Short-Case Series

Breaking the Silence: Caregivers and the Quest for Inclusion

Case theme: raising awareness on DEI issues in SMEs

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Breaking the Silence: Caregivers and the Quest for Inclusion

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Abstract

This case study examines the hidden struggles of employees who are full-time caregivers for children with severe and complex disabilities while pursuing demanding careers. It follows the collective story of four professional women working in different organisational contexts: a mid-size manufacturing company, a public sector institution, an SME, and a service company, each balancing relentless caregiving with workplace responsibilities.

The case highlights the silence surrounding caregiving in organisations due to stigma, the emotional exhaustion of long-term care, and the structural shift that occurs when state support is withdrawn once children turn eighteen. This turning point forces caregivers to manage greater responsibilities with fewer resources, intensifying the pressure on their professional lives.

In their workplaces, colleagues sometimes murmured about “favouritism,” noticing that those who frequently needed to leave earlier or take unplanned absences still received similar performance evaluations or benefits. Behind these perceptions lay a lack of clear communication and understanding, because decisions were often made informally, without transparency or explanation, leaving both caregivers and co-workers uncertain about fairness and expectations.

The women behind the initiative "Nepatogūs" (which means "Uncomfortable") have launched an advocacy movement aimed at recognizing caregivers as a significant and diverse social group. This movement seeks to highlight the importance of caregivers, including both employees and leaders, who share common experiences, face systemic barriers, and have specific inclusion needs that should be acknowledged in diversity and inclusion strategies.

Situated within the context of European small and medium-sized enterprises (SMEs), this case provides an opportunity to analyze issues of organizational justice, workplace fairness, and the role of diversity, equity, and inclusion (DEI) policies in the inclusion of caregivers. Students are encouraged to propose solutions that foster ethical and inclusive workplaces.

Keywords: caregiving, severe disability, SMEs, organisational justice, diversity, equity and inclusion (DEI), stigma, burnout, advocacy, ethical organisational culture.

The case relates to the United Nations’ Sustainable Development Goals: SDG 8 Decent Work and Economic Growth; SDG 10: Reduced Inequalities. It highlights how inclusive workplace policies for caregivers can reduce inequalities, promote fairness, and create decent work environments that value all employees.

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1. The Unseen Burden of Caregivers

A tired gaze. Lips pressed too tightly together. A back slightly bent, as if carrying a weight invisible to others. Small, fleeting signals, almost imperceptible, that colleagues might dismiss or even misinterpret. Perhaps, she trains too hard at the gym, they think. However, to those who have lived it, these micro-gestures tell a different story: the body speaking the truth of unrelenting care.

At first sight, these women appeared to be like any other dedicated professionals - full of passion for their work, and a determination to embrace life with energy. They arrived on time, met deadlines, and demonstrated a commitment that their colleagues admire. To the outside eye, they embodied resilience: balancing between careers, families, and life's daily demands with quiet determination. However, beneath the polished surface, their lives carried a weight few could imagine. Each was a mother to a child with a severe, complex disability.

Caregiving in this context was not about helping with homework or driving to sports practice. For many caregivers, a typical day begins with demanding tasks long before their paid work starts. Every morning, they lift their grown-up child into a wheelchair, help with hygiene and dressing, prepare special meals, and handle possible health issues like seizures. By the time they reach their workplace, much of their energy is already used, yet they must remain calm, focused, and ready to work. However, because of the social stigma attached to disability and caregiving, most choose not to speak about this reality at work. They worry about being seen as less reliable, less ambitious, or as a burden to their colleagues. Silence becomes a survival strategy, even though it deepens the sense of isolation.

Severe disability significantly limits a person's independence in daily life. For families, caregiving is not occasional help but a full-time, lifelong responsibility. According to the official EU data, 4.4% of children in the EU reported a disability (activity limitation due to health problems) in 2021, and about 1% of children in the European Union report having a severe disability, defined as a serious activity limitation due to health problems (Eurostat, 2023). They often have a so-called complex disability where several severe impairments occur together, such as profound physical, intellectual, or developmental impairments, or chronic conditions requiring constant supervision and care. These overlapping challenges make everyday life especially demanding and require continuous, multi-layered care.

Stigma wrapped around their reality like an invisible cloak. Speaking openly about caregiving felt risky: Would colleagues think they were less reliable, less ambitious, or too fragile for leadership roles? So, they concealed their exhaustion, declined business trips, and reported remote work while nursing their children in the hospital. Their silence shielded them from judgment but also deepened their isolation.

From the outside, colleagues saw only fragments of their challenges. Some admired their energy and determination; others quietly resented the schedule adjustments or sudden absences that left extra work behind. When one had to leave early to accompany her child to yet another hospital stay or decline a business trip because her care duties could not be delegated, the extra work often fell on others. These situations were not rare but recurring, and over time, colleagues began to feel the weight of filling in the gaps, even as they struggled to understand the reasons behind them entirely. In whispered conversations, questions surface: Is this fair? Why does she get flexibility when I do not? With no open dialogue, caregiving responsibilities are mistaken by colleagues for favouritism or special treatment. Compassion coexists with frustration, and invisible fault lines begin to run through teams.

And then came the structural blow: the state support that had sustained families for years was abruptly withdrawn when their child turned eighteen. Overnight, the caregiving load intensified, colliding with their own ageing bodies, dwindling resources, and the relentless pressures of professional life. It was the convergence of these pressures - silent stigma deepening emotional exhaustion, and the sudden withdrawal of support - that forced a reckoning.

2. From Quiet Resentment to Breaking Point

The tension at work coincided with changes at home. As their children grew older, the caregivers themselves were also ageing. Years of interrupted sleep and constant vigilance had taken a toll, leaving them physically drained and emotionally exhausted. The exhaustion was no longer temporary but had become a permanent condition of life.

The turning point came when their children reached adulthood. At eighteen, official support shifted or ended entirely. Financial benefits shrank, services were withdrawn, and yet nothing about their child’s condition had changed. The disability had not disappeared, but the state’s recognition has changed. The women found themselves in an impossible situation: still full-time caregivers, but with fewer resources and greater expectations to “cope.”

It was the convergence of these pressures - silent stigma at work, deepening emotional exhaustion, their own ageing bodies, and the sudden withdrawal of support - that forced a decision. Remaining silent was no longer sustainable. If they wanted to protect their health, careers, and dignity, they needed to speak up.

For years, they had endured their invisibility in silence. Yet their experiences varied across organizational contexts. In SMEs, managerial positions often involve unlimited working time clauses and an informal culture of constant availability. In manufacturing and service companies, shift-based or customer-facing work restricts flexibility. Meanwhile, in the public sector, formal HR procedures may provide stability but can also lead to bureaucratic rigidity. Despite these differences, all these women faced the same underlying challenge: a system unprepared to accommodate the realities of long-term caregiving.

Therefore, remaining quiet was no longer sustainable. To protect their health, careers, and dignity, they needed to speak up. This moment of strain and courage led to the creation of *Nepatogūs* (“Uncomfortable”). This advocacy movement demands recognition of caregivers not just as employees, but as leaders whose voices are vital in shaping inclusive workplaces and institutional changes.

Eventually, one individual decided that the silence was more burdensome than the exhaustion. She began to discuss her reality, naming what many had avoided openly: caregivers are employees, colleagues, and leaders, and their struggles are organisational issues, not just personal ones. Gradually, others joined her. Together, they transformed their isolation into a united voice and initiative called NEPATOGŪS (translated from Lithuanian: Uncomfortable).

“It feels uncomfortable to see them. Uncomfortable to think about them. Even more uncomfortable to ignore them. But helping is simple.” (Nepatogūs, 2025, p. 1)

3. The Role of *Nepatogūs (Uncomfortable)*

Nepatogūs (https://nepatogus.lt/) is a foundation and the voice of families who wake up every day to the same dedication: giving their children with severe and complex disabilities a life of dignity, comfort, and security. Behind the public mission lies something deeply personal - parents who know sleepless nights, constant medical routines, and quiet fear of what will happen when they are no longer there to care.

The initiative grew out of this lived experience. It seeks to create a society where people with disabilities can live independently and safely, but just as importantly, where their families are not left alone carrying the invisible load. Caregivers are more than parents because they are also employees, colleagues, and managers. However, their struggles are often hidden behind polite smiles and professional competence.

Research findings from the implementation of the DEI4SME project: Strengthening Diversity, Equity, and Inclusion in Education and SME Management confirm what these families already knew: in most organisations, caregivers are rarely recognised as a distinct group within diversity and inclusion policies (Kiverä, Šilenskytė & Delecour, 2025; Ramanauskaite, 2025). Gender, disability, and ethnicity appear on the agenda, but caregiving rarely does. This invisibility makes the daily strain heavier, as colleagues may see only absences or adjustments, without understanding the reasons behind them.

Nepatogūs exists to change that silence. It asks employers and policymakers to widen their idea of diversity to include those who care. Only then can workplaces and societies become fairer and more humane.

Caregiving also intersects with existing inequalities. In Europe, the majority of long-term caregivers are women, often in mid-career, which intensifies the gender pay gap and limits progression into leadership roles. When caregiving remains invisible in DEI agendas, these structural inequalities deepen, compounding disadvantages already linked to gender and age.

4. The Invisible Caregiving Dilemma

This story highlights a core challenge many organisations face when caregiving remains unseen:

> *Are workplace rules around flexibility and workload applied transparently to all employees, considering their needs, or are they informal, inconsistent decisions?*
>
> *Are responsibilities and rewards shared fairly, or do accommodations appear as special treatment?*
>
> *Is caregiving openly recognised and respected, or kept hidden under stigma and silence?*

From a DEI perspective, the question is sharper:

How can organisations move beyond compliance to actively include caregivers as part of workforce diversity, ensuring that every employee feels valued and feels a sense of belonging?

Caregiving invisibility presents significant organisational risks beyond issues of fairness and stigma. Absenteeism, high turnover rates, and employee burnout not only impact individual caregivers but also affect team stability and knowledge retention. In small and medium-sized enterprises (SMEs), where each employee often possesses unique expertise, the departure of a caregiver due to overwhelming stress can disrupt entire business operations. Therefore, failing to acknowledge the needs of caregivers is not just a matter of social justice; it also poses a serious threat to organisational resilience and sustainability.

At the EU level, the Work–Life Balance Directive (2019/1158) requires Member States to provide caregivers with at least five days of leave and the right to request flexible work arrangements (European Union, 2019). The Equal Treatment Directive further protects caregivers against discrimination by association. These legal frameworks highlight that caregiving is not only a personal struggle but also a regulated employment issue. Organisations that fail to respond risk not only reputational damage but also non-compliance with emerging EU standards.

However, in Lithuania, as in many other countries, the care services for persons with disabilities provided by formal caregivers or public services are only a small portion (Ambrazeviciute, 2022). The majority of support comes from informal caregivers, such as family members, friends, or neighbours, who assist with daily tasks such as healthcare management, transportation, household chores, and personal care. Based on the insights from the Nepatogus foundation, the informal caregiving significantly exceeds formal assistance. On average, caregivers provide around 200 hours of informal care per month, which is over 6.5 hours per day.

Caregivers may be legally recognized as caregivers or legal guardians entitled to state support, or informal caregivers who provide help without official status or financial compensation. Both groups play a crucial role in maintaining the well-being and resilience of persons with disabilities. However, caregiving often involves emotional strain, reduced employment opportunities, and financial hardship, particularly for middle-aged women (Ambrazeviciute, 2022). However, when a person with a disability reaches the age of 18, the caregiver must be reappointed through a legal procedure, and the individual's level of disability and capacity for work must be reassessed. This process is often time-consuming, financially demanding, and emotionally challenging for families. Despite these challenges, formal or informal caregivers remain the backbone of long-term care, ensuring daily stability and dignity for adults with disabilities.

(The teaching notes are available for educators only; register and request them.)

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