic dependence on the father. This dependence further deepens her

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isolation as a caregiver. Insights from the interviews reveal that the unequal distribution of caregiving responsibilities can strain intimate relationships and raise the risk of marital breakdown. While divorce may alleviate some emotional burdens, single parenting can leave these mothers more vulnerable. Living with their original family can help mitigate this isolation; however, divorced daughters with unstable employment may find themselves serving as primary caregivers for their parents, complicating their role as caregivers. The article concludes with recommendations for national policies that address the dual discrimination faced by caregivers and individuals with disabilities.

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The alieniating experiences of caring for a spouse with dementia in a neoliberal society

Sarah Åkerman[1]
[1]Åbo Akademi University, Finland

Nordic welfare states are known for relatively generous public services based on a mainly tax-financed dual-earner model. With its reliance on the public sector, familialism norms in Finland are comparatively low. Due to austerity measures during past decades however, the role of family members has implicitly and explicitly become more central. Spousal caregivers of someone with dementia are generally seen as a vulnerable group with risks of loneliness and social isolation. Partly through public funding, tailored peer support programs are offered to meet the specific social needs of caregivers in Finland. Indeed, apart from practical obstacles to maintaining previous relationships outside of the household, stigma may hinder social participation as caregiving and dementia fit poorly into the Western independent pleasure-seeking lifestyle ideal. For many, caregiving drastically changes the life course trajectory, and the support from the welfare state may not be as generous as expected – forcing caregivers to overcome norms of autonomy and ask for help in the community – or hide one’s misery and minimise contact. This paper critically analyses spousal caregivers' experiences of care and dementia and its impact on social relationships in contemporary society. The analysis is based on interviews collected with sixteen spousal caregivers in Finland. The paper discusses the individualisation and stigmatisation of care and dementia and argues that dementia and care are simultaneously over and under medicalised. The paper ends with a discussion on the potential practical implications of combining medical humanities, care ethics, and social policy perspectives in research.

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Reducing Loneliness, Depression, and Enhancing Quality of Life Among Care Home Residents: An Intervention Study

Yin-Ting Yu[1], Ya-Ching Chang[1], Yueh-Ching Chou[2]
[1]Institute of Health and Welfare Policy, National Yang Ming Chiao Tung University, Taipei, Taiwan, [2]Department of Social Work, Asia University, Taiwan, Taichung, Taiwan

Background
Moving to a care home is uncommon in Taiwanese culture but becomes necessary for older adults with intensive support needs that families cannot meet. Research shows that care home residents often experience higher levels of depression and loneliness compared to those living in the community. This study explored depression, loneliness, and quality of life (QoL) among care home residents and developed an intervention to address these issues.

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Method

A mixed-methods design was used. Literature review and needs assessments, incorporating quantitative and qualitative data from older adults (n=11) and staff (n=2), informed the development of a pilot intervention. The intervention was pretested with 30 residents in two care homes (15 experimental, 15 comparative) using a quasi-experimental design. Based on the pilot results and additional needs assessments, the intervention was revised and tested in a main-field quasi-experimental study with 30 residents in two different care homes.

Results

The pilot test showed no significant quantitative differences but revealed positive qualitative feedback from both residents and staff. The main-field test demonstrated significant quantitative improvements, including reduced loneliness and depression and enhanced QoL in the experimental group compared to the comparative group. Qualitative data further highlighted the intervention’s positive reception by residents.

Conclusion

The revised intervention effectively reduced loneliness and depression while improving QoL among care home residents. The findings underscore the importance of tailoring interventions through needs assessments, iterative modifications, and multiple evaluations to address the needs of this population.

Keywords: older adults, care home, loneliness, depression, quality of life, intervention, mixed methods

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S10 Equal social rights to care and living environments for older people – a question of collaboration: CollAge

Room: F3004
Time: 14:00-15:30
Chairs: Ebba Högström, Katarina Andersson
Discussants: Virve Repo, Karen Christensen

Collaboration between municipal sectors is of vital importance in caring and planning for older people. In Sweden, collaboration between social services eldercare and urban planning is stipulated in the Social Services Act from 1982. The theme of this symposia elaborates on dimensions of social care and urban planning in times of increasing diversity amongst older people and ageing-in-place and active ageing ideologies. Influence and independence are core national values and part of the social rights-discourse to claim one's rights. Arranging for good quality care and good living conditions is of public interest and a prerequisite for ageing societies characterized by inclusion and equal social rights. The WHO Age-Friendly Cities and Communities network raises questions of for whom living environments are planned for.

How would an age-friendly built environment perform to justify its name, specifically if with focus on social infrastructure? (EH, DMV) How is equal access to care secured in rural areas? Ageing-in-place may be challenging in geographically secluded areas (AN). Other topics raises perspectives of what ageing is represented to be from professionals (KA) and how could senior citizens take a more active part in future planning and eldercare as co-researchers (MSJ). This symposium also accounts for discourse and practice of planning and eldercare provision for older people and what social rights that might be at stake in Sweden's municipal eldercare and planning regime (TR). Taken together, the symposium will contribute with discussions of care and living environments for older people relating to the central themes of the conference.

Papers:

Ebba Högström, (EH) and Daniel Movilla Vega (DMV) School of Architecture, Umeå University: Collaboration and innovation in eldercare housing in the light of visions.

Amanda Nyberg, (AN) Department of Social Work, Umeå University: Care, planning, and ageing-in-place in rural areas.

Tirtha Rasaili, (TR) Department of Spatial Planning, BTH: Mapping the discourses around older people and eldercare in Swedens' municipal comprehensive plans: perspectives, implications and challenges.

Maria Sjölund (MSJ) and Katarina Andersson, (KA) Department of Social Work, Umeå University: Age-friendliness for whom? Experienced senior-citizens as co-researchers: accounting for equal social care, sustainable living arrangements and social representations of ageing.

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S13 Transforming care in the lives of people with learning disabilities and their family carers through co production research

Room: U3039
Time: 14:00-15:30
Chairs: Martina Smith, Francesca Ribenfors
Discussants: Katherine Runswick-Cole

This symposium brings together four projects that explore the lives of people with learning disabilities and their family carers in the contexts of health and social care research. Our approach to understanding access to support for people with learning disabilities is guided by a social model of learning disability which argues for a transformative shift away from solely individualised responses and ‘solutions’ to the issues that people with learning disabilities and their families face. We argue that we need to understand the impact of policies and service systems to build better support for people with learning disabilities and their families. Historically, people with learning disabilities have not been given meaningful roles in research about improving their lives and have been excluded from decision making within the health and care systems and services that construct their lives. In contrast, our approach is a collaborative one, drawing on the principles of participatory action research (PAR), which place the perspectives and knowledge of marginalised communities at the centre of research design and practice. Throughout the symposium, we will reflect on working in partnership in this way, and argue for the importance of user-led research. Each project exposes the challenges and discrimination people with learning disabilities face and their family carers face in the context of health and social care. At the same time, each project reveals moments of resistance and possibilities for transformation in care. We conclude with a shared commitment to transforming health and social care policy and practice to enable people with learning disabilities and their family carers to lead flourishing lives.

Papers:

Paper 1: Dr Francesca Ribenfors, Manchester Metropolitan University, UK

Paper 2: Dr Martina Smith, University of Sheffield, UK

Paper 3: Dr Harriet Cameron, University of Sheffield, UK and Professor Katherine Runswick-Cole, University of Sheffield, UK.

Paper 4: Charlie Grosset, University of Sheffield, UK

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Thursday 26 June: Parallel sessions 4

S8 Long-term care policies and intergenerational care support in China

Room: U3029
Time: 14:00-15:30
Chairs: Yingzi Shen
Discussants: Sue Yeandle, Kate Hamblin

In recent decades, China has undergone significant demographic and social changes which are characterised by a rapidly ageing population, low fertility rate and large-scale rural-to-urban migration. The World Health Organisation shows China has one of the fastest growing ageing populations in the world, with an aged population expected to increase to 28% by 2040. China's fertility rate has remained below 1.9 since the 1980s one-child policy. These demographic characteristics mean serious challenges in care arrangements for Chinese families and the state.

In addition, China has witnessed unprecedented urbanisation and modernisation since its opening-up policies in the 1980s, resulting in a divided rural-urban welfare system and hierarchical social rights. In 2023, more than 290 million people moved to cities temporarily without equal access to urban local welfare benefits. The dual rural-urban system has resulted in care deficit and difficulties in migrant families.

The symposium will provide critical insights into institutional and familial approaches of dealing with care challenges in China. Wenjing Jin's paper focuses on transformation of China's LTC policies under the framework of policy diffusion. Her findings suggest a three-stage diffusion process in China's LTC policies. Sha Li's paper examines the one-child generation's expectations about eldercare provision and possible tensions between work and eldercare support. It emphasises gaps in care provision and offers recommendations for tackling eldercare. Jiaxin Liu's paper explores the arrangement and negotiation of intergenerational support under changes in family structure and new public pension schemes. The findings demonstrate both older people's individual agency and familial agency, with family an essential socio-economic actor in eldercare. Yingzi Shen's paper focuses on intergenerational negotiation of childcare practices when three generations are incorporated in rural-to-urban migration. It identifies three patterns of migrant grandparents' roles in childcare provision and explores intergenerational tensions and strategies of coping with these tensions.

Papers:

Paper 1: Diffusion of Long-term Care Policies in China: qualitative research based on policy texts - Dr. Wenjing Jin, Nanjing University of Science and Technology, China.

Paper 2: Who Will Look After Our Older People in China in the Future? - Dr. Sha Li, University of Nottingham, UK

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Paper 3: Two levels of agency: the negotiation of intergenerational support in Chinese families - Dr. Jiaxin Liu, University of York, UK

Paper 4: Intergenerational cooperation on childcare in rural-to-urban migrant families in southern China - Yingzi Shen, University of Sheffield, UK

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Thursday 26 June: Parallel sessions 5

TP13c Dark side of care

Room: Small Hall
Time: 16:00-17:30
Chairs: Tiina Sihto, Paula Vasara

Presentations:

- 71 Jenni Repo: Challenges in Implementing Legislation in Children's Residential Homes in Finland: Care Workers' Views
- 203 Claire Edwards & Carol Kelleher: Challenging care deficits: negotiating the politics and consequences of complaint in neoliberal care configurations in Ireland
- 307 Macgregor Goodman: Routinized violence: Staff perspectives on the acceptability of force in long-term residential care

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Challenges in Implementing Legislation in Children's Residential Homes in Finland: Care Workers' Views

Jenni Repo[1]
[1]Tampere University, Tampere, Finland

Based on an article manuscript, this paper explores the challenges of implementing legislation in children's residential homes, focusing on the perspectives of care workers. Drawing from a socio-legal theory, the study examines how regulatory responses to malpractices—such as breaches of children's rights and poor treatment in care—shape everyday work in residential settings.

While regulation is intended to safeguard children and ensure accountability, in Finland it may have produced a new 'dark side': care workers struggling to comply with complex legal requirements while balancing care, protection, and the diverse needs and rights of children. The study investigates this tension between legal mandates and practical realities, highlighting how workers navigate the intersection of law, institutional expectations, and relational care.

The empirical data consist of interviews with 15 care workers employed in privately operated residential homes. The findings reveal a disconnect between the legislative ideal and the realities of practice, particularly in relation to restrictive measures, bureaucratic demands, and ambiguous legal guidance. These challenges illustrate the gap between 'law in books' and 'law in action' and raise questions about the feasibility of implementing a rights-based approach in everyday care work. By centering practitioners' experiences, the study contributes to critical discussions on regulation, professional discretion, and the relational dimensions of child protection.

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Challenging care deficits: negotiating the politics and consequences of complaint in neoliberal care configurations in Ireland

Claire Edwards[1], **Carol Kelleher**[1], Felicity Daly[2], Cliona Loughnane[1], Jacqui O'Riordan[1]
[1]University College Cork, Ireland, [2]Trinity College Dublin, Ireland

This paper explores the dynamics and consequences of vocalising care deficits within neoliberal care configurations in Ireland. Drawing on a three-year qualitative research study exploring how we might re-envision care relations in Ireland following COVID-19, our analysis focuses on the experiences of two groups accessing different forms of care: asylum seekers living in congregated settings of the Irish state system for international protection (known as Direct Provision), and disabled people living in community settings. Recognising that care relations are always situated (Raghuram, 2016), we reveal how different institutional contexts and politics of identity shape participants' experiences of navigating perceived and actual fears about the consequences of complaining and speaking out about care failings. Thus, we illuminate how asylum seekers living within congregated settings of Direct Provision articulated and challenged systemic care injustices during COVID-19, often defying threats of retaliation. We also foreground disabled people's decision-making around vocalising care deficits in support services, negotiating fears about loss of service or erosion of interpersonal support relationships. Connecting both groups, we reveal how those who speak out about care deficits can be marginalised or left to absorb institutional care failings and highlight the importance of collective activism in challenging care abuses. Our research therefore asks how we might better amplify the voices of those receiving care and build solidarities across diverse constituencies as a way of challenging the power relations that create careless welfare regimes.

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Routinized violence: Staff perspectives on the acceptability of force in long-term residential care

Macgregor Goodman[1], Laura Funk[2], Rachel Herron[3]
[1]York University, Canada, [2]University of Manitoba, Canada, [3]Brandon University, Canada

In long-term residential care (LTRC), sometimes staff provide involuntary care—care that residents refuse or resist—which can cause harm to both staff and residents. There has been a significant amount of research internationally on conditions of care for older adults living in institutions, but there is a lack of research on the factors that influence the acceptability and normalization of forceful and non-consensual treatment. In this analysis, we explored how and when staff provide involuntary care, when they accept or see this practice as necessary and when they reject this practice. Data included interviews with staff, families, and residents working and living in LTRC as well as observations in two Canadian provinces. The acceptability of involuntary care was often influenced by the potential of harm toward staff rather than the potential for harm to residents. This is apparent through the rationale given for what kind of force is acceptable in care, and what kind of force is not. The potential for staff injury and risk of being reprimanded by management are frequently factors in whether or not to proceed in providing care that the resident has not consented to. Staff narratives about the use of involuntary care reflect a lack of both interpersonal and organizational safety that undermines the autonomy and dignity of those for which they provide care. Institutional culture around

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resident autonomy and policy restricting the use of force in care are observed to be accompanied by safer and slower-paced day-to-day conditions of life and work.

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TP9 Strengthening informal carer's social rights through public policies

Room: F3003
Time: 16:00-17:30
Chairs: Mirjam Pot, Selma Kadi

Presentations:

- 171 Maureen D'Eath & Damien Brennan: 'Keeping it in the Family': The rejected Irish Constitutional amendment on family caregiving – Insights from the IDS-TILDA Carer Study

- 234 Francesca Donati: The opportunities of informal carers: the multilevel local policies of southern Europe.

- 301 Kayla Benjamin: Health and social care policies with consequences for unpaid caregivers in Bogotá, Colombia: An intersectionality-based policy analysis

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'Keeping it in the Family': The rejected Irish Constitutional amendment on family caregiving – Insights from the IDS-TILDA Carer Study

Damien Brennan[1], Mary McCarron[3], Phillip McCallion[2], Maureen D'Eath[1]
[1] School of Nursing & Midwifery, Trinity College Dublin, Ireland, [2]Temple School of Social Work, Philadelphia, USA, [3]Trinity Centre for Ageing and Intellectual Disability, School of Nursing & Midwifery, Trinity College Dublin, Ireland

The social contract for care encapsulates the relationship between the nation state, the family and the individual who requires care. The wide scale utilisation of large residential institutions as a societal response to the needs of people with an intellectual disability was common in Ireland during the 19th and 20th centuries. The prevailing social policy in the post-institutional era relies on the family as an entity to provide long term care at a time when family units have also undergone significant changes which have impacted their ability to provide such care.
In 2024 Irish people voted in two referendums on government proposals designed to change Articles of the Constitution relating to the definition of a family, and the interface between state and family. These changes would have had a significant long-term impact on defining and shaping the legal and social policy balance of responsibility for care provision between the State, the family and citizens in need of care. The two referendums were defeated by historic margins.

The Carer's Study within the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) explores the experiences of family carers of older people with an intellectual disability. Data from wave 5 of the study suggests that within the reality of an absence of formal services, it would appear that family-based care (particularly by women) continues to be constructed, as the natural and neutral form of care provision. This paper reflects on these findings alongside the course and outcome of the defeated referendums.

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The opportunities of informal carers: the multilevel local policies of southern Europe.

Francesca Donati[1], Maria Jesus Rodriguez Garcua[2]
[1]Università del Piemonte Orientale, Italy, [2]Universidad Pablo de Olavide, Spain

According to the literature, from the ethics of care (e.g., Tronto, 2013; Kittay, 2015) to feminism (e.g., Orozco-Perez, 2016), the rights and conditions of caregivers are central to the debate. The privatisation and genderisation of care have politically turned caregiving into unpaid or poorly compensated labour, exploiting power imbalances between countries and encouraging migration to meet care needs, particularly within households and often by women. Beyond the precariousness of caregivers, these perspectives stress the need for public intervention.

This paper examines multi-level care strategies in Southern Europe for protecting caregivers' rights, focusing on 0–3 childcare and dependent elderly care in two Italian (Bologna-Ravenna) and two Spanish (Cadiz-Huelva) municipalities. Based on 24 interviews with public actors, third-sector cooperatives, and voluntary associations, alongside 79 legislative documents at national (Italy-Spain) and regional (Emilia-Romagna-Andalusia) levels, we analyse public policies targeting informal caregivers and their implications for social rights.

Our findings reveal differences across national, regional, and local levels. In Italy, caregivers' social rights are primarily addressed economically, while Spain also considers workers' rights. Spain shows progress in addressing the marginalisation and precarisation of informal care workers. Regionally, Italian policies incorporate economic and work rights protections but apply means tests, excluding many caregivers. Locally, Bologna and Ravenna integrate families into public-private networks, offering "cash-for-care" schemes and contract management services. Conversely, Cadiz and Huelva focus on combining formal and informal caregiving. Overall, public policies prioritise economic sustainability over systemic care integration. A holistic approach valuing care's societal importance could better address caregivers' marginalisation and exploitation.

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Health and social care policies with consequences for unpaid caregivers in Bogotá, Colombia: An intersectionality-based policy analysis

Kayla Benjamin[1], Natalia Ramírez-Bustamante[2], Ito Peng[1], Erica Di Ruggiero[1]
[1]University of Toronto, Canada, [2]Universidade de los Andes, Colombia

As is illustrated by Razavi's (2007) care diamond, governments significantly influence their country's volume and intensity of unpaid care through health and social care policy. With a growing demand for care work worldwide, an increasing number of governments have been experimenting with innovative policies and programs to respond to the care needs of their societies. Bogotá, Colombia's District Care System (DCS), a feminist initiative to reduce women's unpaid care work, is one such example. This article addresses the research questions, "How are policies and programs in Bogotá supporting unpaid caregivers caring for children and seniors?" and "Where do policy gaps exist?" Guided by the principles and (sub-)questions of the intersectionality-based policy analysis framework (IBPA), this article reports on the results from (1) a document analysis of national and sub-national health and social care policies with relevance for unpaid care work in Bogotá, with a particular focus on services, regulations, and policies under the DCS; and (2) qualitative interviews with policymakers, local implementers, and caregivers who access DCS services. Findings from this policy analysis reveal that child and senior care policies and programs have differentiated consequences for caregivers, with caregivers who occupy certain social locations facing unique barriers to accessing supports and services and thereby being forced to rely on informal care. Use of the IBPA framework highlights opportunities to strengthen existing policy responses and programs to better target social and structural change and reduce inequities for unpaid caregivers living in Bogotá, Colombia.

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TP19b Disability and human rights: Addressing support gaps across

Room: F3017
Time: 16:00-17:30
Chairs: Teppo Kröger, Yueh-Ching Chou, Salla Era

Presentations:

- 131 Sally Robinson: Responding to everyday harm against people with cognitive disability
- 79 Ruth Bartlett & Laura Cole: Live-in care for people with dementia (LIVE-DEM): Introducing the first study conducted in England
- 132 Ya Ching Chang: The Intersection of Aging, Mental Health, and Care Poverty: Experiences of Adults with Psychosocial Disabilities
- 365 Ching-Wen Chang: Personal Recovery in Individuals with Schizophrenia in Taiwan: A Qualitative Investigation of Enabling Factors and Support Needs

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Responding to everyday harm against people with cognitive disability

Sally Robinson[1], Karen R Fisher[2], Heikki Ikaheimo[2], Ciara Smyth[2], Eleanor Watson[1], Raffaella Cresciani[1], Anna Smith[2], Ruby Nankivell[1], Rachel High[1], Hannah Ogden[3], Tyra Buteux[3]
[1]Flinders University, Australia, [2]UNSW Sydney, Australia, [3]Northcott, Australia

Everyday harm encompasses the negative impacts of actions and omissions (intentional or not) on someone's wellbeing. The harm can be emotional, psychological, or physical. It can limit growth and learning, damage relationships or a person's reputation. This paper reports the findings of an Australian national research project which aimed to learn how young people with cognitive disability and their paid support workers understood and addressed everyday harm in their work together. We interviewed 36 pairs of young people with disability and support workers on two occasions using a range of accessible methods; and 28 disability service managers about how their organisations responded to this form of harm.

In their interpersonal relationships, the pairs related many experiences of everyday harm, but also many ways they prevented and addressed it. Organisational policies, rules and cultures influenced how they enacted their relationships and addressed harm. Managers reported direct and indirect practices to address everyday harm, but prevention, trauma-responsive and restorative approaches were used less. No organisations drew on all identified levers to prevent and address harm.

We developed a typology of everyday harm to help people and organisations to understand and respond to this type of harm which is distinct from the violence and abuse frameworks that

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many organisations already have. Everyday harm is rarely single-incident-based - it accumulates, sometimes it is hard to see, and it is difficult for people to articulate. Understanding and addressing everyday harm is possible, and urgently needed to address the direct and lateral violence disabled people face.

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Live-in care for people with dementia (LIVE-DEM): Introducing the first study conducted in England.

RUTH BARTLETT[1], **Cole Laura**, Catherine Henderson, Stefan Brown, Karen Harrison-Dening, Jo Thompson-Coon
[1]University Of Southampton, United Kingdom

In many countries, including England, relocation to a care home is often presented as the only 'safe' and affordable option for people with dementia who need 24-hour support; in fact, the chance of moving to a care home is increased fivefold for people with dementia compared to people without dementia. Yet, dementia is a disability, therefore people are not obliged to live in a particular living arrangement according to the UN Convention on the Rights of Persons with Disabilities.

One alternative, and an unexamined model of service delivery is live-in care; this is when a care worker moves into (rather than visits) a client's home to provide support. Several companies in England offer live-in care to people with dementia and many local authorities in England list live-in care providers in their service directories. Nonetheless, live-in care is a relatively 'hidden market' and there is a major gap in knowledge about this form of support.

In this presentation, we introduce the first study conducted in England on live-in care. The study aims to understand how and why live-in care packages are arranged and sustained, when dementia is the primary support need, and to characterise the nature of this market in England. It uses mixed methods and 'ageing-in place' as a theoretical underpinning. The team includes a health economist, academic social worker, and a person living with dementia. Our plan is to research live-in care from multiple perspectives to provide evidence for decision makers, including families and policymakers.

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Care Poverty among Middle-Aged and Older Adults Living with Severe Mental Health Conditions

Ya-Ching Chang[1], Yueh-Ching Chou[1]
[1]Institute of Health and Welfare Policy, National Yang Ming Chiao Tung University, Taipei, Taiwan

Background and Aims

Unmet care needs among middle-aged and older adults with psychosocial disabilities remain underexplored. This study uses the care poverty framework to examine how individual and structural factors influence the fulfillment of these needs.

Methods

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Twenty-three participants aged 50 and older, diagnosed with schizophrenia spectrum or bipolar disorders (onset before age 40), were recruited through purposive and snowball sampling. Participants lived in community settings, including halfway houses and group homes. Data were collected via in-depth interviews and analyzed using thematic analysis.

Results

The study found that socio-emotional care needs are widely unmet. Middle-aged and older adults with psychosocial disabilities hope to build interpersonal connections but often face exclusion from both family and society. Even when interacting with others who have experienced illness, mutual understanding and support are not necessarily present.
These individuals encounter both personal and structural barriers in accessing care services. Personal challenges include a lack of awareness of available care resources, physical decline, and the absence of accessible transportation. Structural barriers involve a care system heavily influenced by the medical model, which often overlooks psychosocial needs. Additionally, care services tend to be mutually exclusive, limiting users' flexibility.

Conclusion

Formal care services should address the care needs of people with psychosocial disabilities across different life courses. At the same time, the dynamic changes in family caregiving capacity must be taken into account, in order to respond to the unique care needs of this population.

Keywords: Psychosocial difficulties, mental health, unmet needs, care poverty, health care, long-term care

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Personal Recovery in Individuals with Schizophrenia in Taiwan: A Qualitative Investigation of Enabling Factors and Support Needs

Ching-Wen Chang[1]
[1]National Taiwan Normal University, Taiwan

Introduction: For individuals with mental illness, "clinical recovery" refers to reductions in psychiatric symptoms and functional improvement, whereas "personal recovery" focuses on living a meaningful life despite limitations caused by psychiatric symptoms. Facilitating personal recovery in social care is essential from a human rights perspective. However, research examining personal recovery needs among individuals with schizophrenia in Taiwan remains limited. This study addresses this gap by investigating factors that enable the establishment of a meaningful life and exploring recovery support needs in the Taiwanese context. Methods: A qualitative study design was used to recruit ten individuals with schizophrenia who perceive their lives as purposeful and meaningful. In-depth interviews were conducted. Findings: Analysis revealed five factors that enable the establishment of a meaningful life: (1) social connectivity with peers, both with and without mental illness; (2) utilization of personal strengths in daily activities; (3) exposure to non-stigmatizing environments; (4) access to community engagement opportunities; and (5) support from mental health service providers who validated their autonomy and potential. Additionally, five support needs for personal recovery were identified: (1) ongoing psychotropic treatment and

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psychotherapy/counseling services; (2) diverse psychosocial programming; (3) public anti-stigma initiatives; (4) emotional support from peers; and (5) esteem support from family members. Conclusion: The findings underscore the multifaceted support required for personal recovery in schizophrenia in Taiwan. Addressing these needs through targeted interventions and policies may enhance recovery outcomes and overall well-being in this population. The results provide valuable insights for improving social care delivery in Taiwan.

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S5 A new metric to assess long-term care as a human right: Care poverty and unmet needs

Room: F3020
Time: 16:00-17:30
Chairs: Kirstein Rummery, Ricardo Rodrigues

Long-term care is increasingly understood as a human right and included, for example, in the European Pillar of Social Rights. However, until now studies on whether these rights materialize have been rare. While aggregated indicators on expenditures on long-term care or volumes of services are useful, the key metric to assess whether long-term care systems are fulfilling the right to care is whether the support and care needs of the older and disabled population are being met. We argue that this should be the starting point for the analysis of care policies and that the focus of this examination needs to be on outcomes.

To this end, we propose a symposium that is partially based on book edited by Kröger, Rummery, Brimblecombe and Rodrigues, to be launched in early 2025, making the case for the new alternative term of care poverty. This stands for "inadequate coverage of care needs resulting from an interplay between individual and societal factors". We aim to kick this research and policy discussion off on the international level, by presenting a series of manuscripts that discuss theoretical underpinnings, methods and empirical applications of care poverty. More specifically: Kirstein Rummery (University of Stirling, UK) will situate care poverty in the context of other care theories and the conflicts inherent in these theories; Ricardo Rodrigues (University of Lisbon, Portugal) will discuss some methodological possibilities to assess care poverty; Christine Kelly (University of Manitoba, Canada) will present results from a community-engaged mixed methods study of care poverty in Canada, in which she will share the process of community-engaged development of a care poverty framework; and Mari Aaltonen (Institute for Health and Welfare, Finland) will apply the concept of care poverty empirically by combining survey data and in-depth interviews of people with dementia and their informal carers in Finland.

Papers:

Care poverty and conflicts in social citizenship: the right to care? (Kirstein Rummery)

Methods to match a novel concept: approaches to measuring care poverty (Ricardo Rodrigues)

Care poverty: centering older and disabled people in the care economy (Christine Kelly)

People with dementia and their informal carers: at particular risk of care poverty (Mari Aaltonen)

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Thursday 26 June: Parallel sessions 5

TP11a Care responsibility and social rights in a welfare mix

Room: F3005
Time: 16:00-17:30
Chairs: Hildegard Theobald

Presentations:

- 73 Hanna Sjögren & Andrea Lorenz-Wende: Policy and media constructing the role of families in elder care: Framing “family-care” as the new normal
- 394 Birgit Pfau-Effinger & Thurid Eggers: Familisation of Childcare and Social Rights in the Pandemic COVID-19 - Pandemic-related Childcare Policies in Different Types of Care Arrangements
- 355 Sandra Obiol-Frances & Jordi Bonet-Martí: Continuities and changes in women's discourse on care in the context of COVID-19
- 354 Živa Humer & Lea Lebar: Between familialization and defamilization: development of long-term care system in Slovenia

Short presentations:

- 382 Yumika Shirase: The Public Responsibilities and Social Rights of the Preventive Long-term Care Services for Older People in Japan
- 302 Suzanne Hodgkin: Examining responsibility for care of older people in rural Uganda.

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Policy and media constructing the role of families in elder care: Framing “family-care” as the new normal

Andrea Lorenz-Wende[1], **Hanna Sjögren**[2]
[1]Department of Social Sciences and Philosophy, University of Jyväskylä, Finland, [2]Faculty of Social Sciences, University of Helsinki, Finland

The Nordic social-care regime aims for universalism with its different policies and practices, but especially in elder care, changes in legislation and other reforms have changed the previous arrangements between the state and its citizens. In our empirical paper, we analyse how the role of families and social networks of ageing individuals is constructed in policy and public discourse by analysing national and regional level policy documents and opinion pieces published in the media outlet Helsingin Sanomat. We analyse the policy documents over a longer period of time (2009-2024) and the opinion pieces published during times when significant reforms have been made to the Finnish social- and health care service system.

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By combining a rhetorical and discursive approach, we examine the texts in their social and historical context, and analyse the narratives constructed. The preliminary results show a discrepancy between political and public discourse, where political discourse often fails to recognise the impact of larger reforms for everyday life. The public discourse in turn makes space for the voice of different actors in society (private citizens, family members and social networks of aged persons, informal and formal caregivers, politicians etc.) and more often highlight the shortcomings of the policy documents. However, the role of families in elder care is often framed as the natural and preferred alternative to formal care in both policy and public discourse.

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Familisation of Childcare and Social Rights in the Pandemic COVID-19 - Pandemic-related Childcare Policies in Different Types of Care Arrangements

Thurid Dr. Eggers[2], Christopher Dr. Grages[2], **Birgit Prof. Dr. Pfau-Effinger**[1]
[1]University of Hamburg, Germany, [2]University of Bremen, Germany

In many European societies, welfare states have extended support for public daycare provision for children in the last decade. Consequently, the role of the state vis-à- vis the family in relation to childcare was substantially extended. However, as a consequence of the lockdown and the closure of extra-familial childcare facilities by European government in the COVID-19 pandemic, a “re-familisation” of childcare took place, in that an important part of childcare was provided by parents at home, mainly by women. As a result, parents, and particularly also women often experienced financial and employment risks related to childcare. This paper asks: How can we explain cross-national differences in childcare policies and related social rights during the pandemic? What does this mean in a gender perspective? Scholars often explained childcare policies during the pandemic in terms of institutional path dependence. Using the theoretical approach of the “care arrangement (Pfau-Effinger 2005),” this article introduces a broader theoretical framework that considers the relationship between cultural and institutional factors for understanding cross-national differences in childcare policies during the pandemic. We introduce the findings of a comparative empirical study of childcare policies in Denmark, Germany and England, that represent different types of care arrangements. We find that besides path dependence also path departure played a role in childcare policies of governments in the pandemic, and that the integration of culture into the theoretical framework allows for a more comprehensive understanding.

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Continuities and changes in women's discourse on care in the context of COVID-19

Jordi Bonet-Martí[1], **Sandra Obiol-Francés**[2], Jokin Azpiazu Carballo[3], Màrius Domínguez Amorós[1], Elisabet Almeda Samaranch[1]
[1]University of Barcelona, Barcelona, Spain, [2]University of Valencia, Spain, [3]University of the Basque Country, Spain

In recent years, different discourses have appeared in the social imaginary (care as a collective responsibility, self-care, the vindication of care work, etc.) that aimed to articulate a rights-based response to the care crisis affecting our societies. However, with the outbreak of the COVID-19 pandemic and the associated social distancing measures, these emerging discourses came into contradiction with the official discourses based on the hegemonic

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medical model, which promoted individual responsibility and the return of the responsibility of care to the home.

In this paper, we propose an analysis of how the impact of COVID-19 has led to a transformation of discourses on care, especially those that appeal to new ways of understanding and organizing care. To this end, we based our study on the sociological analysis of the discourse system of a corpus of 29 in-depth interviews with women with care responsibilities in the home in different parts of Spain. Our purpose in these interviews was to find out how they had organized care in their homes before, during, and after the pandemic. The analysis allows us to identify the permanence of the most traditional discourses on the organization of care that coexist - often in conflict - with discursive references to new ways of covering this care, especially in those women with higher cultural capital.

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Between familialization and defamilization: development of long-term care system in Slovenia

Živa Humer[1], Maruša Tomc Arko[1], Andreja Rafaelič[1], Katarina Mauch[1], **Lea Lebar**[1]
[1]Social Protection Institute of the Republic of Slovenia, Slovenia

Social welfare policies shape the relationship between the state, market, family/individuals, influencing gender equality and care responsibilities (Daly & Rake, 2003). Care responsibilities within this triangle vary across European countries, from familialistic models emphasizing the role of family to defamilialistic ones prioritizing public care policies or regulate care through market-based services (Esping-Andersen, 1999). This paper examines Slovenia's long-term care (LTC) system, focusing on its evolution, innovations, and challenges. Traditionally, Slovenia relied on informal, unpaid care for older adults provided by female family members alongside institutional care, reflecting implicit familialism (Leitner, 2003; Chung et al., 2018). Informal care is perceived as a policy-supported choice, as the family is legally obligated to provide care for older adults (Rakar et al., 2024). Slovenia’s LTC system is currently being transformed by the 2023 Long-Term Care Act, which introduces compulsory LTC insurance funded by employers, employees, the self-employed, and pensioners. Additionally, it introduces one-stop shops, new assessment tool for care needs, and services promoting independence. These changes aim to redistribute care responsibilities between the state, market, and family. By enhancing formal care services in communities and at homes, and compensating family carers, the policy seeks to reduce reliance on informal, unpaid caregiving. As Slovenia implements LTC system, a key question remains: What implications will it have on people's lives, gender equality, and the de-gendering of care responsibilities? Will the shift toward formal care services and paid family carers significantly impact gender dynamics, particularly the traditionally gendered role of women in caregiving.

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The Public Responsibilities and Social Rights of the Preventive Long-term Care Services for Older People in Japan

Yumika Shirase[1,2]
[1]Hitotsubashi University, Japan, [2]University of Birmingham, UK

This study aims to analyse why and how preventive services were transformed under the Long-term Care Insurance system (LTCI) in Japan and explore the arguments concerning public

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responsibilities and social rights among central and local governments, service providers, civil society, and family. The LTCI was implemented in 2000, and provides social care, including preventive services, mainly for people aged 65 and over; half of its funding comes from premiums paid by people aged 40 and over, with central and local governments also bearing the cost. In comparison of 2000 and present, the central policy on LTCI service provision has shifted to focusing on the health and social care specialist services for those with severe long-term care conditions. The preventive services have been devolved and the local governments, especially municipalities, have increased responsibilities for assuring various preventive services such as home help, meals on wheels, and social activities. Consequently, more neighbourhood volunteers are expected to engage in these services in the community. However, as long-term care conditions are not inherently preventable, family care burdens remain, and there is a concern that this system relies on an excessive expectation of unpaid work by the family and civil society. There might be arguments that preventive services are basic social rights because they are closely related to individual lifestyles and might seek better living standards, not minimum ones. The current welfare mix situation can be seen as both positive and negative regarding the responsibility to revitalise communities and the right to access professional services.

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Examining responsibility for care of older people in rural Uganda.

Rachel Winterton[2], **Suzanne Hodgkin**[1], Diana Nabbumba[2]
[1]Charles Sturt University, Australia, [2]La Trobe University, Australia

In the context of global ageing trends, there is significant concern around responsibility for care of older people in low and middle income (LMIC) countries. Populations are now ageing more rapidly in LMICs in Africa, Asia, Latin America, and the Caribbean. This anticipated increase in ageing populations will increase demand for social care services, thus requiring a more comprehensive exploration and response. While most developed countries have aged or social care acts that regulate and fund provision of care services to older people and assign responsibility to various actors, many developing countries in SSA lack such regulatory frameworks.
This paper critically examines care responsibility for older people in Uganda, a country experiencing multifaceted challenges in social care provision, particularly in rural areas. Using multiple methods this examination included the analysis of national policy documents, in-depth interviews with 21 key stakeholders and focus groups with 40 rural caregivers. Participants were asked about the current social care services provided or received in rural communities, their perceptions of social care responsibility, their experiences and challenges relating to the provision of social care and their recommendations for improvement. The findings demonstrate that the formal social care system for older people in rural areas is inconsistent, underfunded, fragmented and unregulated, leaving families predominantly responsible for care and and the responsibilities of other stakeholders (in the private, public and voluntary sectors) remain unreliable. The lack of a clear policy framework and responsibility allocation at a macro level influences how stakeholders, informal caregivers conceptualise and assume responsibility.

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TP14 Climate change and long-term care: a perspective on human and social rights of people who receive and provide long-term care

Room: F3010
Time: 16:00-17:30
Chairs: Andrea E. Schmidt, Adelina Comas-Herrera, Liat Ayalon

Presentations:

- 346 Adelina Comas-Herrera & Andrea Schmidt: Climate change and long-term care: a perspective on human and social rights of people who receive and provide long-term care
- 391 Angela Perone: The Five C's of Climate Change and Caregiving: Moving from Catastrophic to Cohesive Caregiving for Older and Disabled Adults
- 42 Giovanni Lamura: The Sustainability Spillover: Uncovering the Link between Informal Elder Care and Eco-Conscious Behaviors across the European Union
- 438 Andrea E. Schmidt: Climate-health profiles of informal caregivers: a time use study

Short presentations:

- 389 Beatrice Ietto: The Role of Digital Technologies in Enhancing the Sustainability of Long-Term Care: Addressing Climate Change Challenges

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Climate change and long-term care: a perspective on human and social rights of people who receive and provide long-term care

Adelina Comas-Herrera[1], **Andrea Schmidt**[2], Liat Ayalon[3], Klara Lorenz-Dant[4], David Palomera[5]
[1]Care Policy And Evaluation Centre, London School Of Economics And Political Science, United Kingdom, [2]Austrian National Institute of Public Health, Austria, [3]Bar Ilan University, Israel, [4]University Hospital of Augsburg, Germany, [5]Universitat Autonoma de Barcelona, Spain

Climate change affects long-term care systems, both in the short run due to increased occurrence of acute extreme weather events, as well as in the long run due to the additional burden it creates for people who use and provide formal and informal care, for instance due to increased psychological stress. The COVID pandemic and recent heatwaves and climate events have shown that many people who rely on care from others live in accommodation that is particularly susceptible to climate events, for example old buildings used as residential care with poor ventilation and thermal properties.

At the same time, the long-term care sector contributes to the climate crisis itself, by adding to the global carbon footprint. Moreover, high consumption of pharmaceutical drugs and heavy reliance on health, social and long-term care services are heavy polluters of the environment.

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Questions around human rights and social rights for a good life of both caregivers and care recipients arise, as questions on how an eco-social transformation of the long-term care sector could look like.
This paper explores the linkages between long-term care, climate change adaptation, climate change mitigation, human and social rights.

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The Five C's of Climate Change and Caregiving: Moving from Catastrophic to Cohesive Caregiving for Older and Disabled Adults

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The effects of climate change are undeniable. Older adults with caregiving needs are particularly vulnerable to climate change (e.g., extreme heat deaths, mobility limitations) and face unique challenges. Climate change also impacts older adults differently, given widespread health, social, and economic disparities that disproportionately impact low-income communities, women, and low- and middle-income countries. These disparities can shape experiences of older adults receiving and providing care as well as caregivers for older adults of all ages during and after climate-related disasters. Disaster preparedness at local, state, national, and international levels has historically focused most on reactive planning to specific acute events (e.g., hurricanes, earthquakes). Climate change has brought more chronic disasters that produce longer heat waves, record-low temperatures, and droughts in addition to more frequent and severe wildfires, blizzards, and other acute disasters. These chronic climate change conditions have heightened health and caregiving needs and exacerbated existing health disparities. This paper presents a new conceptual framework (cohesive caregiving) that builds on current caregiving models that to varying degrees incorporate elements of community, creativity, complexity, collaboration, and comprehensiveness–what we call the 5 C's for climate change and caregiving. Cohesive caregiving shifts paradigms of conceptualization and planning for disaster preparedness by foregrounding creatively complex, comprehensive, and collaborative coordinated care across sectors and partners. It also provides an avenue for healing individual and collective trauma by intentionally and proactively engaging diverse voices into problem-solving spaces. Ultimately, this conceptual framework provides guidance for investigating and addressing complex caregiving needs associated with climate change.

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The Sustainability Spillover: Uncovering the Link between Informal Elder Care and Eco-Conscious Behaviors across the European Union

Aviad Tur-sinai[1], Netta Bentur[2], **Giovanni Lamura[3]**, Ricardo Rodrigues[4], Mirko Di Rosa[5], Marco Socci[3]
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This study explores the association between informal caregiving for older adults and environmentally sustainable behaviors across European Union countries, examining how gendered and domestic nature of environmentalism relates to elder care. Data from 41,742 respondents aged 16–74 were analyzed from "Survey of Gender Gaps in Unpaid Care, Individual and Social Activities," funded by European Institute for Gender Equality (EIGE) in 2022. Frequency of sustainable behaviors was measured across 10 indicators. Multilevel mixed-effects linear regressions examined associations between caregiving and sustainable behaviors, adjusting for demographic, socioeconomic, attitudinal covariates. Informal caregivers engaged in eco-friendly actions significantly more frequently than non-caregivers across sustainable-behavior indicators ($p<0.001$). The "caregiver effect" was strongest for sustainable-consumption choices like buying eco-friendly ($\beta=0.16$), fair-trade ($\beta=0.15$), and used products ($\beta=0.17$), and weaker for household practices such as recycling ($\beta=0.05$) and mindful resource consumption ($\beta=0.06$). Caregivers attained higher composite environmental behavior scores (33.93±8.23) than non-caregivers (31.88±8.00; $p<0.001$). This association remained robust after adjusting for gender, age, education, employment, household size, attitudes, and other covariates. Caregiving had the strongest association with buying used items ($\beta=0.20$) and eco-friendly products ($\beta=0.14$). Country-level analyses revealed consistent differences, with largest gaps in Southern and Eastern Europe. This first large-scale cross-national study demonstrates a consistent association between older-adult caregiving and environmentally sustainable behaviors. Results suggest caring for a vulnerable family member relates to a broader sense of social and environmental responsibility. Findings highlight new avenues for environmental education and caregiver support initiatives that synergistically promote interpersonal and environmental care.

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Climate-health profiles of informal caregivers: a time use study

Andrea E. Schmidt[1,2], Lisa Kaufmann[3], Claudine-Caroline Egger[3], Felix Durstmüller[1], Willi Haas[3], Barbara Smetschka[3]
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Background: Informal, unpaid family caregivers (ICs) represent the backbone of many long-term care (LTC) systems in Europe. In addition, the severe effect and progressing of climate change calls for a better understanding of structures for healthy and climate-friendly living. Previous research shows that time-intensive informal care may have negative health effects. Yet little is known about carbon footprints of ICs.
Aim: For three different IC profiles (intensive care I-IC, care for young children and adults i.e. ‘sandwich care’ S-IC, light care L-IC), we identify patterns of healthy and climate-friendly living. We hypothesise that I-ICs and S-ICs display less healthy behaviours and a high carbon footprint, whereas L-ICs have healthier behaviours and a lower carbon footprint.
Methods: We develop climate-health profiles based on Austrian time use data (2022) combined with carbon footprint profiles per time use category (personal, committed, contracted, free time), complemented by an analysis of the Austrian Health Interview Survey (2019). We also analyse gender and age as potential determinants.
(Preliminary) Results: Compared to non-carers and L-ICs, we find that S-ICs display the highest carbon footprint in mobility, due to dependency on car use for caring activities – a pattern also

found among I-ICs. By contrast, both groups display lower levels of (health-associated) sports and outdoor activities.
Discussion: The different climate-health profiles require specific policy support to promote healthy and climate-friendly living among ICs. Further research is needed to assess additional sources of greenhouse gas emissions stemming from formal care, e.g. mobility of formal LTC workers.

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The Role of Digital Technologies in Enhancing the Sustainability of Long-Term Care: Addressing Climate Change Challenges

Beatrice Ietto[1], Mirko Di Rosa[1], Sabrina Quattrini[1], Aviad Tur-Sinai[2], Ricardo Rodrigues[3], Giovanni Lamura[1], Marco Socci[1]
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Long-term care (LTC) systems face a paradoxical relationship with climate change—they both contribute significantly to carbon emissions and serve populations highly vulnerable to climate impacts. As LTC demand increases due to demographic aging, its environmental footprint grows correspondingly, raising urgent questions about maintaining quality care while reducing environmental harm. This study examines how digital technologies might contribute to environmental sustainability in the LTC sector through their influence on informal caregivers, who provide approximately 80% of all LTC in Europe.
Using data from 5,761 informal caregivers across 27 European Union countries, the study investigates the relationship between digital tool use and eco-friendly behaviors. Findings reveal a significant positive association between digital tool use and environmentally sustainable behaviors ($\rho=0.28$, $p<0.001$), with strongest relationships in consumption-related behaviors and weaker associations with infrastructure-dependent activities.
Results suggest digital tools may help mitigate LTC's environmental impact through multiple mechanisms—enhancing access to information about sustainable options, creating communities that reinforce environmental norms, and making eco-friendly choices more accessible in time-constrained caregiving contexts. However, demographic patterns in digital adoption indicate these benefits may be unevenly distributed, with lower access among older, less educated caregivers who often provide the most intensive care.
The study contributes to understanding how digital technologies might foster environmental sustainability in the care sector. Integrated policy approaches addressing digital inclusion and environmental sustainability in LTC could yield significant co-benefits, reducing the sector's contribution to climate change while maintaining or improving care quality.

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TP5 The emergence and potential of a rights agenda for unpaid/family carers: the roles of state actors, carers' organisations and international agencies

Room: F3006
Time: 16:00-17:30
Chairs: Sue Yeandle, Kate Hamblin

Presentations:

- 445 Jayne Astbury: Supra-national carers' organisations and their impact
- 236 Sarah Claes: Balancing Care: Human Rights Perspectives on Family Caregivers in Long-Term Care Models
- 120 James Janeiro & Liv Mendelsohn: Public Policy and a Rights-Based Triadic Care Model: Strengthening Partnerships between Providers, People Needing care, and Family Caregivers
- 232 Loretta Baldassar & Heli Askola: Care, older people and borders: the struggle for rights in the context of transnational care and global care chains

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Supra-national carers' organisations and their impact

Jayne Astbury[1]
[1]University Of Sheffield, United Kingdom

The mobilisation of a carers' movement, beginning in the 1960s, has given rise to the development of carers' organisations representing unpaid carers' needs at local, national, and international levels. Growing from early collaborations and interconnections forged during the 1990s, two 'supranational' carers' organisations have emerged: Eurocarers ('the European voice for informal carers'), formally established in 2007, now with a secretariat based in Brussels; and the International Alliance of Carer Organizations (IACO), incorporated in the USA in 2012. Both aim to foster and contribute to the advancement of carers' rights through international policy development and the exchange of ideas, expertise, and strategy among member organisations (at national and regional levels). Drawing on an analysis of data gathered during research for a forthcoming book due for publication in autumn 2025, and focusing on the issue of carer recognition, the paper will critically reflect upon the contribution, influence, and impact of these supranational carers' organisations. It will consider their origins, membership, alliances, and strategy, contextualising this in relevant policy landscapes and available mechanisms, through which members can lobby key policy and practice actors and advocate for improved carer rights.

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Balancing Care: Human Rights Perspectives on Family Caregivers in Long-Term Care

Sarah Claes[1]
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As European care systems increasingly rely on informal support, family members are often drawn into caregiving roles without clear legal recognition. This paper examines whether, and to what extent, such caregivers qualify as rights-holders under international human rights law. The analysis focuses on the legal position of informal caregivers in relation to the care recipient and, where relevant, to professional caregivers. It draws on the European Convention on Human Rights (ECHR) and the jurisprudence of the Court (ECtHR), as well as the Convention on the Rights of Persons with Disabilities (CRPD) and the interpretative work of its Committee.

Three forms of rights are distinguished:
(1) Derivative rights, arising when insufficient support for the care recipient places a disproportionate burden on the caregiver;
(2) Autonomous parallel rights, applying when the caregiver's own rights—such as privacy or moral integrity—are directly affected;
(3) Autonomous conflicting rights, emerging when caregiver claims conflict with those of the care recipient, requiring legal balancing.

These developments are assessed in light of the interlinked rights perspective promoted by the UN High Commissioner for Human Rights, which calls for a relational approach that avoids framing caregiver and recipient rights in zero-sum terms. While the CRPD reflects this logic through a structured but subordinate recognition of caregiver rights, the ECtHR applies a balancing model that can, in some cases, afford caregivers greater legal weight.

The findings suggest that a coherent rights-based approach must acknowledge the interdependence between family caregivers and care recipients through principled balancing where rights intersect.

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Public Policy and a Rights-Based Triadic Care Model: Strengthening Partnerships between Providers, People Needing care, and Family Caregivers

James Janeiro[1], **Liv Mendelsohn**[1]
[1]Canadian Centre For Caregiving Excellence, Canada

Effective care in health, social, and community care settings requires collaboration among providers, patients, and family caregivers. However, the traditional hierarchical relationship between providers and caregivers tends to overlook the value and rights of family caregivers as equal partners in care and often the direct care providers. Viewing the care landscape through a social and human rights lens challenges traditional care models by emphasizing the rights and participation of all stakeholders, including family caregivers. This approach also points the way to public policy reform that enables the rights of caregivers and care providers while improving the lives of care recipients.

This session will explore a federal-level Canadian approach to triadic care models, centred on the active involvement of providers, patients, and family caregivers. We emphasize how

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adopting a rights-based framework at individual, practice, and policy levels can promote equitable partnerships, improve care outcomes, and uphold the dignity and autonomy of all parties involved. Liv Mendelsohn speaks to the work of the Canadian Centre of Caregiving Excellence to raise awareness of the value and rights of family caregivers and frontline care providers . James Janeiro will speak to ongoing policy debates and the new National Caregiving Strategy for Canada that addresses the needs of all caregivers, including those connected to disability, health care, illness, and aging. This session aligns with global movements toward recognizing the rights of caregivers, including the implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the European Pillar of Social Rights.

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Care, older people and borders: the struggle for rights in the context of transnational care and global care chains

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This paper explores equality issues involving older people and care mobility in the context of ageing, transnational families and migrant care labour. The mobility of care gives rise to both formal and informal global care chains, where care labour, in the form of migrant care workers or family members, flows or circulates between countries. We conceptualise the regulation and stratification of mobility rights as a great barrier to equality in the context of transnational ageing. The mobility of migrants and their families is subject to the constraints of immigration and settlement policy. Because states have wide discretion on migrant admission, they engage in complex forms of cost-benefit analysis, weighing economic, social and cultural factors as well as values. The resultant ‘social sorting’ reflects and reinforces various inequalities, including those based on class, age, gender and ethnic origin. Access to mobility rights, stratified by factors such as nationality and wealth, is then part of a global system that constrains people’s care rights (rights in relation to care), entailing significant forms of inequality. We argue that the selectivity of migration policies and their constructions of deservingness affect both informal mobile carers - like temporary grandparent visitors who provide unpaid care for grandchildren - as well as formal migrant care workers. Because transnational families resist simple categorisations into ‘insiders’ and ‘outsiders’, they shed light on the construction of legal and social membership in ageing societies, and challenges faced by carers.

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TP23 Transformations in home care markets: organisational intermediaries, platformisation, and the impact of digitalisation on care regimes

Room: F3004
Time: 16:00-17:30
Chairs: Nuno Ferreira Dias

Presentations:

- 186 Helena Hirvonen & Diane Burns: Decent work through AI-driven platform care? Exploring possibilities for equal and inclusive long-term care in the UK, Sweden and Finland
- 160 Lisa Waldenburger & Bernhard Weicht: The mediation of foreign live-in carers in Austria - can a state-funded, non-profit agency improve the very precarious working conditions?
- 212 Dóra Gábriel & Noémi Katona: Shifting Dynamics and Professionalization Trends in the Home-Based Care in Hungary
- 148 Nicole Teke: Digital platforms in domestic and care work in France: strategies for new business models

Short presentations:

- 89 Katja Haunreiter & Maëlle Meigniez: Enhancing Autonomy in Swiss Long-Term Care: Towards a Unified, Accessible Digital Platform for Para-Employers

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Decent work through AI-driven platform care? Exploring possibilities for equal and inclusive long-term care in the UK, Sweden and Finland

Helena Hirvonen,[4], **Diane Burns**[1,2], Sanna Kuoppamäki[5], Kate Hamblin[2], Grace Whitfield[2], Carole Elliott[3]
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AI-driven digital labour platforms are arousing interest as a solution to the ‘crisis’ of care in Europe. Platform work is presented as offering possibilities for higher wages and greater

flexibility. Yet platform work also challenges existing rights and obligations related to labour law, social protection and health and safety as empirical research evidences heightened risks for workers and the informalisation of work (Macdonald, 2021). AI-driven technologies are fast developing, and enable e.g. matching of care workers to clients using machine learning (ML), but also risk increasing gender and racial biases in contexts such as recruitment and facial recognition systems (Drage & Mackereth, 2022). Drawing from a previous case study of a care platform company in England, this paper illuminates how behind the company's claims of 'automation' and 'AI' derived efficiencies and greater worker autonomy over their wage level, erosion of job quality and issues of inequity were evident. Findings show two unintended consequences 1) human labour was necessary to complete matching of care workers to clients, and 2) care workers from minoritised ethnic backgrounds artificially lowered their rate to obtain work. We conclude our paper with further questions for research, and by introducing our objectives for a forthcoming cross-national collaborative project in the UK, Finland and Sweden CareQuAI (JPI/MYBL, 2025-28). This project will: analyse cross-national differences in how AI-driven platform care is provided in Europe; produce cross-national guidelines on equal and inclusive AI-driven care platform work; contribute to policy, practice and frameworks that support decent work via AI-driven care platforms.

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The mediation of foreign live-in carers in Austria - can a state-funded, non-profit agency improve the very precarious working conditions?

Lisa Waldenburger[1], **Bernhard Weicht**[1]
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Austria's 24-hour care system, legalized in 2007 through the Home Care Act, represents a significant component of the country's long-term care landscape. This system relies primarily on circular migration of predominantly female caregivers from Eastern European countries, particularly Romania and Slovakia, who work in Austrian households on rotational four-week cycles. While legalization addressed the previously illegal status of this care arrangement, the sector continues to face substantial challenges including precarious working conditions, bogus self-employment structures, and exploitative practices by commercial placement agencies. This article examines the historical development and current challenges of Austria's 24-hour care system, drawing on ethnographic research conducted as part of the EU-Horizon project LeTsCare. Through interviews and participant observation, the study analyzes the Vorarlberg care pool, a state-owned, non-profit placement agency that serves as a flagship project in Austrian long-term care. The care pool distinguishes itself through four key innovations: comprehensive matching processes with mandatory on-site assessments, integration with local mobile care services, transparent cost distribution, and advocacy for caregiver rights. While the care pool successfully addresses several systemic criticisms and improves working conditions for live-in caregivers, fundamental challenges persist, including transportation risks, wage disparities, and the legitimization of exploitative labor structures. The findings suggest that while non-profit, state-supported models can mitigate some problems within the existing framework, comprehensive reform addressing structural inequalities remains necessary. The study contributes to understanding alternative organizational approaches in migrant care work and their potential for adapted replication across different contexts.

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Shifting Dynamics and Professionalization Trends in the Home-Based Care in Hungary

Dóra Gábriel[1,2], **Noémi Katona**[2,3]
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The landscape of care is shaped by global trends such as the neoliberalization and marketization of care, where states are increasingly outsourcing related services to market actors. This paper studies the ongoing trends of the home-based care sector in Hungary and the emergence of new market actors, focusing on the education activity of companies that may organize matchmaking, or provide care services in addition to the training of care workers. Despite early efforts at professionalizing home-based care in the mid-1990s, the expansion of this area remained limited due to the modest scale of market-based care intermediaries and a low level of care marketization. In recent years, however, the home-based care market has become strongly segmented. While the overall sector is not characterized by professionalization, more and more companies started to provide training to care workers in the higher segments of the market. As a part of a broader research project, we have conducted participant observations at two distinct training companies in Budapest, both specializing in senior care. Through these observations, we aim to explore how these companies contribute to the professionalization of care by providing both theoretical and practical education, addressing workforce shortages, and shaping perceptions of care work as a formalized profession. Our findings highlight the challenges and contradictions in the operation of these companies from the perspective of different stakeholders.

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Digital platforms in domestic and care work in France: strategies for new business models

Nicole Teke[1], Lorena Poblete[2], Clémence Ledoux[3], Annie Dussuet[3], Pascal Caillaud[3]
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Over the past decade, digital platforms have become increasingly important in the domestic and care work sector. However, digital platforms have not developed a single business model, as their forms of intervention vary according to the characteristics of the regulatory framework.

Among European countries, the case of France is interesting to study, because platforms have to find a way to adapt to a dense regulatory framework, including labour and social security legislation, regulations of social benefits, approval and authorisations specific to personal services, as well as tax benefits. Therefore, in order to gain a foothold and market share, digital platforms should therefore develop strategies that enable them to take advantage of the regulations that facilitate their activity and avoid those that act as a barrier to their expansion. This paper seeks to understand how digital platforms adapt to existing standards, circumvent them and sometimes try to change them by intervening directly with public authorities. The aim is to analyse the strategies developed by four digital platforms, two focused on care for elderly and two focused on home cleaning.

This research is part of a European project (ORIGAMI) and focuses on the French case study. The empirical material includes a corpus of norms (labour and social security legislation, regulations of social benefits for dependent elderly people and tax benefits), as well as interviews with workers, digital platform founders and national social partners.

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Enhancing Autonomy in Swiss Long-Term Care: Towards a Unified, Accessible Digital Platform for Para-Employers

Katja Haunreiter[1], **Maëlle Meigniez**[1]
[1]Hetsl, Switzerland

The Swiss Personal Assistance Allowance (Federal Law on Invalidity Insurance) aims to promote the autonomy of disabled persons by enabling them to directly employ care assistants. However, this system imposes complex administrative and legal obligations on recipients, limiting its accessibility and contributing to high rates of non-utilization. This contribution explores a socio-legal project aimed at developing a unique digital platform to support para-employers navigating Swiss long-term care (LTC) requirements.

The platform would centralize essential legal and administrative resources, including tax authorities, pension funds, social insurance offices, and digitalize employment processes while integrating a chatbot AI to assist with labor law inquiries. Key accessibility features would include “Easy Read”, compatibility with assistive technologies (voice, screen readers), and customizable access rights for caregivers and legal representatives.

Our research critically examines the technological and structural barriers faced by LTC beneficiaries, emphasizing the need for digital inclusion and the reduction of non-take-up rates. By focusing on a centralized digital solution, the study addresses the intersection of care policy innovation and the right to accessible information and administrative support. This proposal resonates with the conference's focus on how digital technologies affect care systems, equity in care outcomes, and the lived experiences of both care providers and recipients, offering a perspective on the integration of digital tools in welfare policies.

The platform must not replicate existing inequalities in access to the personal assistance allowance: the ongoing interdisciplinary research aims to co-develop this new tool by involving beneficiaries, their relatives, and disability professionals (social workers, occupational therapists).

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OS2 Support and services to improve carers’ wellbeing

Room: U3039
Time: 16:00-17:30
Chairs: Giovanni Lamura

Presentations:

- 129 Chen-fen Chen: Development of an Innovative Respite Service Model: The Mutual Support Respite Service Approach

- 216 Giovanni Lamura: Supporting unpaid carers of older people in Italy: an analysis of the implementation of international policy recommendations at regional level

- 314 Hongsoo Kim: Characteristics and Healthcare Utilization Disparities Between Domestic and Foreign Care Workers in South Korea

- 38 Chiun-Ho Hou & Christy Pu: The Mental Health Toll: A National Study on the Well-Being of Parents Caring for Children with Disability of Various Ages

Short presentations:

- 359 Thomas Hansen: The double-edged sword of becoming a caregiver: dynamic impact on four dimensions of well-being in Norway

- 239 Maddalena Gambirasio & Giosuè Ruggeri: Innovative Models for Supporting Family Caregivers: The Project "Caregiver Bergamo – Supporting Those Who Provide Care"

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Development of an Innovative Respite Service Model: The Mutual Support Respite Service Approach

Chen-fen Chen[1]
[1]Department Of Long-term Care, National Taipei University Of Nursing And Health Science, Taiwan, Taiwan

Background
The limited availability of respite services for family caregivers presents a significant challenge in the long-term care system. This study collaborates with social organizations and a caregiver-oriented technology team to develop an innovative "Mutual Support Respite Service Model" aimed at enhancing support for caregivers through reciprocal service exchange.
Methods
This model pairs one professional care worker with one volunteer family caregivers to care for four to six care recipients. A time banking system allows volunteers to exchange one duty shift for two respite opportunities. A technology platform facilitates service reservations, shift coordination, care documentation, and volunteer hour tracking via the Mutual Support Respite Service website. This approach enhances service accessibility, creates employment

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opportunities, and reduces the administrative burden on social workers. A comparative analysis with traditional respite care models assesses the impact on government expenditures, workforce distribution, and service utilization.
Results
The model has demonstrated improved efficiency, accessibility, and cost-effectiveness compared to traditional respite care models. The time exchange mechanism ensures equitable distribution of responsibilities, and the platform's automated notifications enhance coordination among stakeholders. In 2023, the model was piloted in two cities across five locations; in 2024, it expanded to six counties and 16 locations, involving 400 family caregivers.
Conclusion
The mutual support respite service model promotes collaboration and efficiency, enhancing care quality while reducing financial burdens. Its scalability offers a promising pathway for sustainable caregiving practices within communities.

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Supporting unpaid carers of older people in Italy: an analysis of the implementation of international policy recommendations at regional level

Giovanni Lamura[1], Cristina Calvi[1,2], Georgia Casanova[1], Federico Sofritti[1,3]
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Introduction: Support for unpaid care is receiving increasing attention from policy makers in Europe and internationally, as shown also by the European Commission's directive on paid care leave (2019), its Care Strategy (2022), and the recommendations formulated by several international organisations in this regard.
Methodology: This study analyses the policies adopted by Italian Regions (including the autonomous provinces of Trento and Bolzano), using as a reference framework the dimensions proposed by international recommendations, grouped into three main categories: recognition, participation and information bases; support measures and services; transversal aspects.
Results: Core results can be summarised as follows: 1) definitions of carer range from more restrictive and familistic formulations (based on kinship bonds) to more inclusive meanings (based on affective bonds, in line with international recommendations), reflecting a quite variegated approach about "who" may deserve public support; 2) the presence of a framework law dedicated to unpaid carers is no guarantee of an adequate support, as this is often better ensured by other provisions, like those adopting (and funding) concrete interventions and measures; 3) this applies also to support services and measures, mainly concentrated on few categories: access to services (especially respite and home care), information and training, monetary benefits; 4) less attention is paid to transversal aspects like gender equity, intergenerational relations and digital solutions.
Conclusions: A key element - beyond the various forms that carer support takes in different regions - is that the extent of such support is closely linked to the amount of resources allocated.

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Characteristics and Healthcare Utilization Disparities Between Domestic and Foreign Care Workers in South Korea

Hongsoo Kim[1,2], Junghyun Kwon[2,3], Hyejin Choi[4]
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Personal care assistants (PCAs) play a critical role in addressing the care needs of aging populations globally. This study examines the characteristics and healthcare utilization disparities of PCAs employed in long-term care institutions reimbursed by South Korea's public Long-Term Care Insurance (LTCI). Using datasets from the National Health Insurance Service (2016–2023), this research provides the first nationwide profiling of domestic and foreign PCAs.

In 2016, foreign PCAs accounted for just 0.43% of Korea's 361,158 PCAs. Both groups are predominantly female and aging, with a significant proportion aged 66 and older, comprising 42.6% of domestic PCAs and 32.2% of foreign PCAs in 2023. Domestic PCAs are more concentrated in non-capital regions, while foreign PCAs primarily work in capital areas. Healthcare utilization disparities are notable: domestic PCAs consistently exhibited higher inpatient (19.8% vs. 14.2%) and outpatient (98.0% vs. 95.1%) care rates and longer lengths of care (18.7 vs. 6.2 days for inpatient; 22.0 vs. 16.6 days for outpatient care in 2023) compared to foreign PCAs.

Multivariate panel data analysis, adjusting for covariates, confirmed significant disparities, with foreign PCAs showing lower utilization rates and shorter durations for both inpatient and outpatient care. These findings address a critical gap in understanding care workforce dynamics in South Korea and provide insights relevant to other countries with aging populations, highlighting the need for further research and policy responses to support equitable and sustainable care workforces.

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The Mental Health Toll: A National Study on the Well-Being of Parents Caring for Children with Disability of Various Ages

Chiun-Ho Hou[1], **Christy Pu**[2]
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Background
Parenting a child with a disability often leads to heightened psychological distress, yet limited research has explored the impact of parent and child ages or disability types on parental mental health. This study investigates mental health service utilization among parents of children with disabilities using data from Taiwan’s National Health Insurance (NHI) program. The NHI program is mandatory for all citizens and provides comprehensive coverage, including all outpatient costs and essential pharmaceuticals.

Methods

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Data from the NHI claims (2017–2021) and the Maternal and Child Health Database were analyzed using a dynamic cohort design. A total of 48,073 parents with a child with a disability and 2,406,963 parents without a child with a disability were analyzed. Parental mental health outcomes were assessed through mood- and anxiety-related outpatient visits. Marginal effects were calculated using generalized estimation equations.

Results
Mothers of children with disabilities averaged 0.99 visits annually, nearly twice the 0.54 visits recorded among mothers without children with disabilties (P < 0.001). Fathers showed a smaller disparity. For mothers, the marginal effect of a child's disability on mother's mental health utilization grew with child's age, rising from 0.227 visits at age 2 to 0.46 visits at age 18 (P < 0.001). Autism had the most pronounced impact on maternal mental health among prevalent disabilities.

Conclusions
The mental health burden on parents, especially mothers, intensifies with a child's age and varies by disability type. Tailored interventions addressing both disability-specific and age-sensitive needs are crucial for sustaining parental well-being over time.

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The double-edged sword of becoming a caregiver: dynamic impact on four dimensions of well-being in Norway

Thomas Hansen[1], Fredrik Methi[1]
[1]Norwegian Institute Of Public Health, Norway

Becoming a caregiver can be a transformative journey with multifaceted implications for well-being. However, existing research predominantly emphasizes the negative aspects of caregiving, paying less attention to the positive sides. We aim to explore the impact of transitioning into a caregiving role on various well-being indicators, such as negative hedonic, positive hedonic, eudaimonic, and social well-being. We use Norwegian panel data (2019–2021) and employ a combination of nearest-neighbour matching and a difference-in-differences approach to analyse well-being trajectories among new caregivers (n=304) and non-caregivers (n=7822). We assess ten items capturing the dimensions of negative hedonic (anxiousness, sadness, and worriedness), positive hedonic (happiness and life satisfaction), eudaimonic (contributing to others' happiness, engagement, and meaning), and social (strong social relations and loneliness) well-being. Our results show a general increase in negative hedonic well-being and a decline in positive hedonic wellbeing for new caregivers. These impacts are larger for caregivers providing daily care, compared to those providing weekly and monthly care, and for those providing care inside rather than outside their own household. We observe only minor differences regarding gender and age. Interestingly, we also notice neutral or beneficial changes for eudaimonic aspects of well-being; of note, caregivers generally experience an increased sense of contributing to others' happiness. Our study reveals that adopting a caregiving role often leads to significant psychosocial challenges, especially in intensive caregiving situations. However, it also uncovers potential positive influences on eudaimonic aspects of well-being. Future research should explore underlying explanatory mechanisms, to inform strategies that enhance caregivers' well-being.

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Innovative Models for Supporting Family Caregivers: The Project "Caregiver Bergamo – Supporting Those Who Provide Care"

Maddalena Gambirasio[1], **Giosuè Ruggeri**[1], Giuseppe Scaratti[1]
[1]Università Degli Studi Di Bergamo, Italy

The recognition of family caregivers' rights is a critical challenge for social and healthcare systems worldwide. These individuals provide essential daily support to non-self-sufficient people, often without adequate economic, social, and psychological protections. Ensuring their rights and offering proper support improves their quality of life while strengthening the welfare system, making it more equitable and sustainable.

This study examines the Agenzia di Tutela della Salute (Health Protection Agency) of Bergamo and its project "Caregiver Bergamo – Accanto a chi si prende cura (Supporting Those Who Provide Care)", which aims to enhance the role of family caregivers. ATS Bergamo adopts an integrated approach based on two key strategies. The first focuses on institutional interventions within the social and healthcare system, including formal agreements between public and private organizations to develop shared strategies for caregiver recognition and support. The second strategy involves creating a territorial support network through the "Caregiver Lab", a collaborative initiative that actively engages caregivers, local authorities, and stakeholders in co-developing solutions.

This contribution analyzes key agreements and policies within these areas, highlighting their potential to improve caregivers' well-being. At the same time, it identifies challenges such as stakeholder fragmentation and the sustainability of these initiatives.

By exploring the ATS Bergamo model, this study reflects on how integrated and collaborative approaches can serve as replicable models for other regions. Strengthening caregiver support systems based on rights recognition and well-being improvement is essential for a more inclusive and sustainable future.

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OS7 Relational, emotional and supportive aspects of care

Room: U3029
Time: 16:00-17:30
Chairs: Paul Willis

Presentations:

- 114 Ditte Andersen: Care as product or presence: Social investments in welfare state provision of care for people in vulnerable positions
- 213 David Palomera: Market and bureaucracy against care? The organisational development of the residential sector for the elderly in Catalonia
- 278 Paul Willis: Connections, conflict, and cliques: examining neighbourly relations and social dynamics in UK housing with care schemes for older people
- 113 Patricia Robinson: Transformations of Touch and Care: Emotional Connections in Irish Nursing Homes During the Covid-19 Pandemic

Short presentation:

- 62 Haley Swenson: Rights, Care, and the Politics of Supportive Policy: Learning from the United States' $5.2 Trillion COVID-19 Investment in Families

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Care as product or presence: Social investments in welfare state provision of care for people in vulnerable positions

Ditte Andersen[1]
[1]Vive - The Danish Center For Social Science Research, Denmark

More than two decades ago, leading social scientists suggested a new welfare state architecture centred around the rationale of social investment (Esping-Andersen et al., 2002) viewing public spending as investments rather than expenses. Today, social investment policies proliferate in welfare states across Europe (Hemerijck 2017), but the consequences of framing public provision of care as social investment remain understudied. This paper draws on new empirical data from several social investments programs in Denmark designed to provide care for vulnerable groups such as people in or at risk of homelessness. In these programs, investments often mean that professional providers of public care (e.g. social workers or pedagogues) are allocated more time in a period to work with recipients to deliver outcomes defined by a contract. If successful, the investment is to be refunded to the public or private investor. The analysis unravels how the temporal orientation of professional care provision are shaped by a social investment approach. Informed by Lefebvre's distinction between presence and the present (2004), the paper investigates, conceptualizes and theorizes the differences

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between care-as-a-product and care-as-presence. The paper ends with a discussion of how time on the one hand is a fundamental dimension of care—creating time for care is “among the most important considerations in rethinking society from a caring perspective” (Tronto 2013, 166)—however, on the other hand how the ways we create and fund time matters. Efforts to translate care into an investable product may derail care as presence.

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Profit without caring: anatomy of the nursing home sector financialisation in Spain

David Palomera[1]
[1]Universitat Autònoma De Barcelona, Spain

Social care has traditionally played a residual role in the development of welfare states. This article examines how, in this context and facing a growing demand for services due to an ageing population, residential services for the elderly have been organised. To this end, it takes as a case study the development of the residential sector in Catalonia between 2000 and 2022. Analysing this case, the article relates the welfare model in the region, the dominant organisational logics in a context of advancing rights and austerity, and their outcomes in the organisation of social care in residences. The study shows that the state has progressed in the universalisation of social care by promoting mercantile and bureaucratic organisational logics through outsourcing, commercialisation, standardisation, and increasing the size of public services, coupled with low public funding and limited control of outcomes. This organisation of care has been accompanied by the concentration of large for-profit private companies, including multinationals and investment funds, and has had negative consequences on the coordination of the system and the working conditions in care jobs.

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Connections, conflict, and cliques: examining neighbourly relations and social dynamics in UK housing with care schemes for older people.

Paul Willis[1]
[1]Centre For Adult Social Care, Cardiff University, United Kingdom

The UN Principles for Older Persons stress the importance of independence, participation and access to good care in later life. Over the last decade there has been a proliferation of housing with care models for older people in the UK, including extra care, that seek to promote these rights in the social care space. Pervious research have indicated numerous social and psychological benefits to living in such schemes, including maintaining independence and reducing loneliness. This paper focuses on a less understood dimension - the social dynamics between residents (or ‘neighbours’) within scheme life. The Diversity in Care (DICE) project (2019-2022) examined the social connections of residents in housing with care schemes in England and Wales, in particular focusing on the inclusion of residents from different social minority groups. Seventy-two residents took part in longitudinal and semi-structured interviews from 26 schemes. Over half (56.9%) were living with disabilities and/ or chronic illnesses and the majority (73.6%) were living alone. Thematic findings presented in this paper highlight complex and varying neighbourhood relations. Affirming neighbours (akin to friendships) present numerous opportunities for fostering inclusive communities. In contrast disruptive neighbours highlight how sub-groups formed between residents can restrict full access to communal life for some. This is further compounded by practices of boundary setting through

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which residents from minoritised groups (including LGBTQ+ and ethnic minority groups) experience separation and marginalisation from others. This presentation concludes with identifying ways for building on and enhancing affirming neighbourly relations within the microcosm of scheme life.

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Transformations of Touch and Care: Emotional Connections in Irish Nursing Homes During the Covid-19 Pandemic

Patricia Robinson[1]
[1]South East Technological University (SETU), Ireland

Abstract

Transformations of Touch and Care: Emotional Connections in Irish Nursing Homes During the Covid-19 Pandemic

The social distancing measures (SD) of the Covid-19 pandemic which were enacted globally to save lives, wrought unprecedented changes to everyday societal routines, norms and practices, affecting how, when and where touch occurred. The choreography of everyday life was disrupted, as routines once taken for granted were reshaped by these invisible boundaries. This presentation examines how the Covid-19 pandemic reshaped the right to relational care in Irish nursing homes, focusing on the transformations of touch and emotional intimacy amidst SD. Drawing on qualitative insights from residents, staff and families, it explores the intersection of physical restrictions, emotional well-being, and the human right to dignified high-quality care.

This paper will focus on:

- The emotional consequences of restricted touch on residents, staff and families during the pandemic.
- The broader implications for ensuring relational care and emotional rights in long-term care setting, particularly during crisis.

By situating touch within the framework of care as a human right, this presentation highlights the need to balance infection control with residents' emotional and relational needs. It invites attendees to consider how lessons learned during the pandemic can inform the development of care practices that uphold dignity, connection and quality in long term care, contributing to discussions on how touch as a fundamental element of care was renegotiated under crisis conditions, offering insights into resilience and adaptation in Irish nursing homes.

Keywords: Touch, emotions, Covid-19, relational care.

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Rights, Care, and the Politics of Supportive Policy: Learning from the United States' $5.2 Trillion COVID-19 Investment in Families

Haley Swenson[1], Brigid Schulte[1], Julia Craven[1], Jasmine Heyward[1], Rebecca Gale[1], Ashley Alvarez[1]
[1]New America, Better Life Lab, United States

This presentation examines a pivotal moment in U.S. social policy history: the unprecedented $5.2 trillion investment in domestic support programs during the COVID-19 pandemic. Through qualitative case studies and focus group research, we analyze how this expansion of social support reshaped the landscape of care and family economic security. By addressing multiple dimensions of care – including healthcare access through Medicaid, economic support for family caregivers through direct payments, and housing stability through rental assistance – these programs demonstrated how comprehensive social policy can strengthen families' capacity to provide and receive care. Our findings reveal many families experienced improved economic stability and enhanced ability to meet their care needs through this integrated suite of supports. Child poverty fell dramatically.

The research shows how comprehensive social support can transform family outcomes, challenging persistent narratives about poverty and social assistance. Our analysis demonstrates how temporary implementation of robust social supports aligned with principles outlined in the European Pillar of Social Rights and emerging human rights frameworks for care. The study particularly illuminates the effectiveness of flexible, direct assistance in meeting families' diverse needs – a finding with important implications for rights-based approaches to social care policy.

Despite widespread public support for these transformative programs and clear evidence of their positive impact on families, the 2024 presidential election marked a decisive shift away from this expanded vision of care. Our findings offer critical insights for understanding both the possibilities and political challenges in strengthening social rights frameworks in care policy.

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Thursday 26 June: Parallel sessions 5

Meet the authors session 3

Room: Fuksi
Time: 16:00-17:30
Chair: Lea Graff & Maria Cheshire-Allen

- Tamara Daly & Susan Braedley (eds.) Aging Equitably with Care: Power, Policy, Practice, Policy Press, 2025.
- Doris Lydah & Niels Christian Mossfeldt Nickelsen (eds.) Ethical and Methodological Dilemmas in Social Science Interventions – Careful Engagements in Healthcare, Museums, Design and Beyond, Springer, 2023.
- Marsh, Pauline & Williams, Allison (eds.) Cultivated Therapeutic Landscapes: Gardening for Prevention, Restoration and Equity, Routledge, 2023.

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TP13d Dark side of care

Room: Small Hall
Time: 9:00-10:30
Chairs: Tiina Sihto, Paula Vasara

Presentations:

- 26 Siobhan O'Dwyer: What can we learn from carers who kill? A critical examination of homicides and homicide-suicides perpetrated by unpaid carers
- 139 Alisoun Milne: Carer Harm: A Challenge for Practitioners, Services and Research
- 169 Diane Burns: When abuse is not abuse: A communication as constitutive of organization (CCO) perspective
- 469 Monique Lanoix & Cayleigh Sutton: Schedules, care provision and workarounds

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What can we learn from carers who kill? A critical examination of homicides and homicide-suicides perpetrated by unpaid carers.

Siobhan O'Dwyer[1], Charlie Bishop[2], Rachel Gimson[2], G.J. Melendez-Torres[2], Daniel Stevens[2], Lorna Hardy[2]
[1]University of Birmingham, United Kingdom, [2]University of Exeter, United Kingdom

The death of a chronically ill or disabled person at the hands of their carer is a "double-sided tragedy" that challenges our understanding of care and vulnerability, and highlights significant gaps in health and social care systems. Although these deaths are often described as rare, isolated events, more than 200 have been reported in the British, Australian, and American press in recent years and there is a clear need to understand why carers kill and how future deaths can be prevented. This paper presents findings from the first in-depth study of homicides and homicide-suicides perpetrated by unpaid carers. The study included 65 cases from England and Wales and used court records, coroners' reports, statutory reviews, and media reports to examine the events preceding these deaths, the circumstances in which they occurred, and the response of health and care professionals, journalists, judges, and surviving families. In most cases, clear warning signs were ignored by health and care professionals before the death. In some cases, the significance of the caring role was overlooked in criminal proceedings and statutory reviews. In all cases, the death failed to prompt meaningful changes in policy or practice. Grounded in these findings, this paper considers the extent to which carer-perpetrated homicides reflect broader trends in social policy on disability and care, and introduces a new framework for the study, prediction, and prevention of carer-perpetrated homicides and homicide-suicides.

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Carer Harm: A Challenge for Practitioners, Services and Research

Alisoun Milne[1], Sarah Donnelly[2], Louise Isham[3], Kathryn Mackay[4], Lorna Montgomery[5], Sarah Wydall[6]
[1]University of Kent, United Kingdom, [2]University College Dublin, Ireland , [3]University of Birmingham, United Kingdom, [4]University of Stirling, United Kingdom, [5]Queens University Belfast, United Kingdom, [6]Swansea University, United Kingdom

This paper considers how carer harm is understood and responded to in contemporary policy, practice and research in the UK. The authors offer a reflective commentary on the current 'state of play' relating to carer harm drawing on existing research and related literature. It focuses on: how we define carer harm and what we know about its impact; lessons from, and for, practice and service provision; and (some) considerations for policy development and future research. We highlight the importance of engaging with the gendered dimensions (and inequalities) that lie at the intersection of experience of care and violence and the need to move beyond binary conceptions of power(lessness) in family and intimate relationships over the life course. We suggest that changing how we think and talk about carer harm may support practitioners to better recognise the impact of direct and indirect forms of carer harm on carers without stigmatising or blaming people with care needs. The paper also considers how carer harm is 'hidden in plain sight' on two accounts. The issue falls through the gaps between, broadly, domestic abuse and adult and child safeguarding policy & services; similarly, the nature and impact of harm is often kept private by carers who often feel responsible for the harm and are also fearful of the moral and practical consequences of sharing their experiences. The authors invite an ongoing conversation about how recognition of harm to carers can be realised and effective responses developed.

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When abuse is not abuse: A communication as constitutive of organization (CCO) perspective

Diane Burns[1], Alex Wright[2]
[1]Sheffield University Management School & ESRC Centre for Care, University of Sheffield, United Kingdom, [2]Audencia, France

This research adopts a communication as constitutive of organization (CCO) perspective to examine how a case of resident abuse in a United Kingdom nursing home facility was reported but not investigated. We utilize a CCO approach to theorize how an abusive incident was revealed by a resident to a postdoctoral research associate, who then raised the matter with the nursing home manager. Despite the resident's experience constituting abuse according to the nursing home's own documentation, the manager decided she had not been a victim of mistreatment and the incident was not investigated. We show how 'abuse' acts as an authoritative text (Kuhn, 2008 & 2024), and highlight its ethical, moral and political quality, as a plurality of voices vie over its meaning. Our interview and field note data drawn from an in-depth case study display how conflicting meanings become attached to abuse until the discourse surrounding it is closed-off by the manager. We contribute to communicative understandings of ethical issues in organizations and to our knowledge of authoritative text as an analytical tool. We also offer some insight into the ethical dilemmas that can be encountered by researchers when researching vulnerable groups.

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Schedules, care provision and workarounds

Monique Lanoix[1], **Cayleigh Sutton**[1]
[1]Saint Paul University, Canada

Enhancing the wellbeing of older persons and their families is a growing concern for Canadian society. Home care services are perceived as a desirable solution to this challenge as they optimize personal choice and reduce health care costs (Crawley, 2019). To understand the experiences of home care aides, a study was undertaken in 2023. Taking an approach of standpoint point epistemology, the team conducted semi-structured interviews with care aides working for two agencies providing care services in Hamilton and Ottawa, Ontario, Canada. This presentation examines workarounds, the way in which workers coped with regulations they believed to be inadequate. If most care aides reported having very good relationships with their clients and had acquired knowledge of clients' needs, their knowledge was not considered in the scheduling. In some cases, the agency was scheduling too much time for the care activities the client required. It might have been an agency oversight, or a way to overbill. Regardless, care aides reported feeling guilty, but powerless to change the schedule. They resolved this conflict by performing additional unscheduled care activities, such as laundry, cleaning or washing dishes. These workarounds highlight systemic failures in highly commodified care regimes. They reveal the missed opportunities to enhance care provision by mobilizing the knowledge of care aides. One solution, which was mentioned by many care aides is to integrate the workers into the organization and increase meaningful communication with management. As one care aide suggested, taking a teamwork approach to review client services and solve challenges together.

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Friday 27 June: Parallel sessions 6

TP18c: Inequalities of care

Room: F3003
Time: 9:00-10:30
Chairs: Teppo Kröger, Nicola Brimblecombe, Lina Van Aerschot

Presentations:

- 218 Richard Brunner: How should we be defining unmet needs in contemporary adult social care? Incorporating the 'missing link' to independent living outcomes
- 276 Syazwani Hamzah: The Plight of Informal Domestic Workers in Malaysia: A Study on Indonesian and Filipina Care Workers
- 118 Nicola Brimblecombe: Housing quality and condition as a determinant of unmet need and inequalities in care among older people in England
- 260 Leena Forma: The association of income and dementia diagnosis with receiving long-term care

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How should we be defining unmet needs in contemporary adult social care? Incorporating the 'missing link' to independent living outcomes.

Richard Brunner[1], Nafsika Zarkou[1]
[1]University of Glasgow, United Kingdom

It is long-established in Scotland's public policy that the aim of social care is to enable independent living outcomes for disabled people. If social care should be enabling independent living outcomes, it follows that how unmet needs is defined should also be tied to independent living outcomes. Recording – and acting on - unmet needs was recommended by Scotland's authoritative Independent Review of Adult Social Care (Scottish Government, 2021). However, there remains no statutory definition of unmet needs in social care in Scotland, and unmet needs in adult social care continue to be inconsistently recorded. These gaps potentially obscure a multiplicity of geographical and social inequalities in unmet needs. This paper presents findings from a critical exploratory literature review analysing how academic, policy and practice sources conceptualise unmet need in adult social care. The review focused on disabled adults (not older people) and people living in the community (not care homes). Over 100 conceptual/theoretical and empirical sources were found. Drawing on evidence and concepts from disability studies, and contemporary interpretations of 'need', the analysis proposes that unmet needs in social care should be based on how life is actually lived by disabled adults through the lifecourse, in social contexts and inter-dependently, with rights and aspirations. The analysis produces an innovative definition of unmet needs in adult social care,

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which ties unmet needs to independent living outcomes. The paper concludes with discussion of the emerging policy impact of this new definition, and its wider implications.

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The Plight of Informal Domestic Workers in Malaysia: A Study on Indonesian and Filipina Care Workers

Syazwani Hamzah[1], Prof. Dr. Denise Spitzer[2], Prof. Dr. Shanthi Thambiah[3], Alicia Lee[1], Anis Farid[1], Shazana Agha[1]
[1]Women's Aid Organisation, Malaysia, [2]University of Alberta, Canada, [3]University of Malaya, Malaysia

Migrant domestic workers in Malaysia, predominantly women, play a crucial role in the care ecosystem, yet they continue to face social discrimination and exploitation. Issues of statelessness, particularly in East Malaysia, further worsen their situation. In West Malaysia alone, at least 10,000 individuals have been denied nationality, while the numbers remain unknown but are certainly higher in East Malaysia. These workers provide care for children and the elderly as if they were their own, yet their struggles and wages remain largely unrecognized by the government.

This research explores the lived experiences of Indonesian and Filipino domestic workers, highlighting their unacknowledged needs and the absence of basic labor and human rights protections. Using a mixed-methods feminist approach, the study examines their realities and well-being during the COVID-19 pandemic until the present. Quantitative surveys and participatory approach were employed, engaging local communities and surveying 324 respondents. Findings reveal that 77% of respondents fear job loss due to informal employment and lack of job protection, while 73% reported that employers have increased expectations of them.

The study finds that domestic workers in East Malaysia are paid below minimum wage and work excessively long hours, particularly during the pandemic. These challenges underscore the urgent need for policy interventions to protect the rights and well-being of this vulnerable workforce. Recognizing and valuing their contributions is essential for improving their working conditions and ensuring fair treatment. This paper highlights evidence-based recommendations in supporting quality care work and uphold the rights of informal domestic workers in Malaysia.

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Housing quality and condition as a determinant of unmet need and inequalities in care among older people in England

Nicola Brimblecombe[1], Javiera Cartagena-Farias[1], Bo Hu[1], Madeleine Stevens[1], Jayeeta Rajagopalan[1]
[1]London School of Economics and Political Science (LSE), United Kingdom

Receipt of care and support for people with care needs is seen as a fundamental human and social right and key to many other rights. However many people do not get their long-term care needs met with substantial patterns of inequalities in receipt. There are both individual and structural contributors to unmet need and care poverty. This paper focuses on non-specialist

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housing as a structural or social determinant of care use among older people in England and as an intersection of established rights to care and to adequate housing. Our study explores the relationship between housing quality and condition and older people's use of formal care and/or informal/unpaid care. Methods comprise secondary analysis of quantitative data from a large representative sample, the English Longitudinal Study of Ageing (2012/2013 to 2018/2019), and semi-structured in-depth interviews with 72 people aged 65 and older with care needs and/or their unpaid carers. Our results show that that poor quality or unsuitable housing can affect use of formal and/or unpaid care in two ways – indirectly through increasing or precipitating care needs thus necessitating (potentially avoidable) care use and undermining independence, and directly through being a barrier to receiving needed care resulting in unmet need. Our study shows the importance and role of structural factors – in this case housing - in shaping care use and care poverty. Inequalities in care need and in housing quality compound disadvantage for older people with care needs and result in inequalities in unmet need.

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The association of income and dementia diagnosis with receiving long-term care

Leena Forma[1,2], Jutta Pulkki[1], Marja Jylhä[1], Jani Raitanen[1,3], Mari Aaltonen[4,1]
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Dementia is a leading cause of need for long-term care (LTC), but income, describing also other resources associated with socioeconomic status, may influence receiving LTC. We study how income is associated with receiving home care and/or 24-hour care among older people with and without dementia (D+, D-).

The data were derived from national registers with the study population of all people aged 70 or over in 2020 in Finland (N=944 777, 57% women). Binary logistic regression and negative binomial regression analyses were performed to examine the association of income quartiles with receiving home care and/or 24-hour care in 2020. The analyses were run separately for women and men D+ and D-. Age group, living alone, multimorbidity and closeness of death were adjusted for.

Receiving LTC was most common among older and those with dementia. People in highest IQ were less likely to receive home care than people in the lowest IQ, when need factors were adjusted for. In the number of home care visits, only men with dementia had no differences between the income groups. In 24-hour care, receiving was least common in the lowest IQ, and among the receivers, those with higher income had more days in care.

Although the most important determinants of LTC were taken into account, income level was associated with receiving LTC. This suggests that access to LTC or applying for it is, to some extent, connected to the income level, even though access should be needs-based.

Friday 27 June: Parallel sessions 6

TP2 Carer rights and risks of inequalities throughout the life-course

Room: F3017
Time: 9:00-10:30
Chairs: Norah Keating, Ricardo Rodrigues

Presentations:

- 305 Fiona Alpass: Caregiving Across Decades: The Cumulative Impact of Caregiving on Late-Life Disadvantage
- 67 Ester Gubert: Caring trajectories: exploring the dynamic experiences of working carers in England and the Netherlands
- 18 Maxine Watkins & Louise Overton: Understanding the lived experience of unpaid caregiving and risks to financial wellbeing
- 286 Ricardo Rodrigues: Trajectories of care utilization and unmet needs for long-term care in Europe

Short presentations:

- 198 Tjasa Potocnik: The Interplay of Previous Life Experiences and Contextual Factors in Shaping Caregivers' Choices and Quality of Life in Slovenia

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Caregiving Across Decades: The Cumulative Impact of Caregiving on Late-Life Disadvantage

Fiona Alpass[1], Mary Breheny[1], Brendan Stevenson[1]
[1]Health And Ageing Research Team, Massey University, New Zealand

Caregiving across the life course can interrupt employment, relationships and health trajectories, potentially influencing overall wellbeing in later life. This study utilises life course theory to examine whether caregiving episodes throughout early, mid- and later life affect wellbeing outcomes for older adults. Specifically, it explores whether caregiving limits work participation, thereby contributing to disadvantage in later life. We analysed retrospective life course data collected in 2017 from 785 participants aged 65-81. Data included caregiving status in each adult life decade (ages 16 to 80), and the impact of caregiving on the ability to work during employment years (aged 16 to 69). Wellbeing outcomes, including an index of multiple disadvantage, were drawn from survey data collected from participants in 2018. Cluster analysis was used to describe caregiving profiles. Multiple regression models evaluated relationships between caregiving variables and later life outcomes. Thirty-one percent (N=242) of participants had provided care at least once across the life course. Four care profiles were identified, defined by age at first care episode, impact on employment and number of care

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episodes. Cluster membership was unrelated to wellbeing outcomes in 2018. The number of caregiving episodes was significantly associated with greater multiple disadvantage in later life ($\beta = 0.171$, $p < 0.05$) when controlling for gender, marital status, education level and age. While caregiving profiles differed based on caregiving factors, these patterns did not independently predict outcomes in older age. Repeated experiences of care did predict disadvantage, highlighting the cumulative, long-term impact of caregiving across the life course.

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Caring trajectories: exploring the dynamic experiences of working carers in England and the Netherlands

Ester Gubert[1], Mara Yerkes[2]
[1]University of Trento, Italy, [2]University of Utrecht, The Netherlands

Existing literature shows how informal caregiving is a dynamic process resulting in various ‘caring trajectories’. Despite notable exceptions (Di Gessa & Deindl 2024), more research is required to understand the factors underpinning the dynamics of caring trajectories, particularly regarding personal motivation, relational dynamics and sociocultural norms. This gap hampers understanding why caregivers adhere to one trajectory over another, especially when caregiving responsibilities conflict with other life-course domains, such as family and employment.

This qualitative study, grounded in a life-course perspective on care (Keating et al. 2018), contributes to this issue by focusing on working carers whose caring trajectories are linked with the paid work domain. The aim is to identify which individual, relational, and sociocultural constraints shape each caring trajectory and how they pattern among working carers.

The study employs thematic analysis of longitudinal qualitative interviews with a purposive sample of working caregivers, ensuring maximum variation in gender and socioeconomic backgrounds. Data were collected from 2021 to 2023 in two capital cities and two big cities in England (N = 15; 26% attrition) and the Netherlands (N = 17; 23.5% attrition).

Preliminary findings from the English sample show patterns connecting caring trajectories and how working carers attribute meaning to caregiving, especially when caring is an integral part of one’s identity. Those feeling constrained in a caring role are more prone to withdraw or find alternative caring arrangements. However, the intended change in one’s caring trajectory and the actual change is influenced by cultural and gender norms that perpetuate existing inequalities.

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Understanding the lived experience of unpaid caregiving and risks to financial wellbeing

Louise Overton[1], **Maxine Watkins**[1]
[1]University of Birmingham, United Kingdom

The financial costs associated with providing unpaid care to family members or friends due to long-term health problems, disability or needs related to older age have been identified as multiple, complex, and overlapping (Watkins & Overton, 2024). A growing body of primarily quantitative evidence suggests there are negative employment and income outcomes of unpaid caregiving and risks to financial security. However, relatively little is known about how and why the experience of caring affects financial wellbeing.

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This paper reports on a recent qualitative study involving 50 in-depth interviews with unpaid carers to understand the diversity of caring experiences and the challenges faced by those at different life stages and in different circumstances. Drawing on an ecological life-course approach to financial wellbeing (Salignac et al., 2019), our findings show how unpaid caring creates risks to current and future financial wellbeing due to forgone income and (pension) savings, job opportunities and increased expenses. Importantly, they underscore how these risks are exacerbated or mitigated through the interaction of factors at three different levels: the individual (e.g. financial capability, financial resources, employment), the familial (e.g. care roles, responsibilities, relational dynamics) and the societal (e.g. workplace policies, state benefits and care services) as well as interacting with the individual's life course.
This more nuanced and in-depth understanding of the factors shaping unpaid carers' financial wellbeing, and the dynamic interaction between them, provides greater opportunity for policy makers to adequately address the risks to their financial wellbeing.

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Trajectories of care utilization and unmet needs for long-term care in Europe

Ricardo Rodrigues[1], Stefan Hopf[2], Victoria Kontrus[2], Susana Marques[1], Rebekka Steinlechner[3]
[1]Iseg Research, Iseg, University Of Lisbon, Portugal, [2]Vicesse Research, Vienna Centre for Societal Security, Austria, [3]Karl Landsteiner University, Austria

There are concerns that demand for care may outstrip supply and that older people may experience unmet needs. Most studies on use of care and unmet needs in long-term care (LTC) have focused on specific time points and have not considered changes across time. Taking advantage of the longitudinal characteristics of the SHARE survey (2013-2022), we estimate care use/unmet needs trajectories after the onset of needs. Using Latent Profile Analysis, 5 types of trajectories arise around the time till onset of unmet needs, changes of state, time spent with unmet needs, limitations with ADLs and IADLs and age at onset of needs. Two of these trajectories are marked by early onset of unmet needs and either long spells in unmet need albeit with moderate needs ('the bad') or high needs ('the worst'); one is characterised by an immediate, short and unrepeated spell of unmet needs; another by absence of unmet needs; and one trajectory is defined by multiple changes of state. A multivariate analysis of determinants of these trajectories shows that women and individuals in high-expenditure on LTC countries are less likely to be part of 'the worst' trajectory, while household composition and lower economic resources at the individual and societal level are associated with the 'the bad'. We go on to explore the association of these trajectories with mortality risk. Results confirm that older people with care needs markedly oscillate in having these met or not across time and that a substantial socio-economic gradient exists in these trajectories.

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The Interplay of Previous Life Experiences and Contextual Factors in Shaping Caregivers' Choices and Quality of Life in Slovenia

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The aging population is contributing to a significant increase in the demand for family care, even more so in unsupported familialist welfare states in which family caregivers are primary sources of long-term care (such as in Slovenia) for older adults. As the pension age increases, increasing numbers of family carers are still active in the labour market (working caregivers (WCs), when care needs of their family members increase. Their reconciliation practices are shaped not only by the availability of resources but also by their perceived freedom to make choices. The aim of this article is to understand how both previous life experiences and contextual factors influence WCs choices in assuming caregiving role, the strategies they adopt to reconcile paid work and caregiving responsibilities, and the implications for their overall quality of life. The study reveals that working carers, particularly women, those living in the same household or close to the care recipient, and individuals from lower socioeconomic backgrounds face disproportionate challenges both in assuming the caregiving role and in balancing paid employment with caregiving responsibilities. These challenges are shaped by a combination of factors, including care recipients' needs, social and familial expectations, insufficient formal care services, and a lack of adequate support at the national, organizational, and family levels. As a result, many carers are forced to adopt coping strategies that may compromise their well-being and quality of life. These findings underscore the urgent need for comprehensive and inclusive work-care reconciliation measures across all levels of society.

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S6 Understanding, Enhancing and Sustaining the Quality of Life at Work for Long-Term Care Workers

Room: F3020
Time: 9:00-10:30
Chairs: Barbara Da Roit, Shereen Hussein
Discussants: Teppo Kröger

The working conditions in long-term care (LTC) services have garnered growing attention from both scholars and policymakers due to rising global demand and the tragic toll of the COVID-19 pandemic on both care recipients and workers. Despite variations across and within countries, employment in this sector continues to be burdened by long-standing structural issues. These include low wages, non-standard contracts, job precariousness, increased workloads, frequent job shifting, high turnover rates, and elevated levels of stress or burnout.

These persistent challenges not only undermine the wellbeing and dignity of care workers, who often face immense physical and mental strain, but also disrupt the continuity and quality of care services. This, in turn, jeopardizes the overall sustainability of the care sector.

The situation presents a stark contrast to policy efforts aimed at balancing the provision of sufficient, high-quality LTC in ageing societies while managing costs, promoting the employment of women and older workers, and expanding “good quality” service jobs. At the same time, there is a growing need to uphold workers’ rights to fair working conditions, foster social inclusion, and ensure the physical and mental wellbeing of those employed in this critical sector.

This pressing issue demands a deeper understanding of how to measure, explain, and ultimately improve the quality of life at work for LTC workers, with the goal of building a more resilient and sustainable care system for the future.

This session brings together, illustrates, and discusses three distinct research projects that focus on understanding, measuring, explaining, and facilitating the quality of life at work of care workers in England, Italy, and the United States.

The ASCK-WELL project aims to develop a scientifically validated instrument to assess LTC workers' work-related quality of life in England. This tool is essential for addressing the sector's long-standing challenges, including workforce retention and emotional strain heightened by the COVID-19 pandemic. Utilising a mixed-methods approach, the study combines qualitative interviews and advanced psychometric testing (both Rasch and classical methods) to ensure the instrument is robust and applicable across diverse care settings. Key components include a conceptual framework and detailed questionnaire items that reflect the unique experiences of social care workers. The practical utility of ASCK-WELL is emphasised by its co-production with sector stakeholders and the development of an implementation strategy to facilitate widespread use. The ASCK-WELL scale’s practical relevance will enable the sector to monitor,

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compare, and improve worker well-being, ultimately leading to enhanced care quality, staff satisfaction, and retention. This project holds the potential to transform workforce support by providing a tailored, standardised measurement tool that can inform interventions, improve staff well-being, and enhance care quality across the fragmented care sector.

The QWoRe project, funded by the Italian Ministry of Research and University as a Research project of National Interest under the National Recovery and Resilience Plan, aims to develop a multidisciplinary and integrated analytical framework to understand quality of work in residential LTC services in Italy. The research strategy is based on a mixed-method approach, with the integration of multidisciplinary knowledge and insights ranging from care and welfare analysis, sociology of work and organisations, social psychology, employment/labour/social security law, sociology of health and illness, statistics, innovation studies. This framework theoretically apprehends how care, employment and migration regimes, service organisation and provision interact with the logics of care and with the profile and strategies of care workers in shaping working conditions and quality of work, in residential care. A combination of secondary quantitative data analysis and analysis of regulations in the field of care, employment and migration will allow the reconstruction of the distinctive features and variations over time of the working conditions in the residential care sector. Furthermore, an in-depth understanding of the quality of work in residential LTC services in three Italian Regions absorb the bulk of Italian residential care facilities draws from mapping the specific care regulation in these regions and through an original qualitative survey of care workers. The data are the object of a fuzzy-set, comparative qualitative analysis (Fs/QCA) to identify the configurations of conditions (e.g. the individual, organisational, regulative factors) that are associated with a quality of work outcomes. Finally, six organisational case studies investigate the mechanisms and processes that are at work in determining specific outcomes.

The National Dementia Workforce Study, sponsored by the NIH National Institute on Aging, is conducting the first large, annual surveys of the dementia care workforce in the United States. Survey data and other linked data sources will create an unprecedented resource for researchers to answer critical questions about the workforce and its impact on care and outcomes for persons living with dementia. The study includes surveys of nursing assistants and personal care aides in nursing homes and assisted living communities, where a large percentage of residents have dementia. Data from first round of the surveys will be available in early 2025. With the data, we will explore the factors associated with these staff reporting high levels of burnout and intention to quit their job. Such factors may include a lack of confidence in their skills, a lack of training opportunities, irregular work schedules, poor interactions with coworkers or supervisors, long commutes, stressful personal circumstances including concerns about immigration status, low wages, risk of injury, and harassment by coworkers and others in the workplace. Organizational characteristics such as facility size and for-profit ownership also will be examined. Using descriptive and multivariate analyses, this presentation will identify the factors most closely associated with burnout and intention to quit to guide future efforts to improve retention and mitigate stress.

The Symposium will be organised as follows. The objectives, research design, and preliminary findings of the three research projects will be presented. A discussion will follow that will highlight conceptual, methodological, and empirical key points based on a comparative analysis of the projects’ endeavours and findings.

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Presentations:

- Shereen Hussein, Developing and Prepare for the Implementation of the ASCK-WELL Instrument for Measuring Work-Related Quality of Life in Adult Social Care

- Marco Arlotti, Barbara Da Roit, Stefano Neri, Studying the quality of working life in Italian residential long-term care facilities

- Joanne Spetz, Understanding the factors that are linked with burnout and intentions to quit among aides in nursing homes and assisted living in the U.S.

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TP11b Care responsibility and social rights in a welfare mix

Room: F3005
Time: 9:00-10:30
Chairs: Hildegard Theobald

Presentations:

- 380 Jelena Matancevic & Danijel Baturina: Contemporary challenges and prospects of the long term care in Croatia: who cares and whom do we care for?
- 423 Neda Deneva & Mihaela Hărăguş: Transformation of Elderly Care in Romania: Shifting Boundaries of Family, Market, and State Responsibility
- 258 Chi-wei Chen: Ideal Care Responsibilities and Arrangements: Their Relationship with Gender and Political Socialization
- 93 Jamie Woodworth & Dröfn Birgisdóttir: Ageing in community – connecting seriously ill older people to supports in civil society using the community connector model

Short presentations:

- 341 Blanca Valdivia: Community care infrastructures to sustain life in neighborhoods

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Contemporary challenges and prospects of the long term care in Croatia: who cares and whom do we care for?

Jelena Matancevic[1], **Danijel Baturina**[1]
[1]University Of Zagreb, Faculty of Law, Croatia

Croatian elderly care is characterized by a widespread informal care, a growing and today's dominant role of private, for-profit and non-for-profit providers, and a stagnant public sector. It is one of the first social policy areas after transition that had opened for the processes of privatization and introduction of the welfare mix model in Croatia, heavily demand-driven. Reluctance to policy reforms, limited state's capacities for service provision and contested processes of decentralization, in the context of growing and unmet needs, have resulted in strong trends of privatization and marketization of both, residential and community based services for the older people. It has subsequently led to territorial disparities and social inequalities in access to formal care on one hand, and on the other, growing burden on the informal sector of family care with genderizing effects (Matančević, Baturina and Gergorić, forthcoming).
Against this background, the aim of the paper to present the recent trends shaping long-term care system, relating to privatization, marketization, diversification of service and their effects

on accessibility and affordability of services. Methodology includes analysis of all available secondary data (mainly official statistical data and official reports).
The results will be discussed in the context of the identified institutional, organizational, financial and other prerequisites to transforming the long-term care system in Croatia to meet the current and future needs of older people, to strengthen the system's capacities for innovations, and to address the access to formal care as social right.

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Transformation of Elderly Care in Romania: Shifting Boundaries of Family, Market, and State Responsibility

Neda Deneva[1], **Mihaela Hărăguş**[1]
[1]Babeș-Bolyai University, Austria

Elderly care in Romania has traditionally been considered a family responsibility, with state intervention being subsidiary. However, economic transformations, welfare decentralization, and large-scale migration have reshaped the welfare mix, creating new care challenges and inequalities. This paper examines the changing distribution of care responsibilities among families, state institutions, private providers, and NGOs, considering the evolving legal and policy framework governing long-term care (LTC).
Despite the development of formal LTC services, family-based informal care remains dominant, particularly in rural areas where service availability is limited. The marketization of elder care has introduced new inequalities, as the affordability and accessibility of private services remain out of reach for many. The state, while expanding regulatory frameworks and funding mechanisms, continues to place the primary burden on local governments and individual families, resulting in highly fragmented service provision and regional disparities. Migration further complicates these dynamics, as transnational and internal mobility weaken traditional caregiving arrangements. In response, new care strategies emerge, including financial remittances, neighborhood-based informal support, and growing reliance on private nursing homes. However, societal perceptions continue to stigmatize institutional care, reinforcing moral discourses about family responsibility and intergenerational solidarity. Drawing on policy analysis, media discourse, and empirical data, this paper explores how the transformation of the care economy in Romania reshapes the social rights of both care providers and recipients. It critically examines how welfare policies mediate between family-based expectations and market-based solutions, offering insights into broader trends in Central and Eastern European welfare systems.

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Understanding Care Intentions in Taiwan's Long-Term Care Reform: The Roles of State Responsibility and Family Ethics in aTransforming Welfare Context

Chi-Wei Chen[1], Shu-Yung Wang[2]
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[2]Associate Professor, Department of Social Welfare, National Chung Cheng University, Taiwan

In recent years, Taiwan has actively promoted LTC reform to address the growing care deficit. While the public may support state responsibility in caregiving, their preferred care arrangements—and the extent to which such preferences are shaped by institutional

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contexts—remain unclear. Drawing on the Theory of Planned Behavior (TPB), this study conceptualizes state responsibility (SR) as an attitudinal factor, family ethics (FE) as a subjective norm, and incorporates the institutional environment (IE) as a contextual moderator to explore care intention (CI) when individuals face family LTC needs.
Using nationally representative data from 2016 and 2021, support for state responsibility (SR) is associated with a stronger preference for community-based care and reduced reliance on family or migrant caregivers. Although the SR × institutional environment (IE) interaction is not statistically significant, marginal effects suggest that post-reform changes in IE may amplify community care preferences among those moderately supportive of SR.
Stronger family ethics (FE) are linked to a higher preference for family care and lower support for external options. Among individuals with strong FE, those also endorsing SR show an even greater preference for family care, indicating an expectation for state support to uphold family caregiving.
Overall, the TPB effectively explains variation in CI. Reliance on migrant caregivers appears disconnected from FE, indicating such choices are often involuntary. In contrast, community-based care policies have gained broad public acceptance, reflecting support for ongoing care reforms.

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Connecting care in the end-of-life: Co-producing a model for collaboration between healthcare and civil society to enhance social support

Jamie Woodworth[1], **Dröfn Birgisdóttir**[1]
[1]Lund University, Sweden

Many seriously ill and frail older people experience a lack of practical support and meaningful social engagement. While healthcare provides good medical support, it lacks the full competence and resources to help with social, practical and existential challenges that can arise near the end-of-life. Increasingly, resources in civil society are enlisted to fill this care gap. One such attempt to bridge healthcare with the third sector is the “community connector” model, which has been researched in the UK and Australia. Within the CONNECTED project, we will adapt this model to the swedish healthcare and welfare context. While the third sector can bring a significant amount of value to healthcare, enlisting third sector actors as reinforcements to the welfare system can contribute to shifting responsibility out of the public sector. Our research therefore critically considers how establishing collaboration between civil society and health and social care providers (HSCPs) can enhance care outcomes for users while also contributing to making care systems more equitable and sustainable.

We have organized a series of co-production workshops together with HSCPs, civil society actors, and patient/relative representatives to construct an adapted model. The following questions are explored:

1) What are the unmet social support needs amongst seriously ill individuals and their informal caregivers and what community resources are available to address them?
2) How should the community connector role work in practice and what qualities and qualifications are required to do this work?
3) How did participants engage in dialogue and power-sharing in the workshop setting?

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Community care infrastructures to sustain life in neighborhoods

Blanca Valdivia[1,2], Roser Casanovas[2]
[1]Universitat Autònoma De Barcelona, Spain, [2]Col·lectiu Punt 6, Spain

Around the world, there continues to be an asymmetrical distribution of caregiving work, which continues to fall mainly on women, and especially on migrants and the working classes. Moreover, the lack of material and non-material conditions for care penalizes caregivers who face poorer physical and mental health, poorer economic conditions and time poverty.

This precariousness has led grassroots groups to organize themselves to democratize care from a local perspective. Some of these organizations prioritize advocating for better conditions for high-intensity caregiving. Others build community infrastructures to collectivize everyday care. In the neighborhoods, self-management and public resources are mixed to reproduce life, carrying out social tasks that complete and replace deficient or non-existent services (Cavallero and Gago, 2022).

The research question of this work is what social and urban elements favor the construction of community care infrastructures.

The methodology used in this work has been the case study approach, allowing for the analysis of three different groups: a collective that supports migrant women working in domestic and care roles; a group of mothers caring for children with disabilities; and a food bank in a community center.

The importance of urban configuration for collective organization around care has been confirmed. Physical proximity, being connected by public transport, and having physical spaces to gather, meet, or share care are key factors in building community care infrastructures.

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Friday 27 June: Parallel sessions 6

TP4 Participatory rights as social rights: institutions, consequences, and concepts in long-term care

Room: F3010
Time: 9:00-10:30
Chairs: Thurid Eggers, Ruth Abramowski, Miriam Laschinski

Presentations:

- 417 Birgit Pfau-Effinger & Ralf Och: Agency and Social Rights in Care Policies
- 285 Sheila Novek: Participatory Rights, Resident Councils and Power Relations in Residential Long-Term Care Settings
- 147 James Caiels & Rasa Mikelyte: Enhancing Participatory Rights: Co-Designing an Accessible Adult Social Care Outcomes Toolkit to Amplify the Voices of People Living with Dementia
- 408 Amber Cagney & Maria-Teresa Ferazzoli : IMPACT Networks: a model to implement co-production

Short presentations:

- 177 Rosie Read: Common interests or distinctive demands? Participation and activism in campaigns to transform social care in the UK.
- 366 Malin Björk: Exploring human rights and the value foundation in Swedish elderly care

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Agency and Social Rights in Care Policies

Birgit Prof. Dr. Pfau-Effinger[1], **Ralf Dr. Och**[2]
[1]University of Hamburg, Germany, [2]CNRS Paris, France

The paper introduces an analytical framework for the analysis of policy support for the agency of care recipients in care policies. The starting point is the neoliberal idea that welfare states should promote 'consumer choice' of older people in need of care, based on a narrow concept of agency. This idea is part of a strategy to weaken the role of the state and strengthen the role of markets in care (Rostgaard 2006). The paper introduces a broader concept of agency of care recipients that is integrated into the concept of social citizenship. The paper discusses the extent to which concepts such as 'active social citizenship' (Eggers, 2023; Eggers et al., 2019; Halvorsen et al., 2017; Hvinden and Johansson, 2007; Jensen & Pfau-Effinger 2005) and 'reablement' (Rostgaard et al. 2024) provide adequate analytical approaches for this purpose. The paper presents a multi-dimensional approach to analysing the construction of agency in

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care policies. It focuses on the extent to which policies aim to enhance the agency of care recipients in their individual care arrangements and social life (see also Eggers 2023). It then evaluates the scholarly value of this approach by using it to analyse the role of agency in the development of the institutional basis of care policy from 1994 to 2017 in the German welfare state, and how this is linked to cultural change.

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Participatory Rights, Resident Councils and Power Relations in Residential Long-Term Care Settings

Sheila Novek[1], Isabel Huang[3], Belinda Mayer[2], Genevieve Thompson[2], Laura Funk[2], Mary Shariff[2], Heather Cooke[4], Alison Phinney[3]
[1]Brandon University, Canada, [2]University of Manitoba, Canada, [3]University of British Columbia, , Canada, [4]Alzheimer Society of B.C., Canada

Resident councils are forums in which people living in residential long-term care homes meet on a regular basis to discuss concerns and share input with management. The concept can be traced back to patient and consumer rights movements in the 1970s and 1980s and the notion that care users should have a say in the services that affect their lives. Over the last two decades, the right to participate in a resident council has been enshrined in provincial regulations and various policies across Canada, leading to the institutionalization of this participatory practice. Despite their ubiquity, little is known about how resident councils actually work or the forms of participation they enable. To understand how resident councils work in practice, we conducted ethnographic research with two resident councils with distinct structures (one resident-led; one staff-led) in two Canadian provinces. Data collection included: 1) analysis of relevant laws and policies; 2) observation of council meetings; and 3) semi-structured interviews with 12 residents, 12 family members, 13 staff, and 6 policy stakeholders. Drawing on Gaventa's (2006) concept of 'invited spaces' for participation, we analyzed resident councils as spaces imbued with power relations in which residents are invited to participate in particular ways. By comparing councils with distinct structures (resident-led vs. staff-led), we explored how residents respond to, and challenge, participatory arrangements and unpack the power relations that shape these processes. This research sheds light on the links between council structures, power relations and participatory action and the limits and possibilities of these forums.

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Enhancing Participatory Rights: Co-Designing an Accessible Adult Social Care Outcomes Toolkit to Amplify the Voices of People Living with Dementia

Rasa Mikelyte[1], **James Caiels**[1], Stacey Rand[1], Elizabeth Field[2], Lucy Webster[1], Ann-Marie Towers[3]
[1]University of Kent, Canterbury, United Kingdom, [2]Kent and Medway NHS and Social Care Partnership Trust, United Kingdom, [3]King's College London, London, United Kingdom

Older people living with dementia are frequently excluded from participating in the planning of their own care and the quality assessment of care services. In England, the Adult Social Care Outcomes Toolkit (ASCOT; www.pssru.ac.uk/ascot) is included in national surveys to benchmark quality and capture unmet need. However, the format, layout and structure of standardised questionnaires disproportionately excludes those living with dementia and the

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oldest-old (Aznar et al., 2021).This project sought to co-design a more inclusive and accessible ASCOT self-report tool in collaboration with people living with dementia and their carers/supporters with a view to improving participatory rights for this marginalised group.

Through a series of co-design workshops and iterative testing, older people, including those living with dementia, worked alongside researchers to adapt the questionnaire, focusing on removing barriers to participation and ensuring the process was informed by lived experience. Cognitive interviews with 25 people using social care services, who had difficulties completing the standard tool, demonstrated that the adapted toolkit substantially improved accessibility and usability.

This presentation will explore the outcomes of our work, emphasising the narratives of people living with dementia and their supporters on inclusivity, fostering collaboration and promoting social inclusion. By ensuring that lived experience is at the centre of how we measure social care-related quality of life, this project offers a way for embedding participatory rights into social care evaluation and policy development.

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IMPACT Networks: a model to implement co-production

Amber Cagney[1], **Maria-Teresa Ferazzoli**[1]
[1]University Of Sheffield, United Kingdom

International health and social care systems have seen a paradigm shift toward a more co-produced and participative model (Beresford, 2018; Hedberg et al., 2022). This change aligns with a human rights model of disability and an increased appreciation of people with lived experience having more choice and control over their own healthcare support. However, this change requires the creation of different modalities of participation and a power shift in decision-making and knowledge production. This paper will present the experience of the IMPACT network as a model to enable democratic participation of people with lived experience in health and social care. Drawing on the Blended Learning Network model (Hanson et al., 2011), IMPACT Networks are one of the ‘delivery models’ of the UK-based implementation centre called IMPACT (IMProving Adult Care Together). Networks aim to bring people together to discuss a specific topic/issue in adult social care across the four UK nations and ultimately, co-produce a local action plan to create change.

Here, we reflect on how networks enable the involvement of people with lived experiences in participatory and leadership roles. We discuss how this model challenges power dynamics and traditional modalities of knowledge production, creating a space where lived experience is recognised as expertise. We also look at systematic and institutional challenges that we have encountered and how we have overcome them. The aim is to provide some practical lessons for more values-led collaborative approaches to empower people with lived experience to participate in decision-making in health and social care.

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Common interests or distinctive demands? Participation and activism in campaigns to transform social care in the UK.

Rosie Read[1]
[1]Bournemouth University, United Kingdom

This paper examines the demands made by various campaigning organisations seeking to change and improve the long-term care (social care) system in the UK. Campaigns usually represent the interests of a particular group within social care. Trade unions push for better pay and working conditions for workers in social care, whilst carers, older people and disabled people each have distinctive pressure groups seeking to improve the rights and entitlements for their constituencies. Whilst their respective demands may overlap, these campaigns are mostly not advanced collectively. This phenomenon is mirrored in models of public and patient involvement and participation in social care research, service development and delivery, which also tend to emphasize the separateness and distinctiveness of different constituencies of interest. This paper considers the theoretical and practical potential for social care campaigns to recognise shared interests and develop common goals. It argues that feminist social reproduction approaches to analysing social care, and its present state of crisis, can advance understanding of the shared history and points of connection amongst seemingly distinct interest groups. Finally, the paper reviews the emergence of campaigns which bring together care workers, family carers and disabled activists around the common political demand for a fully publicly funded social care system in the UK.

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Exploring human rights and the value foundation in Swedish elderly care

Malin Björk[1]
[1]Malmö University, Sweden

This ongoing research explores how human rights can be operationalized in Swedish elderly care through the “value foundation” (Swedish: värdegrund) of the Social Services Act (SFS 2001:453, Chapter 5, §4), emphasizing the right to a dignified life for older adults. The project consists of two qualitative document studies, applying a human rights-based approach (HRBA) as the theoretical framework, with reflexive thematic analysis.

The first study investigates the application of the principle of accountability in municipal elderly care, focusing on municipal elderly care as a duty-bearer in relation to human rights obligations. The study also examines key concepts such as dignity, participation, and self-determination, and analyzes how the "value foundation" aligns with human rights through a review of preparatory works, national guidelines, local policies, and international human rights instruments.

The second study analyzes 100 individual care plans (Swedish: genomförandeplaner) for older adults receiving municipal home care services. These plans detail how care services should be provided according to individual needs and preferences, ensuring alignment with the value foundation by integrating considerations of participation, self-determination, and integrity.

By addressing both structural and practical dimensions of human rights in elderly care, this research highlights challenges and opportunities of using the value foundation as a tool for

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implementing human rights in practice. The findings could contribute to a deeper understanding of the role of municipal elderly care as a duty-bearer and how human rights can be operationalized in practice.

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TP10 The emerging interaction between familial and paid care: a comparative Global South perspective

Room: F3006
Time: 9:00-10:30
Chairs: Elisabeth Schroeder-Butterfill, Annapurna Pandey

Presentations:

- 28 Saana Raittila-Salo: Finding a person with a “long heart”: Paid helpers as caregivers for older adults in rural South Africa
- 200 Catalina Ganga León: Emotion work in aging societies: A qualitative study of (family and paid) caregivers in Chile and Germany
- 379 Emily Freeman: Conceptualising the costs of dementia care for families in India in light of the interaction between familial and paid care
- 196 Pragya Dev: Representations of Care: Invisible Paid Caregiver(s) in Piku

Short presentations:

- 474 Annapurna Pandey: Eldercare Homes – A New Model of Care in India

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Finding a person with a “long heart”: Paid helpers as caregivers for older adults in rural South Africa

Saana Raittila-Salo[1,2]
[1]University of Helsinki, Finland, [2]University of the Witwatersrand, South Africa

In rural South Africa, close to the Mozambique border, global care chains play out in a local context. In this paper, I explore the dynamics of informal care for older adults in Mozambican-background families that employed a paid helper. Drawing on 8.5 months of multi-sited household ethnography in rural South Africa, I address unacknowledged practices of care by paid helpers. Companionship and attentiveness to need through watching and waiting was possible because of the constant presence of paid helpers in the households. The study included 111 home visits to 13 families (formal participants, n=39), complemented by interviews with professionals (n=24) and visits to local social, health and care services. Even relatively poor families, where the only regular income was an older person’s grant, were often financially able to employ a helper. Paid helpers were readily depicted as “family” but they were often marginalized and exploited – many were undocumented and illiterate, and all were of Mozambican-origin. Although participants often felt that care should be delivered by kin, some older adults found that having a paid helper provided them with independence from family. At

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the same time, financial support to pay for a helper was understood as family caregiving, and the emerging 'care manager roles' of adult children reconfigured norms of intergenerational reciprocity. This study contributes to understandings of the diverse arrangements of elderly care in Southern Africa, and the distinctiveness of care in migrant-background families and in rural borderlands.

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Emotion work in ageing societies: A qualitative study of family and paid caregivers in Chile and Germany

Catalina Ganga León[1,2]
[1]University of Bremen (BIGSSS), Bremen, Germany, [2]Millennium Institute for Care Research (MICARE), Santiago, Chile

Long-term care (LTC) for older adults involves significant emotional challenges, yet this dimension remains understudied. Drawing on Hochschild's (2003) conceptualisation of emotion work and emotional labour, this study examines emotion work among family and paid caregivers in Chile and Germany—two aging societies offering Global South-North insights. Based on 35 in-depth interviews conducted in 2023-2024, and analysed using constructivist grounded theory (Charmaz, 2014), the findings reveal key contrasts in the emotional management of professional and family caregivers. In Chile, paid caregivers' emotional labour reflects societal views of old age, emphasising loneliness and abandonment, whereas in Germany, it centres on institutional pressures and workplace dynamics. Among family caregivers, emotion work was tied to their personal histories with the care recipient. Both contexts imposed non-negotiable obligations and neither setting granted true autonomy. Yet, the logics governing care differed: as an act of love in Chile, and as a normative obligation in Germany. These findings underscore how welfare systems and kinship ideologies naturalise unequal emotional burdens, urging deeper reflection on the gendered and cultural dimensions of care.
Keywords: emotion work, emotional labour, older adults care, long-term care, Global South-North comparison.

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Conceptualising the costs of dementia care for families in India in light of the interaction between familial and paid care

Emily Freeman[1], Jayeeta Rajagopalan[1,2], Saadiya Hurzuk[2,3], Priya Treesa Thomas[2], Meera Pattabiraman[3], R Narendhar[3], Suvarna Alladi[2]
[1]Care Policy And Evaluation Centre, London School of Economics and Political Science, United Kingdom, [2]National Institute of Mental Health and Neurosciences, India, [3]Alzheimer's and Related Disorders Society of India, India

In India the dementia care system relies on families to pay for access to private or subsidised public specialist healthcare, and to provide needed social care, either directly, or indirectly through the unorganised care labour sector. This paper explores how care is conceptualised and costed – by families and scholars – after a decision to combine family and paid social care has been made. It builds on the body of evidence on the challenges of deciphering the social and economic costs of family care, by examining the further complexity added when paid care is introduced.

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We draw on interviews (N=56) with 24 ostensibly low and middle-income adults supporting family members living with moderate or severe dementias in East and South India. We find that individual family members frequently provide primarily ‘hands-on’ instrumental care OR financial care, and that the associated indirect and direct costs of each are not considered equal by those bearing them. As a result, for some cases, families providing care are composed of individuals who each perceive themselves to be shouldering the care provision alone. Further nuance in the family care and paid care nexus comes from families’ use of India’s unregulated domestic worker sector. We identified considerable variation in families’ perception of the roles played by workers who provided dementia care but were not employed “attenders” (carers). We reflect on the methodological implications for understanding the social and economic costs of care for families in light of the growing use of paid care in this context.

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Representations of Care: Invisible Paid Caregiver(s) in Piku

Pragya Dev[1]
[1]Indian Institute Of Technology Roorkee, India

Piku: Motion Se Hi Emotion (2015) is a comedy-drama Bollywood movie revolving around the lives of a financially independent daughter and an ageing widower father. The film depicts how the daughter Piku (played by Dipika Padukone) cares for her ageing father, Bashkor Banerjee (played by Amitabh Bachchan). It illustrates the presence of a paid caregiver, Budhan (played by Balendra Singh), but fails to recognise his efforts and relevance in the Bashkor family. This paper explores the cinematic representations of how care (paid and personal) is understood, interpreted and delivered in an upper middle class Indian household. I begin by juxtaposing the trope of expectations against the delivery of paid care and expand on the interaction between masculinity and paid care, as iterated by Thomas Chambers and Shalini Grover (2023). I further contrast the character of Budhan (the live-in paid caregiver) with the female maid (who cooks and cleans) to unfold the biases entailing the profession of paid care and examine their degrees of vulnerability (Mackenzie et al. 2014).

Keywords: Cinematic representation, masculinity, paid care, upper middle class, vulnerability

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Eldercare Homes – A New Model of Care in India

Annapurna Pandey[1]
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Matt Sedensky’s study (Associated Press, Aug 2, 2024) reiterates the popular narrative that in Aging India, adult children, especially sons, have moved away from natal homes for higher education and employment opportunities, have rescinded their Dharma (ethical duty), leaving their elders to live alone. Sedensky argues that more and more elders in rural and urban areas are abandoned and find solace in charity Elder Care homes. This paper will present an alternative narrative to this popular one. Based on participant observation and extensive interviews of the residents, carers, and owners at the Elder homes in Odisha, I will analyze many factors responsible for mushrooming new carers for the older generation.

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As people in India live longer at 67. Seven years of life expectancy, and expected to reach 81.96 in 2100, older adults are more likely to face frailty and vulnerability without the traditions of family support and lack of state support (Pandey, 2022). In this paper, I will explore the background of the people moving to these homes and why. What are the dimensions of age, caste, class, gender, religion, and rural-urban background of these residents? What are their life expectations? Who are the people and organizations establishing these Eldercare Homes, and what is their purpose? What is the relationship between the owners as carers in these homes and the residents? To support my argument, I will present an ethnographic account of the Eldercare Home residents.

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Friday 27 June: Parallel sessions 6

TP6 Digital technology and care: resources, rights and risks

Room: F3004
Time: 9:00-10:30
Chairs: Emma Garavaglia, Kate Hamblin, Grace Whitfield

Presentations:

- 264 Bernhard Weicht & Lisa Waldenburger: The “problem” of ageing – addressing or shaping problem constructions?
- 187 Gemma Hughes: Artificial intelligence and social care for older people: a typology of care automating technologies informed by a configurational approach
- 110 Mai Yamaguchi: Human Rights Issues in Care in the Era of Digitalization: Challenges Found in Japan
- 416 Annika Hudelmayer & Johanna Schütz: “I find the app very helpful, but haven't used it” Investigating the promises of a mobile app for home care

Short presentations:

- 116 Blanca Deusdad: Robotics to support ageing and social inclusion in nursing homes: MyRobot project, an ethical approach
- 424 Vilja Levonius: Empathy and Power in Social Media – Who Defines What Care Looks Like?

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The “problem” of ageing – addressing or shaping problem constructions?

Bernhard Weicht[1], **Lisa Waldenburger**[1]
[1]University Of Innsbruck, Austria

Austria has been debating the application of Artificial Intelligence (AI) in the context of ageing and long-term care (LTC). While the potential of AI in the context of LTC has been praised in politics, by developers or in public media, it often remains unclear which problems should actually be addressed. Discussions circle around how AI could turn LTC into a less labour-intensive sector, namely as a sector in which some human labour can be replaced by AI. Additionally, questions of safety, support, communication, surveillance and even comfort have been addressed in imaginations for the inclusion of AI in care practices. However, often AI is framed as a problem-solution to unidentified problems.

This paper adopts a ‘problem framing’ approach, utilised with a document analysis of key texts, in order to investigate how these problems are framed, constructed and shaped, for which AI could be a solution. Documents involve policy texts and proposals, research initiatives and other materials that advertise the implementation of AI solutions to questions of care.

The paper thus explores how different key actors represent the problem of ageing, long-term care and the possible inclusion of AI in the sector. It is argued that scrutinising how and by whom the 'problem' of 'ageing' and 'AI' is represented, sheds important light on what kind of solution is envisaged. The main aim lies in understanding the ways different key actors, such as policymakers or AI innovators frame the 'problem' of ageing and AI's role in addressing these challenges.

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Artificial intelligence and social care for older people: a typology of care automating technologies informed by a configurational approach

Gemma Hughes[1], Mary Daly[2]
[1]University Of Leicester, United Kingdom, [2]University of Oxford, United Kingdom

The recent developments of algorithmic technologies and large data infrastructures of artificial intelligence (AI) are expected to extend and support technology-enabled care for older people by: improving access to care and independent living, enhancing preventative care and labour productivity and improving working conditions for carers. This interventionist logic assumes that AI will positively affect the delivery of care. It also reduces diverse data sets, models and bundles of technology to a single thing.

Our response to this logic, which permeates UK public policy, is twofold. First, we define care as the meeting of perceived welfare-related need in a configuration that comprises need, relations/actors, tasks, resources, ideas and values. Second, we interrogate how AI contributes to the care of older people by asking three questions: What is it that is being automated by AI in care configurations? How do AI applications affect care understood as a configuration? What are the risks involved? In asking these questions, we open up the 'black box' of AI to show the variety of applications, data sources, intended users and beneficiaries.

We apply these questions to the existing evidence of empirical studies to classify AI interventions in care for older people according to the domains of need, relations/actors, tasks, resources, ideas and values. Our findings will be synthesised in a typology of AI interventions for older people. This typology will inform discussions about the resources, rights and risks of AI in the context of care configurations.

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Human Rights Issues in Care in the Era of Digitalization: Challenges Found in Japan

MAI Yamaguchi[1], **Masaya Shimmei**[2]
[1]Japan Lutheran College, Japan, [2]Den-En Chofu Gakuen University, Japan

Due to digital transformation of the society, various types of digital technology are used in social/ long-term care. Although Japanese government insists on the importance of collaboration between humans and technology, especially artificial intelligence (AI), few studies have examined human rights issues in care in the era of digitalisation. The presentation aims to explore the human rights issues in care and to consider ethical and practical

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challenges. A qualitative study was conducted using a semi-structured interview method with Japanese social workers. Thematic analysis was used to explore the participants' perceptions of technology in daily practice. Three interrelated themes regarding the use of technology were identified: ethically passive, ethically sceptical, and ethically proactive perceptions. Social workers passively and reluctantly adapted to the government-led gradual transition towards the daily use of technology but they did not fully trust technology. They proactively engaged in using various types of technologies to transform digital practices and improve the quality of care. These findings indicated that social workers were ethically struggling to determine ways to not exclude disadvantaged persons in the era of digitalisation. The findings also showed that Japanese social workers faced a radical but gradual transition to digitalisation without sufficient preparation, readiness, and training. Within the strong governmental-led political context, we need to pay attention to digital divide, not only among service users but also among organizations and social care work practitioners. It is considered that a more thoughtful ethical consideration of human right issues in care, especially in use of AI is needed.

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"I find the app very helpful, but haven't used it" Investigating the promises of a mobile app for home care

Johanna Schütz[1], **Annika Hudelmayer**[1]
[1]Bavarian Research Centre For Digital Care, Kempten, Germany

Informal caregivers play a crucial role in long-term care and often face significant challenges in planning, organising and coordinating tasks across complex care networks. While digital technologies offer potential to support these activities, their usage remains limited. This is due to various reasons that are not (only) of technical nature. Following an explorative approach, we examine the use of a market-ready mobile app designed to support informal caregivers in planning, organising, and coordinating care tasks. Through semi-structured interviews with 18 South German caregivers who used the app in real-life settings over several months, we analyse the interplay between technology and care practices.

Findings reveal that while the app offered tools for task-sharing, communication and documentation, its integration into everyday care was limited by the carer's established offline routines, distrust of digital processes, and concerns over data privacy. These barriers highlight a disconnect between the socio-technical imaginaries of technologically mediated care and the realities of caregiving. Our findings point to a fundamental mismatch between the ideation of 'digital solutions to tackle the care crisis' and the fragmented, underdeveloped digital infrastructure of Germany's care and health systems. Despite their potential, a digital tool can fail to provide meaningful support when broader systemic and structural barriers are not addressed.

By linking empirical insights to these systemic challenges, this presentation contributes to a deeper understanding of the limitations and possibilities of digital care technologies in transforming care work.

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Robotics to support ageing and social inclusion in nursing homes: MyRobot project, an ethical approach

Blanca Deusdad[1]
[1]Department of Anthropology, Philosophy and Social Work. Rovira I Virgili University, Spain

Digital technology can be a tool to complement care, but their use raises ethical questions concerning consent, the replacement of human care, the potential for increased dependency, and the burden on carers. The use of robotics is seen as an innovative tool to prevent profound loneliness in older adults or social isolation in people with dementia. The MyRobot project analyses the use of a social and companion robot, PARO, in care homes, looking not only at the technological approach of human-robot interaction or its therapeutic benefits, but also at the formal and informal caring relationships and experiences of receiving and giving care that emerge when robots are used for care. The study will address the following research questions: first, whether the use of robotics can be regarded as a tool for social inclusion and innovation in care homes, and the ethical dilemmas and constraints that arise from its use; secondly, what kind of relationships do older adults and other stakeholders develop with these 'other-than-human' beings, and whether Paro facilitates relationships between them. Fieldwork is being carried out in eight nursing homes across different regions of Spain, with the involvement of public administrations. The study will follow a qualitative methodology, using as research techniques: participant observation, focus groups, in-depth interviews, a discussion group and questionnaires to measure societal impact Identifying possible changes in how people view and think about using the robot after using it for a month. Funded by the Spanish Ministry of Science, Innovation and Universities, FEDER, EU (PID2023-147169NB-I00).

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Empathy and Power in Social Media – Who Defines What Care Looks Like?

Vilja Levonius[1]
[1]Finnish Institute Of Occupational Health, Finland

This study explores the role of empathy in shaping the public image of care work through social media, specifically focusing on the visual and discursive ways empathy is produced in organizational social media posts and images shared by care practitioners. In this context, empathy is both an organizational dynamic and a communicative tool used to influence the public representation of care work.

The research investigates how empathy is visually constituted in the images shared by care practitioners and the minimal text accompanying them, which often consists of organization-mandated hashtags. These hashtags, while seemingly simple, serve as powerful discursive tools that guide the public perception of care. Through a socio-material lens, the study critically examines how these hashtags contribute to narratives about care, influencing the way empathy and care are perceived by the public.

By analyzing the interplay between images and hashtags, this study highlights the power dynamics involved in defining what care looks like in the digital realm. It investigates how care organizations use social media to construct narratives around empathy and care, raising important questions about representation, authority, and the ethics of these mediated portrayals of care.

The study draws on a selection of social media content from care practitioners, focusing on the performative aspects of these posts and how they contribute to constructing the organizational

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image of care. The research aims to shed light on the implications of digital communication in care settings and its role in shaping both public understanding and organizational identity.

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Friday 27 June: Parallel sessions 6

OS5 Gender, precarity and new care futures

Room: U3039
Time: 9:00-10:30
Chairs: Shu-Yung Wang

Presentations:

- 153 Shu-Yung Wang: Caring Time Poverty and Parenting Practices in Taiwan: Impact of Workplace and Parental Leave Policies Reform
- 99 Aija Lulle: Menopause – new ageing and care futures?
- 228 Yueh-Ching Chou: Being both a Personal Assistant and a Home Care Worker: Reimagining Feminist Care Ethics through a Human Rights Lens
- 458 Janna Klostermann: Granny dumping? Gender, aging and extreme precarity in post-welfare states

Short presentations:

- 108 Carol Kelleher: Navigating In/ter/dependence : Complicating Care and Care Relations in Chronic Disease Management

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Caring Time Poverty and Parenting Practices in Taiwan: Impact of Workplace and Parental Leave Policies Reform

Shu-Yung, Brenda, Wang[1]
[1]National Chung Cheng Univ., Taiwan

Modernization of labour markets and family structures has shifted the traditional male breadwinner model to a dual-income model. Taiwan faces declining birth rates and the modernization of maternal and paternal roles. To address these challenges, the parental leave policy underwent reforms in 2021, including higher income replacement rates (60% to 80%), allowing both parents to take leave simultaneously, enabling receive childcare subsidies while on leave, and reducing the minimum leave duration from six months to one month to increase flexibility.

Gender norms, family dynamics, workplace resources, and public policies shape parenting practices. While many studies focus on the first two factors, research on the effects of labour policies—such as working hour regulation and scheduling autonomy—and leave policies remains limited. To address this gap, this research examines "caring time poverty" among working parents, the gap between parental leave applicability and usage, and how parenting scripts, labour market dynamics, and leave policies shape work-family arrangements.

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Between 2023 and 2024, interviews were conducted with 13 mothers, 8 fathers, 4 labour union members, and 8 employers. Analysis reveals that Taiwan's SME-driven, export-oriented labour system deepens working parents' caring time poverty. Deregulation, flexible schedules, and non-standard shifts intensify work-family conflicts. The study also uncovers the emotional politics of parenting, challenges in democratizing household labour, and workplace negotiations in policy implementation, including hidden structural penalties, performance discrimination, and dual workplace cultures influenced by enterprise type, company size, and union presence. These findings highlight the complex interactions between parenting practices, the labour market, and leave policies.

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Menopause – new ageing and care futures?

Aija Lulle[1]
[1]University Of Eastern Finland, Finland

Menopause – new ageing and care futures?

Menopause has emerged as a critical and highly visible issue in the discourse on long-term care, with international organizations, employers, governments, and other actors increasingly striving, indeed, even competing, to project themselves as advocates of menopausal well-being. This shift represents a growing recognition of menopause as a significant factor shaping individual health, workplace equity, and broader societal structures in our rapidly ageing world. Yet, in many countries, legislative reform imposing a duty of care for individuals experiencing menopause remains an inconceivable prospect. This presentation critically examines global trends in the recognition of menopause within frameworks of care and policies. By analyzing emergent policies, corporate initiatives, and advocacy efforts, I interrogate the implications of this trend for broader discussions on ageing and care. I also raise some pivotal questions about the intersection of gender, age, and care responsibilities in a rapidly evolving global context. In doing so, this presentation contributes to scholarly understandings of menopause as not only a personal health experience but also a site of institutional and societal transformation, thus offering new directions for research in ageing and care studies.

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Being both a Personal Assistant and a Home Care Worker: Reimagining Feminist Care Ethics through a Human Rights Lens

Yueh-Ching Chou[1], Bo-Wei Chen[3], Shao-fen Lee[2]
[1]Asia University, Taiwan, [2]National Yang Ming Chiao Tung University, Taiwan, [3]National Kaohsiung Normal University, Taiwan

Background and Aims: Personal assistance allows disabled people to make decisions about their support, while homecare services support both disabled and older adults. This study compares the roles of personal assistants and homecare workers, focusing on workers who have experience from both services, exploring how individual, cultural, and structural forces shape these roles and how workers develop agency within the service system.
Methods: Twenty participants with experience as both personal assistants and homecare workers were recruited using purposive and snowball sampling in 2024–2025. In-depth

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interviews were conducted, and data were analyzed using a comparative approach. Conceptual approaches included care ethics and the human rights perspective.
Findings: Participants preferred working as personal assistants with disabled people, aligning with values of autonomy and independent living. They appreciated being the “hands, legs, eyes, or ears” of disabled people, finding the work flexible and meaningful despite challenges. In contrast, participants described homecare work as hurried, regulated, and lacking opportunities to build close relationships with older adults, who were often perceived as unhappy. Despite low pay and undervaluation of care work, participants were motivated by a desire to “do good.” Personal assistance offered limited hours and income, appealing to retirees or trainees seeking flexible employment, while homecare provided stable income through the long-term care system.
Conclusions: This study calls for integrating feminist care ethics, cultural understanding, and disability studies into both services. It advocates reframing care and disability services from charity to a rights-based approach, benefiting both service users and care workers.

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Granny dumping? Gender, aging and extreme precarity in post-welfare states

Janna Klostermann[1], Karine Côté-Boucher[2], Susan Braedley[3]
[1]University Of Calgary, Canada, [2]Université de Montréal, Canada, [3]Carleton University, Canada

In the context of sociodemographic ageing, transnational migration and social welfare sustainability issues, recent media coverage features examples of family carers abandoning their older relatives, permanently or temporarily, which some refer to as “granny dumping.” Such stories ‘run counter’ to dominant conceptions of family caregiving (and common-sense policy assumptions) that privatize the costs of care (with gendered moral, familial, cultural ideals at play). Seeking to develop a more nuanced understanding of this pressing issue, our research takes the stories of older adults who themselves have been ‘dumped’ and discarded as a critical starting point for thinking about ageing, care and migration in contemporary post-welfare states. Drawing on feminist ethnographic research in five international cities (Auckland, Melbourne, Ottawa, Taipei, Vancouver), our approach weaves a feminist political economy lens with literary, rhetorical tools and Indigenous approaches to link older adults’ narratives to the structuring conditions of their lives. In this particular paper, we present a deeply contextualized account of one older adult’s experience that brings together her own hard-won insights, as well as the insights of other older adults, service providers and city officials that further speak to her circumstances. What emerges is a story about the limits of family caregiving in the context of welfare state retraction.

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Navigating In/ter/dependence : Complicating Care and Care Relations in Chronic Disease Management

Carol Kelleher[1], Eluska Fernandez[1], Paula Leocadio[1], Colin Hawkes[1]
[1]University College Cork, Ireland

Extant theories of self-management locate the responsibility of the active management of a chronic illness primarily with the individuals living with such conditions, in assumed collaboration with their family members and clinicians. Critically, feminist care scholars have developed an umbrella of relational autonomy approaches challenge such individualist

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biomedical perspectives by highlighting that the care capacities, relations and environments to become autonomous or ‘self-manage’ chronic conditions are developed, scaffolded, and supported relationally in social, political and other structures/contexts.

The purpose of this paper is to explore how young adults experience care and develop autonomy in relation to the management of chronic illness (Type 1 diabetes). Drawing on the analysis of qualitative data collected via 18 interviews with adolescents with type 1 diabetes and their parents, our findings reveal the unresolved relational tensions that emerge in the context of transitioning autonomy in relation to T1D management: desire for normalcy Vs constant medical gaze, desire for embodied corporeal control vs unpredictability of the ‘diabetic body’, desire for independence vs need for support and guidance.

We make four contributions to care, relational autonomy, and chronic disease management scholarship. First, we characterise the entwinements between care and relational autonomy development during adolescence. Second, we reveal the embodied nature of c relational autonomy , comprising care relations between the person, the self and the body or the condition. Third, we highlight the social dynamics of relational autonomy. Fourth, we highlight the entanglements between relational autonomy and material care relations, where technologysimultaneously liberates and controls.

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Friday 27 June, Keynote 3: Professor Håkan Jönson & Associate Professor Tove Harnett, Lund University, Sweden

Room: Main Building, the Great Hall

Time: 11:00-12:00

Chairs: Tine Rostgaard, Roskilde University/Stockholm University & Costanzo Ranci, Polytechnic of Milan

Håkan Jönson is Professor in Social Work at Lund University. His main areas of research concern eldercare, ageism, user involvement and social problems of older adults. Together with Tove Harnett he is currently heading research on user perspectives in home care and on care for older adults with substance use and complex needs. Jönson has published extensively on the problem of ageism and on comparisons between disability policies and eldercare. Recent publications include: 'Being an older person or a person with disability: Are supportive policies ageism?' (Jönson & Norberg, 2023), 'Age-based entitlement: An ageist practice or a tool for combatting ageism?' (Jönson, Carlstedt & Harnett, 2023) and 'Age logics in social work' (Jönson & Harnett, 2024). Together with Harnett, Jönson is currently editing an upcoming Handbook on Ageing and Social Work (Elgar).

Tove Harnett is Associate Professor in Social Work at Lund University, Sweden, and holds a PhD in Gerontology. She has headed projects comparing rights in disability services and eldercare and has an interest in age-based rights and ageism. Together with Håkan Jönson she is currently heading research on user perspectives in home care and on care for older adults with substance use and complex needs. Recent publications include: 'Rethinking the concept of successful ageing: A disability studies approach' (Harnett, Taghizadeh Larsson & Jönson, 2021), '"Wet" eldercare facilities: three strategies on the use of alcohol and illicit substances' (Harnett & Jönson, 2022) and 'The logic of "home care time"' (Jönson & Harnett, 2024). Together with Jönson, Harnett is currently editing an upcoming Handbook on Ageing and Social Work (Elgar).

Title: The Rights of Older People in Eldercare – A Matter of Comparisons

Eldercare systems tend to become self-contained universes of thought and reasoning, with an emphasis on costs, underscoring the need for a stronger focus on rights of care users. In this keynote, we apply a "disability lens" to rethink care for older adults, an approach we have used

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in several research projects. We argue that models and comparisons developed in disability studies make it possible to identify "cognitive traps" embedded in how we think about older people and their rights. These traps include the tendency to define justice for older care users as a comparison to others who also use care, rather than to other citizens. Other cognitive traps include the use of ageist stereotypes that portray aging itself as the main cause of support needs. In contrast, a key contribution of disability movements has been the promotion of active citizenship, challenging the passive roles often reinforced by the medical model. In this keynote, we highlight how older care users are often socialized to accept limited possibilities and to see themselves as collaborators within the care system, rather than as rights-holders.

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