Invisible Care, Unmet Needs: The Situation of Ukrainian Caregivers of Persons with Disabilities in the EU

iNKuLtur
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SUSTENTO

Contents

List of Abbreviations

- **AMIF** – Asylum, Migration and Integration Fund
- **AZR** – Ausländerzentralregister (German Central Register of Foreigners)
- **CRPD / UN CRPD** – United Nations Convention on the Rights of Persons with Disabilities
- **DG EMPL** – Directorate-General for Employment, Social Affairs and Inclusion
- **DG ECHO** – Directorate-General for European Civil Protection and Humanitarian Aid Operations
- **DE** – Germany
- **EESC** – European Economic and Social Committee
- **EDF** – European Disability Forum
- **EIGE** – European Institute for Gender Equality
- **EP** – European Parliament
- **EPSR** – European Pillar of Social Rights
- **ESF+** – European Social Fund Plus
- **EUAA** – European Union Agency for Asylum
- **EU** – European Union
- **FG** – Focus Group
- **IAB** – Institut für Arbeitsmarkt- und Berufsforschung (German Institute for Employment Research)
- **IDP** – Internally Displaced Person
- **IOM** – International Organization for Migration
- **LT** – Lithuania
- **LTC** – Long-Term Care
- **MSNA** – Multi-Sector Needs Assessment
- **MLSA / MoSA** – Ministry of Labor and Social Affairs (generic national use)
- **NGO** – Non-Governmental Organisation
- **PL** – Poland
- **PWD** – Person(s) with Disabilities
- **RRF** – Recovery and Resilience Facility
- **SPC** – Social Protection Committee
- **TFEU** – Treaty on the Functioning of the European Union
- **TPD** – Temporary Protection Directive (EU 2001/55/EC)
- **UA** – Ukraine / Ukrainian
- **UNHCR** – United Nations High Commissioner for Refugees

1. Introduction

Russia's war in Ukraine has forced millions to flee [1] into the European Union (EU), including many persons with disabilities (PWD), and their family members or friends who care for them. This project-based research was launched to shed light on the invisible yet crucial role of Ukrainian caregivers of PWD who have resettled across the EU. The purpose of the study is to document the needs and challenges of these caregivers – an often overlooked group – and to inform evidence-based policy responses at the EU level. [2]; [3]

By focusing on this specific population, the research addresses a critical gap in understanding how refugee caregivers are coping and what support they require to ensure that both they and the persons they care for can live with dignity and further their inclusion in their new communities.

1.1 Why Focus on Ukrainian Caregivers of Persons with Disabilities?

This group faces a unique "double burden" [4]: they shoulder all the hardships of displacement as refugees and the ongoing responsibilities of caring for a person with disability. Fleeing a war zone and arriving in a foreign country with a person with disabilities as a family member involves confronting a lot of barriers – from the struggle to find accessible housing and suitable medical care to managing trauma and disability needs in an unfamiliar and inaccessible environment. It is important to note that, owing to movement restrictions (recently amended) affecting men and the persistence of gendered caregiving roles, these overlapping responsibilities are most often assumed by female relatives of different ages. Although many of these women are highly educated, experienced, and willing to work, evolving labor market regulations and limited flexibility in employment arrangements contribute to their exclusion from the labor market.

Many people, including Ukrainians with disabilities, have been deeply traumatized by war and forced displacement, while their caregivers often face social isolation and severe psychological strain in addition to their caregiving responsibilities.

1.2 Research Questions and Objectives

Key research questions include access to housing, employment and livelihood, receipt of social services and support, and social inclusion. With reference to three countries within the EU and at EU level, this qualitative study aims to document the current situation, including the needs of Ukrainian refugee caregivers of PWD and the barriers they are facing. In addition, it will identify good practices and gaps in support systems at national level, and will generate insights to inform EU-level policy recommendations.

1.3 Context within EU Frameworks

The study aligns with the European Commission's European Care Strategy, which stresses the importance of supporting informal carers, and with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). Supporting both the caregivers and the people they care for is essential to fulfilling these commitments.

1.4 Key Definitions

- **Caregiver:** An individual who provides care and assistance to another person who has different degrees of support needs.

- **Informal Caregiver:** A person who provides care outside of a professional framework, typically a family member or friend, without payment.

- **Person with Disability (PWD):** Someone with a long-term physical, mental, intellectual or sensory impairment who, in interaction with external barriers, is hindered from fully participating in society.

1.5 Scope of the Study

This qualitative research takes an EU-wide perspective, drawing on comparative findings from Germany, Poland, and Lithuania. Based on a limited number of qualitative interviews, the findings are not statistically representative and should be interpreted accordingly. The study aims to identify common patterns and key issues across countries, while explicitly acknowledging national differences and contextual specificities. The insights generated serve to inform EU-level recommendations, grounded in qualitative evidence and expert perspectives rather than generalisable data.

1.6 Research Limitations

Limitations include the lack of disaggregated data on caregivers, language and cultural barriers, and variations within national systems for social care and disability services. Despite these limitations, the study offers qualitative insights and comparative evidence for EU-level policymaking. While the data collected is not representative in every case, it provides an understanding of general administrative, communication, and institutional barriers faced by people with disabilities in each country, particularly refugees with disabilities and their caregivers, whose situations are often further exacerbated by these barriers.

1.7 Inclusion of National Case Studies

This EU-level study integrates comparative findings from three national case studies—Germany, Lithuania, and Poland—which offer a deeper understanding of how Ukrainian caregivers of persons with disabilities experience life across different EU Member States. These country reports provide a nuanced view of the legal, social, and policy frameworks influencing access to care, integration opportunities, employment, and social services. The qualitative data, focus group insights, and stakeholder interviews from these reports serve as a critical foundation for the broader EU-level recommendations.

2. Background and Methodology

2.1 Context of the War in Ukraine and Refugee Flows into the EU

Russia's full-scale invasion of Ukraine in February 2022 triggered the largest displacement in Europe since the Second World War, with more than 6 million Ukrainians fleeing abroad by late 2023 [1]. The EU's activation of the Temporary Protection Directive (TPD) on 4 March 2022 granted immediate legal stay, healthcare access, education, and labor market rights across all Member States. Germany currently hosts approximately 1.3 million Ukrainian refugees, Poland around 950,000, and Lithuania about 76,400. [2]

Most Ukrainian refugees are women, children, older persons, and persons with disabilities (PWD) [3]; [4]. Following the introduction of martial law in Ukraine, men aged 18–60 were initially restricted from leaving the country; however, this framework has evolved over time, with certain exemptions allowing some men to leave.

As the conflict entered 2026, the demographic profile of the Ukrainian refugee population has evolved from its initial 2022 composition. While women and children continue to represent the majority of those seeking protection abroad, recent data indicate a noticeable increase in the proportion of adult men. According to Eurostat [3] and UNHCR [4] data from late 2025, adult women account for approximately 44% of the Ukrainian refugee population in the EU, while the share of adult men has risen to around 26%. This shift is largely associated with family reunification processes and successive legislative adjustments to Ukraine's martial law framework, which have gradually expanded the categories of men permitted to leave the country.

The legal framework governing cross-border travel for men aged 18–60 has been progressively refined since 2022. In late 2025, the Government of Ukraine introduced regulatory amendments allowing men aged 18–22 temporarily to leave the country for purposes of education and participation in international academic or internship programmes. [5] At the same time, previously established exemptions remain in force, including for fathers of three or more children, single parents, and men acting as primary caregivers for family members with significant medical or care needs. Together, these measures indicate a calibrated adjustment of the martial law regime, balancing ongoing mobilisation requirements with humanitarian considerations, family unity, and the preservation of educational pathways for younger generations [6].

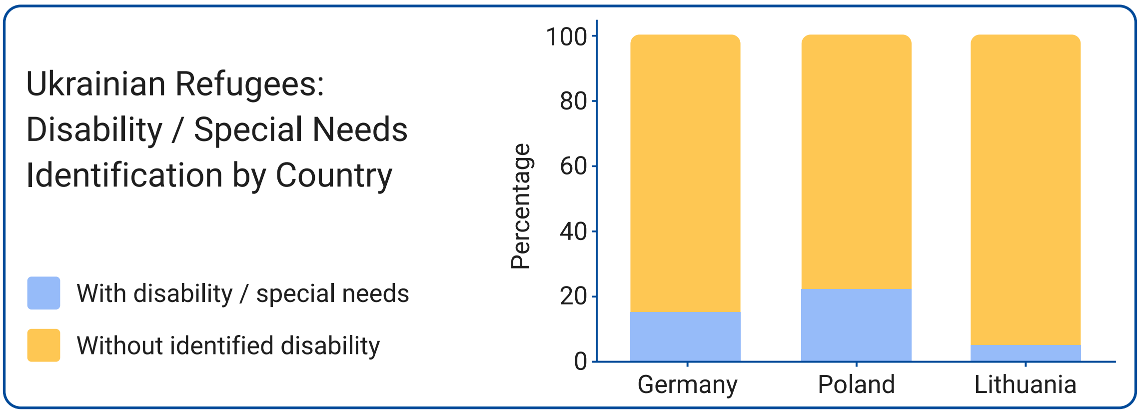
Vulnerability within the refugee population remains high, with a significant concentration of persons with disabilities and chronic illnesses. Current assessments indicate that approximately 20% of refugee households include at least one person with a disability. This demographic is particularly prevalent among the elderly: in some host regions like Moldova, more than half of the older refugee population reports mobility or sensory impairments [7]. For these households, the challenge of displacement is compounded by the need for specialized medical care and accessible housing, placing a sustained demand on the social welfare systems of host countries across Europe.

2.2 Description of the Target Group: Ukrainian Caregivers of Persons with Disabilities

The target group comprises informal, unpaid caregivers of persons with disabilities among Ukrainian refugees. The group consists predominantly of women, including mothers, grandmothers, aunts and other female relatives, who assume primary caregiving responsibilities within the family. These caregivers must navigate integration challenges in the host country while providing continuous daily care to a family member with disabilities or chronic health conditions. As a result, their caregiving role significantly limits their opportunities for employment, language learning, education and social participation, increasing the risk of social isolation and economic insecurity.

National contexts differ significantly.

In Germany, available administrative and survey-based evidence suggests that approximately 15% of Ukrainian refugees live with a disability or a chronic health condition, although the identification and registration of disability vary considerably across federal states and data sources [8]; [9]. In Poland, UNHCR profiling data indicate that 22% of Ukrainian refugee households report at least


Ukrainian Refugees:
Disability / Special Needs
Identification by Country

one member with special needs, including disability, chronic illness, or age-related functional limitations [10]. In Lithuania, official statistics record around 5% of Ukrainian refugees as having severe disabilities (disability level 3 or above) [11]; however, disability organisations and service providers consistently report higher proportions in practice, reflecting barriers to assessment, under-registration and delayed access to formal disability determination procedures.

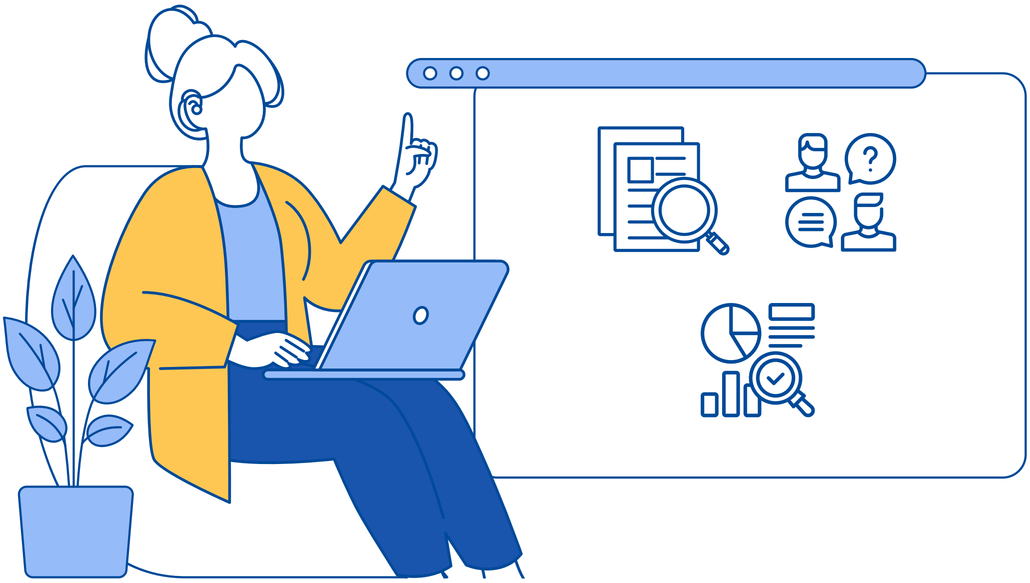
Caregivers across all three countries face common challenges: securing accessible housing, navigating administrative systems, lack of respite care, insufficient psychological support, reduced employment opportunities, and high levels of social isolation. In addition, reduced employment opportunities also result from the lack of day care services for children and children with disabilities of different ages in general.

2.3 Methodological Approach

A two-level methodology was applied:

A. National-Level Methodologies (Germany, Poland, Lithuania)

The national research in Germany (DE), Poland (PL), and Lithuania (LT) was conducted using a harmonised comparative framework based on a common National Report Template. The methodology combined desk research, qualitative interviews, focus group discussions, statistical data analysis, and stakeholder consultation.



Given the absence of systematic and comparable administrative data on Ukrainian caregivers of persons with disabilities across all three countries, a mixed-methods approach was applied to ensure triangulation of findings and analytical robustness. The research design allowed national adaptation while maintaining cross-country comparability.

All country teams conducted structured desk research covering national refugee protection frameworks (including implementation of the Temporary Protection Directive), disability certification systems and care assessment procedures, labor market integration policies, housing and social protection regulations, national disability and migration strategies, and alignment with relevant EU-level frameworks.

Desk research provided the legal and institutional framework necessary to contextualise qualitative findings and ensure comparability across countries.

Semi-structured interviews were conducted with Ukrainian caregivers of persons with disabilities, representatives of disability NGOs, social workers and municipal authorities, employment service representatives, academic experts, and, where feasible, employer representatives.

The number of interviews conducted was as follows: Germany – 7 in-depth interviews with caregivers; Poland – 5 interviews with caregivers; Lithuania – 6 interviews with caregivers and persons with disabilities.

Interview guides were harmonised across countries and addressed living conditions, access to healthcare and social services, disability certification procedures, employment barriers, housing challenges, care burden, psychological well-being, social integration, and policy recommendations.

Focus groups were organised to capture collective experiences and validate patterns emerging from desk research and interviews. In Germany, two stakeholder focus discussions were conducted. In Poland, two focus groups were organised with Ukrainian caregivers. In Lithuania, one caregiver focus group was conducted.

Focus group discussions enabled triangulation and identification of systemic barriers such as language, certification delays, limited respite services, and fragmented information systems.

Owing to the absence of dedicated caregiver registries in all three countries, statistical analysis relied on indirect and proxy indicators. National refugee registries, UNHCR profiling data, MSNA findings, and national disability statistics were analysed.

Where caregiver-specific data were unavailable, proxy indicators were used, including the share of refugee households including a member with disability, gender composition of refugee populations, employment rates among refugees with disabilities and social benefit participation.

National research teams collaborated closely with disability umbrella organisations and civil society actors to ensure ethical engagement with vulnerable participants, voluntary participation, informed consent, confidentiality, trauma-sensitive interviewing, and interpreter support where required.

Stakeholder consultation was used for validation of findings and identification of systemic gaps and policy inconsistencies.

Comparative Overview of Data Collection

Methodological Component	Germany	Poland	Lithuania
Desk Research	Yes	Yes	Yes
Semi-Structured Interviews (Caregivers)	7	5	6
Focus Groups (Caregivers)	0	2	1
Stakeholder Interviews and Focus Groups	Yes	Yes	Yes
Statistical Data Analysis	AZR, IAB	UNHCR, PFRON	MSNA, National Data

The research encountered structural limitations, including the absence of national registries of informal caregivers, inconsistent disability-related data collection among refugees, limited disaggregation of employment data, rural-urban disparities affecting accessibility, and limited employer participation.

Despite these limitations, triangulation of legal analysis, qualitative interviews, focus group discussions, and administrative data ensured analytical robustness and cross-country comparability.

B. EU-Level Comparative Methodology

The EU-level analysis synthesised the national findings into a broader comparative framework. Methods included:

- Analysis of EU legal documents and policy frameworks (European Care Strategy, EPSR, Work-Life Balance Directive, UN CRPD).
- Triangulation of qualitative and quantitative data across all three countries to identify structural similarities and divergences.
- Integration of EU-wide datasets from UNHCR, Eurostat, IOM and FRA to contextualise national findings.
- Expert consultations with EU civil society bodies—including the European Disability Forum (EDF) and EESC—to validate policy interpretations.
- Development of a unified analytical framework ensuring consistency of terminology, guided by UN CRPD standards.

By combining national and EU-level data and expertise, this mixed-methods approach ensures both a detailed understanding of each country's situation and a coherent, EU-wide perspective.

2.4 Justification for Starting from the EU Level

Beginning the study at the EU level is justified for four key reasons:

1. **EU frameworks shape national responsibilities.** Temporary Protection [12], the European Care Strategy [13], ESF+ [14]; [15] and AMIF [16] funding and the EPSR collectively influence Member States' approaches to refugee support and caregiving.
2. **Challenges faced by caregivers are shared across Member States.** Data gaps, service barriers, inaccessible housing and high caregiving burdens affect Ukrainian caregivers across Europe, regardless of national context.

3. **EU-wide obligations under international law apply uniformly.** The UN CRPD [17], ratified by the EU [18] and all Member States, mandates community-based support, independent living and adequate social protection for PWD and their families. An EU-level lens ensures compliance gaps are clearly identified.
4. **EU-level comparisons strengthen policy recommendations.** A macro-level analysis reveals systemic obstacles [19]; [20]; [21] (e.g., lack of disability identification during refugee registration, limited respite care) that require coordinated EU-level solutions.

An EU-level framing therefore ensures a coherent, rights-based understanding of the challenges faced by Ukrainian caregivers and prepares the foundation for robust policy recommendations.

3. European Legal and Policy Framework

The European legal and policy framework shaping the situation of informal caregivers—particularly Ukrainian caregivers of persons with disabilities — is built on a multilayered combination of rights-based instruments, soft-law recommendations, funding mechanisms and political commitments related to social inclusion, disability rights, care systems and migration. Taken together, these instruments signal an emerging European commitment to recognise informal care as a structural component of social protection systems. At the same time, significant gaps remain between EU-level ambitions and Member State implementation. This chapter provides a synthetic, policy-oriented overview that contextualises Ukrainian caregivers of PWD within the broader EU care landscape.

3.1 Foundations: EU Rights-Based Commitments

The European Union's fundamental social and human-rights commitments frame all care-related policies. Two instruments are particularly influential: the European Pillar of Social Rights (EPSR) [14] and the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) [17]. Their interplay defines both the rights of PWD and the obligations of states to support family members providing care.

Principle 9 of the EPSR [22] establishes that "parents and people with caring responsibilities have the right to suitable leave, flexible working arrangements, and access to care services." This is complemented by **Principle 18**, affirming "the right to affordable long-term care services of good quality, in particular home-care and community-based services." These commitments make clear that the EU's vision of social inclusion includes carers' ability to combine care responsibilities with participation in society and the labor market.

The **UN CRPD** [17] reinforces this framework by obliging states to provide access to community-based support systems (Article 19) and adequate social protection (Article 28), including targeted support to families of persons with disabilities. The CRPD's explicit reference to training, counselling, financial support and respite for families underscores that supporting informal caregivers is a human rights issue, not a purely social or welfare concern. This rights-based framing carries particular weight when considering the precarious situation of Ukrainian caregivers who are navigating care and displacement simultaneously.

Independent Living and Caregiver Rights

The right to independent living and being included in the community, as enshrined in Article 19 of the UN CRPD [17] and further clarified in General Comment No. 5 [35], is central to understanding the structural position of informal caregivers. Independent living does not refer to living alone, but to having choice, control, and access to the support necessary to participate in society on an equal basis with others. This includes access to personal assistance, community-based services, accessible housing and inclusive education.

Where such services are unavailable or inaccessible, responsibility shifts disproportionately onto families – and in practice most often onto women. In the case of Ukrainian refugee families, the absence of adequate community-based support and personal assistance services often results in a de facto institutionalisation within the private sphere: caregivers are compelled to provide full-time care, limiting their ability to access employment, education, language courses and social participation. This structural gap undermines both the rights of persons with disabilities to independent living and the socio-economic rights of their caregivers.

Ensuring access to independent living services is therefore not only a disability-rights obligation but also a precondition for labor market inclusion, gender equality and social integration of refugee caregivers.

3.2 The European Care Strategy: A Shift Toward Systemic Transformation

The 2022 European Care Strategy [13] represents the EU's most comprehensive attempt to modernise care systems, address demographic pressures, and formally recognise the contribution of informal carers. The strategy proposes a life-course approach to care—from early childhood to long-term care—and explicitly acknowledges the crucial but often invisible role played by family caregivers, most of whom are women.

A central component of the strategy is the **Council Recommendation on Access to Affordable High-Quality Long-Term Care (2022/C 476/01)** [23]. Given that women constitute the majority of informal carers across the EU — and an even higher proportion among Ukrainian refugee caregivers — the effective implementation of this Recommendation is also a matter of gender equality. Without adequate support structures, care responsibilities risk reinforcing existing gender gaps in employment, income, and pensions.

The strategy also emphasises improving the availability and quality of professional long-term care services, which directly affects the burden placed on families. Where formal services are insufficient, informal carers carry a disproportionate load. The European Care Strategy therefore positions family support and professional care development as mutually reinforcing objectives.

3.3 Directive (EU) 2019/1158 on Work–Life Balance

The Work–Life Balance Directive [24] was the first EU legal act to explicitly establish rights for informal carers. It introduced:

- A minimum of five working days of carers’ leave per year;
- A right to request flexible working arrangements;
- Stronger provisions for parental leave, indirectly benefiting carer households.

While groundbreaking, the directive has limitations. Carers’ leave need not be paid, resulting in significant disparities between Member States. Moreover, the directive applies only to individuals in formal employment, omitting many caregivers—especially those providing intensive daily care—who are forced to leave the labor market entirely. For Ukrainian caregivers, many of whom as women with children and often without their partners [25] face significant care burdens, the directive’s limitations are especially pronounced.

3.4 Informal Care as the Backbone of EU Care Systems

Informal caregivers provide an estimated 80% of all long-term care in Europe. Around 45% of EU residents support a family member or friend, and more than 52 million people provide intensive, long-term care. This unpaid work is valued at hundreds of billions of euros annually—representing one of the largest invisible subsidies to European social protection systems. [23], [21], [26], [27]

Gender disparities are striking: women make up approximately 60% of informal carers. They are more likely to reduce working hours, decline promotions, or leave the labor market altogether, resulting in lower earnings and reduced pensions. The European Institute for Gender Equality (EIGE) repeatedly highlights caregiving responsibilities as a driver of gender gaps in employment and poverty. [28], [29], [30], [31]

For Ukrainian caregivers—many of whom are female relatives raising children with disabilities—the gender dimension is even more pronounced. Disruption of social networks, language barriers, and lack of accessible services and limited day care opportunities in host countries exacerbate the care burden.

3.5 Structural Gaps and Implementation Tensions

Despite progress, EU policy on informal caregiving remains constrained by systemic gaps and uneven implementation at Member State level. In several countries, existing policy commitments have not yet translated into comprehensive registration systems or coordinated support structures for informal carers:

- **Lack of formal recognition.** Most Member States do not formally register informal carers, leaving them invisible to public administrations. This invisibility affects Ukrainian refugee carers particularly strongly as their caregiving role is rarely documented during registration.
- **Patchy social protection.** Few Member States offer pension credits or adequate caregiver allowances. Many carers risk long-term impoverishment as a direct result of their caregiving responsibilities.
- **Barriers to employment and reintegration.** The EU lacks specific instruments to support carers who have exited the labor market. Retraining, job placement incentives, and recognition of skills acquired through

caregiving remain underdeveloped. In particular, for refugees, adequate time to acquire the language of the host country (mostly a key requirement) to access the labor market, remains limited, further excluding them.

- **Uneven availability of services.** Access to support such as day care/after-school care, respite care (including short-term replacement care), personal assistance, community-based rehabilitation, and accessible housing varies dramatically across the EU. For Ukrainian caregivers, barriers are compounded by housing shortages, lack of adapted school or day-care places, limited information and navigation support, administrative complexity, and language/communication barriers. Where services exist, they do not always follow a human-rights based approach in line with the UNCRPD—instead of enabling independent living and participation, support may be organised in segregated or paternalistic ways, which can reduce choice and push families into “exclusive” options rather than inclusive mainstream solutions.

- **Persistent data gaps.** Reliable, disaggregated data on informal carers—including migrant, refugee, and disability-related caregiving—is scarce. This constrains both EU-wide monitoring and the development of a targeted policy.

3.6 The Role of Civil Society and the Emerging Call for a European Care Guarantee

Civil society has played a decisive role in pushing caregiver issues onto the EU agenda.

Recent EESC opinions of the European Economic and Social Committee (SOC/730 and SOC/761) [33], [34] are particularly influential in framing the EU's response to caregiving. They call for a coherent, long-term European framework recognising informal carers as a structural pillar of social protection systems, while at the same time reducing excessive reliance on family-based care. The EESC opinions advocate for a common EU definition of informal carers, accessible and high-quality respite services, psychological and peer-support mechanisms, financial safeguards to prevent caregiver poverty, and measures enabling carers to return to employment [13]. Importantly, these recommendations are closely linked to the implementation of independent living under Article 19 of the UN CRPD [17]: where community-based services, personal assistance, and accessible housing are insufficient, responsibility shifts disproportionately onto families. In this sense, proposals such as a **European Care Guarantee**—modelled in spirit on the European Child Guarantee [32] —would not only strengthen support for carers, but also contribute to a transition from a "caring for" paradigm toward a rights-based model of support that enables persons with disabilities to live independently [35] while preventing long-term socio-economic exclusion on the part of their caregivers.

For Ukrainian caregivers of PWD, such a guarantee could be transformative, addressing fragmentation across host countries and ensuring equitable access to support regardless of nationality or migration status.

4. Short Mapping of the Situation in the EU (Desk Research)

4.1 Data Gaps and Invisibility of Informal Caregivers

Informal caregivers form the backbone of care in Europe, yet they often remain statistically and socially invisible. Eurofound estimates that around one-fifth of people provide unpaid long-term care (roughly within a 20% range across population groups), while nearly half (45%) of the EU population provides some form of unpaid care when childcare is included—and many carers do not identify themselves as "carers," contributing to "hidden caring." [36], [37] This hidden caregiving represents a major data gap: definitions and recognition of unpaid carers vary across Member States, leading to fragmented measurement and uneven data collection. Young carers and those outside formal employment are especially under-reported and, as a result, their needs are not adequately captured in official statistics. Family carers have repeatedly been described as Europe's "invisible workforce," reflecting how essential support is delivered—often at significant personal cost—without consistent formal recognition [40].

The invisibility issue is even more pronounced for Ukrainian caregivers of persons with disabilities (PWD) who have come to the EU. There is **virtually no official data** on this subgroup; upon arrival in host countries, the fact that they are caregivers is usually not recorded. They are typically counted simply as refugees, meaning any specific needs as caregivers remain unseen by authorities. This lack of early identification makes outreach and support difficult. According to UNHCR, systematic identification of refugees with disabilities (and their carers) at an early stage is essential, as without it the most vulnerable families risk falling through the cracks in support services and some of them may return to Ukraine.

In summary, both at EU level and for displaced Ukrainian caregivers, a key challenge is the paucity of data and recognition – caregivers remain largely invisible in public policy and statistics, despite their crucial societal role.

4.2 Living and Housing Conditions

Households that include persons with disabilities often face difficult living and housing conditions across the EU. Statistics show that people with disabilities are more likely to live in substandard or financially precarious housing. For example, in recent Eurostat data, 17% of people with disabilities in the EU reported problems like a leaking roof or damp in their dwelling, compared to about 12% of those with no disability. Affordability is another concern: about 12.3% of individuals with disabilities spend over 40% of their income on housing (a sign of housing cost overburden), versus around 9.9% for the general population. They also face slightly higher rates of overcrowding in some age groups. These disparities stem from multiple factors – lower average incomes (due to reduced work capacity of carers or disabled members), extra costs related to disability, and a shortage of accessible social housing. In short, caring for a dependent family member can put serious strain on a family's housing quality and stability [41].

Ukrainian caregivers of PWD encounter acute housing challenges in host countries. Many fled war with severely disabled or ill family members, and finding suitable accommodation has been a constant struggle. Accessible housing (e.g. wheelchair-friendly, ground-floor, near public transport and services) is limited and often expensive. As a result, a large number of these families remain in temporary arrangements – such as reception centers, collective shelters, or hosted in private homes – long after arrival. UNHCR reports that refugee households, including someone with a disability, are more likely to reside in collective shelters or with host families, rather than independent rented housing, and this trend has been observed in countries receiving Ukrainian refugees. The reliance on short-term housing not only jeopardizes their comfort and privacy but also has knock-on effects: unstable living conditions make it harder to enroll children in local schools, access local healthcare, or integrate into the community. Furthermore, overcrowding and lack of appropriate facilities (like accessible bathrooms) can diminish the well-being of both the caregiver and the person with disabilities. In summary, while poor housing conditions are a broader issue for many EU families with care needs, Ukrainian refugee caregivers face an especially precarious situation in securing safe, adequate housing for their loved ones.

4.3 Employment and Labor Market Access

Caring responsibilities heavily influence employment prospects and patterns in Europe, particularly for women. EU-wide data clearly show that many informal caregivers reduce their working hours or leave the labor market entirely due to care duties. This creates a significant gender gap in employment. Nearly one in three inactive women (of working age 20–64) cite caring for children or incapacitated adults as the main reason they are not employed, compared to only about 5% of inactive men. In absolute terms, about 7.7 million women across Europe are prevented from taking up paid work because of unpaid care responsibilities, versus roughly 450,000 men. Consequently, women caregivers often forego earnings and career advancement, contributing to an 11% gender employment gap as well as long-term effects like a wider gender pension gap [45]. Even those who remain employed may struggle to balance work and care, often taking part-time jobs below their skill level or declining promotions. Intensive caregiving can lead to absenteeism, lower productivity, or exiting work early. Recognising these challenges, EU policy measures (such as the Work–Life Balance Directive of 2019) have introduced concepts like a right to short-term carers' leave and flexible working arrangements. However, uptake of these benefits depends on national implementation and many carers still receive limited support from employers or social protection systems [3].

For Ukrainian refugee caregivers, accessing the labor market is particularly daunting. Most are women (often mothers of children with disabilities) who must juggle full-time care with the demands of resettlement. They typically need local jobs that are compatible with their caregiving – for instance, part-time or flexible hours and located near home or care facilities. Such opportunities can be scarce. Language barriers and the non-recognition of Ukrainian qualifications further restrict suitable job options, as these caregivers cannot easily retrain or validate their past experience while caring for a high-need family member. Employers may also be hesitant to hire someone who has obvious constraints on availability (e.g. needing frequent time off for medical appointments or emergencies). The result is that many caregiver-refugees remain unemployed or under-employed despite being of working age.

Overall, the combination of caregiving duties, language/integration hurdles and limited support means Ukrainian caregivers face a high risk of long-term unemployment or financial insecurity. This underscores the need for targeted labor market inclusion measures (such as supported employment programs or childcare/respite services) to help them reconcile work and care.

4.4 Social Services and Support Systems

Across the EU, there is growing awareness that informal carers need better support, but provision remains uneven. Family caregivers often step in due to gaps in formal long-term care services – and in many countries they do so with minimal state support. Some Member States have introduced policies such as caregiver allowances, respite care services (structured short-term care arrangements designed to temporarily relieve informal caregivers), counseling or training for carers, and inclusion of carers in social security schemes. For example, a few countries count caregiving periods towards pension entitlements or offer tax credits. However, these supports vary widely and are frequently insufficient or hard to access [22].

In practice, a majority of long-term care needs in Europe (especially for the elderly and disabled) are met by unpaid family members: it is estimated that 80% of all long-term care in the EU [27], [21] is provided informally by families and friends. Yet most of these carers receive no regular compensation and often forfeit their own social rights, such as accruing pension, unemployment, or sickness benefits, because they are not in formal employment [21]. A stark indicator of the strained support systems is the prevalence of unmet care needs. EU surveys indicate that almost half of people aged over 65 with disabilities have an unmet need for help with regard to personal care or household activities, due to lack of accessible services or affordability issues [41]. Likewise, about 50% of children with disabilities in Europe are cared for exclusively by their parents, with no external support services involved [42].

These figures highlight that formal social services – including home care, community-based support, daycare centres, and structured alternative care services – are either not sufficiently available or not reaching many families. Alternative care services refer to formal arrangements that partially or fully substitute informal family care on a temporary or long-term basis, such as professional home care, personal assistance schemes, supported living arrangements, or residential care. In many Member States, such services remain underdeveloped, geographically uneven, or financially inaccessible, leaving families to absorb the care burden.

The European Care Strategy (2022) [13] aims to address some of these structural gaps by urging Member States to improve the availability, affordability and quality of care services, and to better support caregivers, including through training, social protection measures, and improved access to respite care. Nevertheless, implementation remains uneven, and informal caregivers continue to depend on a fragmented mix of NGO support, family networks, and limited public programs.

For Ukrainian caregivers of persons with disabilities, navigating social services in a foreign country represents an additional layer of complexity on top of demanding caregiving responsibilities. Many arrived from a system in Ukraine where family members were typically the primary caregivers and formal disability support services were limited. As a result, they may be unfamiliar with the scope of entitlements in host countries, including personal assistance, respite services, rehabilitation programs, or income-support schemes.

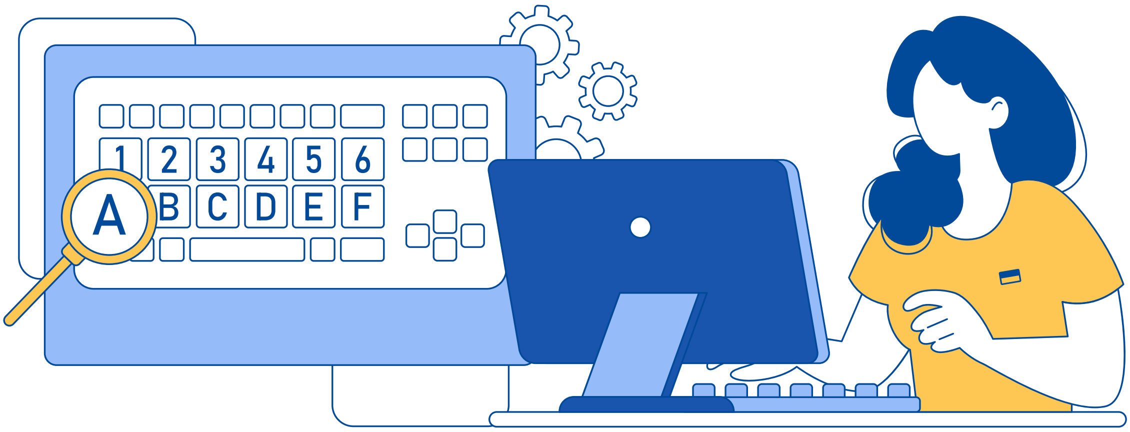
Language barriers, lack of accessible information, and complex administrative procedures can prevent refugee caregivers from accessing even existing services. In some cases, eligibility for disability benefits, caregiver allowances, or long-term support services may depend on residency status or require lengthy application processes. There have been reports of refugee caregivers not receiving benefits either due to lack of awareness and procedural barriers, or because certain schemes initially excluded temporary protection holders.

In practice, this often means that refugee caregivers rely disproportionately on humanitarian actors, refugee NGOs, faith-based groups, or informal community networks. While such actors may occasionally provide short-term relief or ad hoc respite arrangements, these do not replace systematic access to structured respite care services or sustainable alternative care models within national systems.

International guidance, including by UNHCR, emphasizes the importance of early identification and case management for refugees with specific needs, including persons with disabilities and their caregivers. However, systematic screening and proactive outreach are not consistently implemented. Consequently, caregivers must frequently self-identify, navigate unfamiliar bureaucracies, and advocate for support without professional guidance.

This situation may result in a form of double exclusion. Refugee caregivers may be unable to participate in integration measures (such as language courses or employment programs) because caregiving responsibilities prevent them from leaving home, particularly in the absence of accessible respite services. At the same time, they may face barriers in accessing disability-related alternative care services as a result of their newcomer status. The lack of coordinated pathways between refugee integration systems and disability support systems reinforces this structural gap.

Addressing these challenges requires more than general refugee support. It calls for targeted, coordinated responses, such as specialized social workers trained in disability inclusion, culturally and linguistically accessible information, and "one-stop" multifunctional service hubs that integrate refugee support with disability services. Ensuring access to both structured respite care services (to relieve caregiver burden) and sustainable alternative care services (to provide long-term support where needed) is essential to prevent social isolation, economic marginalization, and caregiver burnout among Ukrainian families caring for persons with disabilities.



4.5 Integration, Social Inclusion and Well-being

The social inclusion and personal well-being of informal caregivers is a significant concern in Europe. The caregiving role, while often a labor of love, can be **highly isolating and stressful**. Many carers experience reduced time for social activities, leisure, and self-care as they prioritize the needs of their dependent family member. This can lead to feelings of loneliness and social exclusion. Studies have found, for instance, that intensive caregiving is associated with higher rates of chronic stress and depression, especially among women who provide the bulk of care and often juggle multiple roles [43]. Caregivers commonly report health problems of their own (both physical injuries from lifting or assisting, and mental health issues like anxiety or burnout) [21]. Without adequate respite or support, the constant responsibility can erode their quality of life. Community and peer support can make a positive difference – some EU countries and NGOs facilitate caregiver support groups or respite breaks – but not all carers have access to these. Notably, the COFACE survey of family carers highlighted that carers see themselves as under-appreciated and socially invisible [39], despite being indispensable for society.

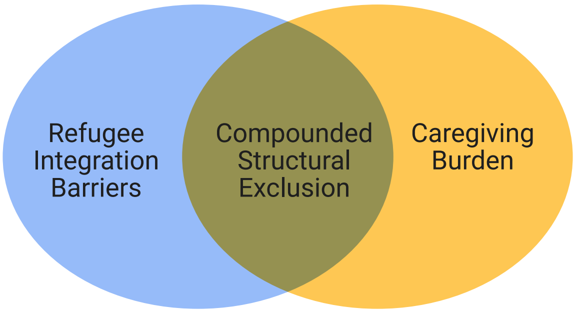
As one respondent put it, “without us everything collapses.” Lack of recognition and inclusion can further diminish carers’ well-being. In terms of integration into society, informal carers may withdraw from friendships, clubs, or public life due to the demands on their time, which in turn affects their sense of belonging and even civic participation.

For Ukrainian refugee caregivers, issues of social inclusion are compounded by their status as newcomers in a foreign country. They contend with the general challenges faced by all refugees (such as adapting to a new culture, learning a new language, building a social network from scratch) and the specific challenges of caring for a person with a disability under difficult circumstances. This combination often leaves them extremely isolated. Many caregivers among the Ukrainian refugees have little opportunity to engage with their host community – attending language classes, local events, or even going to meet other fellow caregivers – because they cannot leave their disabled family member unattended. In interviews and assessments by refugee organizations, caregivers frequently mention being confined to the home or hospital with the person they care for, which prevents them from forming new social connections in the host country. There is also the emotional toll: these families have endured trauma from the war and displacement, and the caregivers must shoulder not only their own distress but also that of the person with disabilities (who may be even more traumatized). Without targeted psychosocial support, this can lead to severe strain. Indeed, field reports note that refugee caregivers often neglect their own mental health as they focus on survival and caring tasks. Another aspect of inclusion is facing stigma or misunderstanding. Refugees with visible disabilities or behavioural challenges (for example, a child on the autism spectrum) sometimes encounter prejudice, which the caregiver has to navigate, potentially feeling further alienated. All these factors mean that the well-being of Ukrainian caregivers of PWD is at risk: they are at high risk of exhaustion, burnout, and social isolation. To improve their situation, initiatives in some host countries have started to provide tailored integration support – for example, creating support groups specifically for Ukrainian carers, or arranging respite care so that the caregiver can attend language lessons or simply rest. Such efforts are crucial for the social inclusion and mental health of these caregivers. In essence, while informal carers across Europe need better inclusion and well-being measures, those who are also refugees warrant particular attention in order to ensure they are not left behind in either sphere of life.

5. Comparative Analysis and EU Policy Gaps

5.1 Common Challenges across Germany, Lithuania, Poland

Ukrainian caregivers of persons with disabilities face a double burden: they must cope with the general hardships of displacement and the specific challenges of caregiving in a new country. Across Germany, Poland, and Lithuania, several recurring problems emerge [46]. Limited access to disability support is a persistent issue [4]. Upon arrival, refugees with disabilities are often not systematically identified by authorities, leaving caregivers to navigate support services on their own [44]. This invisibility means many families struggle to obtain disability benefits, assistive devices, or specialized services in the host country. For example, most EU countries did not collect data on refugees with disabilities under Temporary Protection, making it difficult to plan or provide tailored assistance. As a result, caregivers frequently encounter additional bureaucratic hurdles and information gaps when seeking medical care, therapy, or educational support for their disabled family members.



Housing instability is another common challenge. Many caregivers and their families live in temporary or precarious accommodation. Finding affordable, accessible housing is difficult due to high costs and the scarcity of adapted homes. Refugees often rely on short-term solutions (collective shelters, host families, NGO-provided housing), which may not meet the needs of a family member with a disability. In all three countries, qualitative interviews and focus group discussions indicate recurring obstacles, including discrimination by landlords and a lack of social housing options. In Lithuania, 45% of refugee respondents in 2023 had experienced discrimination when searching for housing or jobs, and adequate accommodation was cited as a top priority need. Similar trends are seen in Germany and Poland, where families with disabled members are more likely to remain in shelters longer owing to the difficulty of securing suitable independent housing. Overcrowded or inaccessible living conditions add to the stress on caregivers and hinder the well-being of PWD.

Employment barriers are profound and cut across the countries profiled in this study. The majority of Ukrainian caregiver refugees are women (often mothers) who cannot engage in full-time work because they must provide constant care. All three countries show significantly lower employment rates for refugee households that include persons with disabilities. In Germany, for instance, only 18% of refugees from households with a disability were employed as of late 2023, compared to 54% among other refugee households. Caregivers often have to stay home due to the lack of respite and alternative care services for their family members, making it nearly impossible to maintain or get a job. Accessing daycare, respite care or special schools is limited, so caregivers cannot commit to regular working hours. In Poland and Lithuania, NGOs observe the same pattern of near-zero employment for mothers of children with disabilities, largely because no one else is available to provide care. Language barriers and the non-transferability of Ukrainian social support (such as losing any caregiver allowance they had in Ukraine) only compound the problem. Many highly educated Ukrainian women are thus economically inactive in the host countries, despite policy efforts to facilitate their labor market integration. However, these policy efforts specifically state that people in caregiver roles are not included. In addition, as a result of limited care alternatives, informal caregivers in Germany reported that it is difficult to gain language skills. This not only causes financial strain but also isolation and loss of skills over time.

Across all countries, **social isolation and psychological strain** are widespread among these caregivers. Being a full-time carer in a foreign country often means they have little opportunity to attend language classes, employment programs, or social activities – trapping them in a cycle of isolation. These findings echo a 2022–2023 European Disability Forum study [44] covering hundreds of Ukrainian families, which identified labor market exclusion, insufficient social support, and marginalization from community life as key issues faced by refugee caregivers of PWD. Despite some country-specific initiatives, these problems are prevalent in Germany, Poland, and Lithuania alike, indicating structural gaps in how refugees with caregiving responsibilities are supported.

5.2 Differences due to National Systems

While the challenges are similar, the experiences of Ukrainian caregivers vary between Germany, Poland, and Lithuania due to differences in national policies and support systems. Social service structures and disability assessment processes diverge significantly.

In **Germany**, refugees benefit from a relatively robust welfare state – after mid-2022, Ukrainians were brought under the regular social security system, theoretically giving them access to mainstream benefits and healthcare. However, Germany's support is tied to formal procedures: to receive disability benefits or in-home care services, the person with a disability must be assessed and recognized under German law. This can be a lengthy bureaucratic process, often with language and documentation barriers. Many Ukrainian families struggle to navigate the complex web of offices (health insurance, social welfare, youth services) to obtain a disability certification or care level for their family member. The result is that, in practice, access to services is delayed. For example, in the German case study, one caregiver reported waiting four months merely to obtain an appointment for submitting documentation required for the recognition of her child's disability status. During this period, no interim support was provided, and the child remained without access to appropriate educational or therapeutic services. This delay illustrates how procedural waiting times alone can significantly postpone access to essential disability-related rights and services, placing additional strain on caregiving families.

Poland's support system, by contrast, initially relied heavily on emergency measures and civil society rather than long-term institutional support. The Polish government provided immediate assistance to Ukrainian refugees (e.g. one-time cash allowances, access to basic healthcare, and education for children), and many disabled refugees were helped by a vast grassroots response. However, Poland's existing disability support schemes – such as the official disability certification and caregiver allowance for Polish residents – have been less accessible to refugees. In Poland, obtaining the caregiver benefit (a stipend for those who stop work to care for a disabled child) requires a recognized disability status. In practice, very few Ukrainian caregivers have managed to secure this, owing to procedural obstacles and backlogs in the assessment system. Instead, much of the help has come from NGOs and volunteer networks (for instance, specialized NGOs in Kraków or Warsaw helping to match families to services or donating equipment). Local support networks thus play a larger role in Poland, but they are uneven across regions. Moreover, policy coordination in Poland has been challenging given the scale of arrivals – with over a million Ukrainian refugees, authorities focused on broad measures (like free public transport, inclusion in schools) but had less capacity individually to case-manage families with special needs. This means Ukrainian caregivers in Poland often depend on the luck of connecting with an active NGO or sympathetic local official. Where German support might be bureaucratic but structured, in Poland it has been more ad-hoc, leading to inconsistencies in the care that families receive.

Lithuania, hosting a smaller number of Ukrainian refugees, illustrates a different set of national responses. Lithuanian authorities have introduced some innovative policy adjustments to support caregivers, though resources remain limited. Notably, in 2022 Lithuania created a temporary legal status of “carer of a person with a disability” for family members looking after a child with very high care needs. This status (granted for up to 36 months) allows the caregiver to receive social insurance coverage and a stipend, formally recognizing their caregiving role. This policy reflects an understanding that, previously, parents (mostly mothers) simply dropped out of the labor force without any support. However, the measure has clear drawbacks: it cannot be combined with employment and effectively confirms that the caregiver will be out of work during that period. Thus, while Lithuania offers such dedicated caregivers a benefit (something Germany and Poland do not explicitly provide to refugees), it reinforces dependence on welfare and does not facilitate labor market integration. Another difference in Lithuania is how housing and integration are managed. There is no central system to assist refugees in finding long-term accessible housing – beyond an initial stay at a Refugee Reception Centre, individuals must find accommodation largely on their own or with NGO help. In Germany, each federal state has different regulations. In Berlin, for example, the situation with housing for refugees was and remains difficult. Refugees were not given flats (they had to find them themselves), but were housed in shared accommodation. Lithuanian municipalities were not mandated to prioritize refugees (indeed, refugees are not listed as a vulnerable group eligible for expedited social housing). This has left some Ukrainian families in Lithuania searching for suitable housing in the private market, where language barriers and limited supply of accessible homes are significant hurdles. In terms of community support, Lithuania’s disability NGOs (such as the Lithuanian Disability Forum) have been very involved in directly assisting Ukrainian families, helping them navigate local services and connecting them with peer support. This contrasts with Germany, where mainstream disability service providers are larger but sometimes less flexible in outreach, and with Poland, where informal volunteer initiatives took the lead early on.

In summary, national systems diverge in policy design and service delivery for caregiver refugees. Germany's model offers more formal benefits and services but is heavily procedure-bound and may initially exclude newcomers from specialized support. Poland's approach has been characterized by rapid mobilization and generosity at the societal level, but with slower incorporation of refugees into official disability support programs. Lithuania has shown policy creativity (e.g. introducing a carer status) but faces capacity constraints and relies on non-governmental actors to fill implementation gaps. Furthermore, differences in labor laws and integration support mean the day-to-day realities of caregivers vary: for instance, German integration courses are available but practically inaccessible to full-time carers, whereas Poland and Lithuania may not even expect caregivers to enroll in such courses. Each country's disability assessment system also affects refugees differently – some accept Ukrainian medical documents as evidence, others require new examinations, creating varying delays. Local support networks range from well-established (Germany's formal caregiver support organizations) to nascent (Poland's quickly formed refugee-assistance groups). These national divergences highlight that the well-being of a Ukrainian caregiver can depend greatly on where they reside in the EU, with some environments being somewhat more accommodating than others. However, even the best national system has struggled to fully accommodate this group's needs without targeted policies.

5.3 Gaps in EU Framework or Implementation

The comparative evidence points to several gaps at the European Union level – in both the existing policy framework and its implementation – that contribute to the difficulties faced by Ukrainian caregivers of PWD.

One major gap is the lack of an EU-wide recognition of carers and a coherent strategy to support them. Unlike some areas (e.g. asylum procedures or basic reception standards), there is no EU directive that grants informal caregivers a specific legal status or rights across Member States. The EU's Work-Life Balance Directive (2019/1158) introduced a few days of carers' leave and flexible work arrangements for workers, but it only helps those caregivers who are already in formal employment – a minority in the context of newly arrived refugee carers. There is no equivalent of a "carer's allowance" or formal EU definition of family caregiver status that Member States must adhere to. The European Economic and Social Committee has highlighted this issue, calling for a common definition of the role and situation of family caregivers as a basis for better support and recognition in all countries. Under the current framework, support for caregivers is patchy and left entirely to national discretion, leading to uneven protection. For example, a Ukrainian mother caring for a disabled son might be eligible for some allowance in one country but get nothing in another, owing to the absence of EU-level standards in this area.

Another gap is the uneven implementation of the Temporary Protection Directive (TPD) with respect to vulnerable groups like persons with disabilities and their carers. The TPD, activated in March 2022, was unprecedented in granting millions of Ukrainians immediate protection status, including the right to reside and work in any EU country. However, the Directive itself did not spell out detailed provisions for persons with special needs, and it left broad latitude to Member States in how to deliver social support. Consequently, we have seen a very inconsistent landscape. Some countries (like Germany) leveraged TPD to extend full social welfare and healthcare coverage to refugees, whereas others provided more basic support. Critically, identification of disability and care needs under TPD was not systematically mandated – as noted, most EU countries did not even gather data on disability status during the registration of refugees. This meant that the "temporary protection" in practice often failed to promptly protect those who needed additional help. In theory, the TPD guarantees access to necessary services, but without clear EU guidelines or monitoring, implementation varied: in some places refugees with disabilities were quickly linked to specialized services, while in others they were left to discover the system on their own. Even within countries, the lack of EU standards led to local authorities improvising responses (e.g. NGOs stepping in). Moreover, as the situation evolves, the TPD's limitations are becoming evident. With temporary protection now set to potentially end by 2026, the EU has not yet ensured a durable plan for those who cannot easily transition to normal residency, such as caregivers who remain out of the labor market. Current discussions about post-TPD solutions often focus on employment-based residence permits, but many caregivers will not meet such criteria. Advocacy groups warn that a solely labor-based approach will "leave many people in a vulnerable situation behind, including some people with disabilities...

and those who cannot work full-time because they are caring for children or infirm family members”. In short, the EU’s emergency framework helped avoid a refugee reception crisis, but it did not specifically cater to disabled refugees or their carers, and its one-size-fits-all approach now risks marginalizing them in the long term.

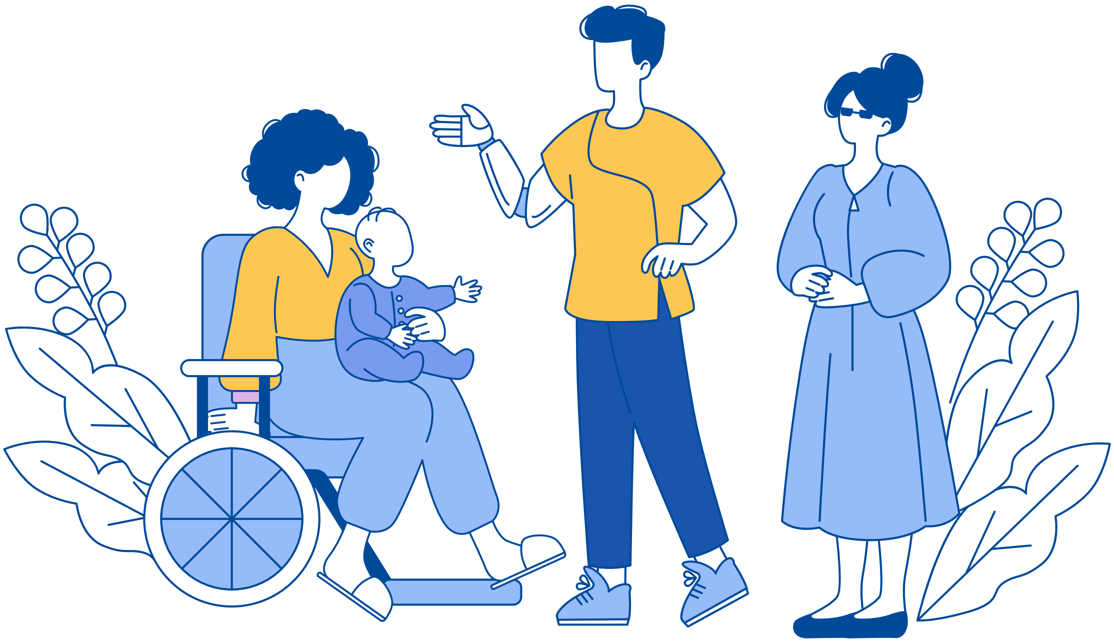
A further gap concerns the limited EU-level enforcement of the right to independent living and access to community-based services, as enshrined in Article 19 of the UNCRPD. While EU disability policy promotes deinstitutionalisation and independent living, implementation remains uneven across Member States. The lack of sufficient alternative care arrangements, respite services, and personal assistance schemes directly affects caregivers’ ability to participate in employment and social life. Without strengthening community-based support systems, policy measures aimed at labor market inclusion risk remaining ineffective.

The mainstreaming of disability in emergency response is another area of weakness. Despite the EU and Member States being party to the UN Convention on the Rights of Persons with Disabilities (which demands inclusion of PWD in all policies, including disaster and displacement contexts), the early refugee response did not fully uphold this. For example, while special efforts were made to assist unaccompanied minors or other vulnerable groups, there was no EU-coordinated mechanism to prioritize people with disabilities for evacuation or reception. On the ground, this translated to situations like major refugee hubs lacking accessibility or targeted support – one report from Germany noted that at Berlin’s central station, dedicated reception points existed for certain groups (e.g. LGBTQ refugees), but “there [were] no arrival services for people with disabilities” and “people come and are initially lost,” highlighting the oversight in planning for disability needs. Similarly, information about rights and services was often not provided in accessible formats (plain language, sign language, etc.) at reception centers, a gap observed in multiple countries. The EU did issue general guidance urging Member States to pay attention to vulnerable persons, but enforcement was weak. It largely fell to disability advocacy organizations (like the European Disability Forum and national NGOs) to push for inclusive measures. These groups, supported by EU funds in some cases, had to fill the gap by identifying families with disabilities and advocating for their support. The failure to embed disability considerations from the outset meant that many Ukrainian PWD and caregivers experienced delays or exclusion in receiving aid – a lesson that EU institutions have acknowledged needs addressing in future responses. For instance, ensuring that refugees with disabilities are immediately flagged and referred to appropriate services was not uniformly done under the TPD, and only some countries created dedicated pathways (like priority medical referrals or fast-track social housing) for them. The EU's own recent Care Strategy (launched in 2022) and the Council Recommendation on long-term care urge Member States to improve support for informal carers and include refugees in care systems, but these are soft instruments. The gap between high-level commitments and on-the-ground action remains evident.

Finally, the insufficient enforcement or uptake of existing EU social policies contributes to gaps. The European Pillar of Social Rights proclaims the right to affordable long-term care services and support for those in need (Principle 18) and calls for active inclusion of people with disabilities (Principle 17). Yet, in the emergency of the Ukraine displacement, these principles were not operationalized into concrete guarantees. Likewise, EU funding instruments (such as the Asylum, Migration and Integration Fund or the Recovery and Resilience Facility) were available to support refugee integration and social services expansion, but not all Member States channeled these effectively toward disability-specific support. Inconsistent use of EU funds means opportunities were missed to, for example, establish respite care centers for Ukrainian families or hire additional special educators and translators – initiatives that could have been funded with EU support. This highlights an implementation gap: the tools exist, but without explicit direction and monitoring, they were not uniformly applied to assist caregiver families. In sum, at the EU level there is a policy gap in recognizing and protecting informal carers, an implementation gap in temporary protection measures reaching those with special needs, and a coordination gap in mainstreaming disability in crisis response. These gaps have left Ukrainian caregivers of PWD insufficiently protected by the otherwise strong show of solidarity, pointing to areas for urgent improvement.

5.4 Mismatch between Policy and Lived Realities

A clear mismatch has emerged between the promises of policy and the lived realities of Ukrainian caregivers in the EU. On paper, both EU and national authorities have affirmed commitments to support refugees and uphold disability rights, but many caregivers experience a different reality on the ground. This discrepancy is evident in everyday barriers to accessing purported rights.



For example, **Ukrainian refugees under temporary protection have the right to work and to access services**, yet a mother caring for a child with severe disabilities finds that these rights are hollow if no practical support exists to enable her participation in society. One caregiver described how her son's special school initially offered only two hours of classes per day (later extended to four hours), which left her "hardly enough time to do anything… there is simply no time to drive to a language school and spend several hours learning [the local language]". This testimony illustrates how integration measures like language courses or employment services are effectively out of reach for those with intense care duties. The policy may guarantee access to training or jobs, but without flexible provision (such as childcare, personal assistance, or remote learning options) the **lived reality is one of exclusion**. While refugee caregivers face compounded challenges due to displacement and integration pressures, it is important to note that many of these structural barriers also affect national caregivers. Across the three countries, gaps in the implementation of disability rights — including limited access to alternative care arrangements, personal assistance, independent living support and inclusive education — shape the broader context in which refugee caregivers attempt to integrate.

There is also a stark contrast between **formal entitlements and actual uptake** of services. Many Ukrainian caregivers are entitled to health care on the same basis as nationals under EU temporary protection rules. However, in practice they frequently encounter obstacles like long waits for specialist appointments, lack of interpretation, or officials unfamiliar with Ukrainian medical documents.

As a result, families do not always receive the continuous care management that national policy ostensibly offers to people with disabilities. In Germany, for instance, although refugees with disabilities had been moved into the regular social security system by mid-2022 (with the aim of giving them better support), bureaucratic rules initially limited some crucial services. During the first months, disability-related needs beyond emergency care were not fully covered, and caseworkers often did not know how to fast-track support for these refugees. The intention of the policy (equal access) was undercut by administrative inertia and narrow rules, leading to delays in children getting into appropriate schools or therapy. Similar stories are reported in Poland, where formally a disabled refugee child can attend public school, but without additional assistant teachers or training for staff, the child may end up staying home – and the caregiver thereby loses the chance to gain respite or employment. Thus, the lofty goal of inclusion in education falls short in reality as a result of insufficient adaptation on the ground.

Another area of mismatch is between integration policies and employers' attitudes. EU and national policies encourage refugees' labor market integration, and anti-discrimination laws prohibit employers from unfair treatment. Yet Ukrainian caregivers routinely face skepticism from potential employers about their availability and reliability. From the caregivers' perspective, they feel penalized for circumstances beyond their control: they might be highly skilled and willing to work, but require part-time hours or remote work to balance care, which few employers are ready to accommodate. One Lithuanian assessment noted prevalent reports of mothers of disabled children facing discrimination in job searches – employers fear that these caregivers will need excessive time off work or cannot focus on the job. This reveals a gap between the inclusive rhetoric of policy and the persisting biases in practice. In effect, the promise of equal opportunity is not realized for caregivers, who continue to experience obstacles in hiring processes that policies alone have not remedied.

Crucially, the experiences of Ukrainian caregivers highlight how policy goals in disability and refugee inclusion are not being met on the ground. European and national strategies emphasize independent living for people with disabilities and gender equality in care and work. However, in reality many refugee families with disabilities find themselves, contrary to those goals, in a situation of dependency and encumbered by traditional gender roles (mothers at home full-time). For example, the EU's care strategy and disability rights agenda promote community-based support to reduce the burden on informal carers. Yet these

Ukrainian caregivers often rely almost entirely on family effort, with community services either unavailable or inaccessible to them. Promises to “leave no one behind” ring hollow when caregivers report feeling left behind by fragmented systems and overwhelmed trying to secure basic support. In concrete terms, bureaucratic processes often clash with lived reality: to get a disability allowance, a caregiver may have to fill out complex forms in a foreign language, travel to multiple offices, and wait months for a decision – tasks extremely onerous while caring for a high-need individual. Many give up or go without, despite the theoretical right to assistance. This bureaucratic exclusion is the opposite of the user-friendly, person-centered approach that policy documents espouse.

Finally, the gap between policy and reality is evident in unmet care and integration needs that persist despite official programs. All three countries have policies aiming to integrate refugees and support persons with disabilities. However, Ukrainian families with disabilities still report many needs going unmet: appropriate housing, regular respite breaks, adequate financial support, social inclusion activities, and so on. For instance, EU and national funds have been made available for refugee housing, yet a significant number of the most vulnerable (including those with disabilities) continue to struggle with insecure or unsuitable housing arrangements. This indicates an implementation failure – resources exist, but they have not fully reached those who need them most. The lived experiences gathered from Germany, Poland, and Lithuania show a pattern of rights not effectively realized: rights to social protection are curtailed by practical barriers, rights to education are limited by lack of reasonable accommodations, and rights to work are nullified by inflexible labor markets and caregiving obligations.

In conclusion, there is a clear disconnect between what policies promise to Ukrainian caregivers of PWD and what they experience in everyday life. Bridging this gap will require not only new policies and better EU-level frameworks (as identified above) but also diligent implementation and the enforcement of existing ones. Caregivers’ testimonies underscore that well-intentioned policies must be matched with on-the-ground support and flexibility. Aligning the reality with the rhetoric is crucial to ensure that Ukrainian caregivers and their loved ones can truly benefit from the protection, inclusion, and rights that the EU and Member States have pledged to them.

6. Conclusion and Recommendations

The research confirms that Ukrainian caregivers of persons with disabilities face a double burden as both refugees and informal carers, yet their needs remain largely invisible under current support systems. They encounter compounded barriers in accessing suitable housing, healthcare and employment, being often unable to pursue work or integration opportunities because of full-time care responsibilities and lack of support. Indeed, most EU+ countries do not even collect data on refugees with disabilities under temporary protection, underscoring a critical gap in awareness and policy planning. **Addressing these shortcomings requires coordinated action** at multiple levels. Based on this study's findings, targeted recommendations are outlined below for EU institutions, Member States, and civil society, followed by suggested next steps.

6.1 To EU Institutions

EU institutions should strengthen the policy framework to recognize and support this vulnerable group across the Union. At the EU level, the main conclusions point to insufficient disability mainstreaming and a need for better enforcement of existing rights. EU institutions should:

- **Mainstream disability and caregiving in EU policy:** Incorporate the needs of refugees with disabilities and their caregivers into all relevant EU migration, asylum and integration policies. This includes ensuring the upcoming EU Migration and Asylum Strategy adopts an intersectional, rights-based approach that guarantees equal access to education, healthcare, social protection and employment for displaced persons with disabilities. EU actions should be firmly grounded in the UN Convention on the Rights of Persons with Disabilities (CRPD) and the European Pillar of Social Rights, so that disability inclusion becomes a standard element of refugee support (i.e. disability mainstreaming in all funding and programming).

- **Develop a common recognition of caregiver status:** Promote the formal recognition of informal carers at European level to unlock their access to rights and support. The EU should encourage Member States to adopt a common definition of "caregiver" and exchange best practices on legal status, social security entitlements and respite rights for family carers.

Elevating the status of caregivers – for example through an EU-wide carers' card or guidance – would acknowledge their contributions and facilitate mobility of support services for caregiver refugees across Member States.

- Enhance independent living opportunities, alternative care opportunities and overall disability-rights implementation.
- **Strengthen implementation of the Temporary Protection Directive (TPD):** Ensure that refugees with disabilities and their caregivers can fully exercise the rights guaranteed under the TPD. These rights include access to a residence permit, suitable housing, social welfare, medical care and education, but the research shows gaps between paper and practice. The European Commission should issue guidance and monitor TPD implementation with disability-sensitive indicators, pushing Member States to provide accessible accommodation, prompt healthcare and targeted social assistance for this group. EU-level oversight (e.g. via the European Commission or EU Agency for Asylum) is needed to close the implementation gap and ensure no caregiver or person with disabilities falls through the cracks of emergency protection.
- **Ensure funding reaches those in need: Leverage EU funds and programs** to support initiatives targeting these caregivers. The EU should make dedicated resources available through instruments like the European Social Fund Plus (ESF+), the Asylum, Migration and Integration Fund (AMIF), and the European Care Strategy's funding framework, prioritizing projects that improve accessible housing, rehabilitation services, caregiver training and psychosocial support. Targeted EU funding for accessibility measures and disability support services at local level is crucial. The Commission can encourage Member States to use recovery and cohesion funds to invest in inclusive long-term care infrastructure, and could introduce incentives or earmarks in EU funding calls to ensure refugee caregivers are not overlooked in reconstruction and integration efforts.

6.2 To Member States

National governments play a central role in delivering concrete support to Ukrainian caregivers and their families. The study highlights that many obstacles – from housing to healthcare access – are manifested at the country level owing to policy gaps or administrative barriers. These barriers are faced by informal caregivers and refugee informal caregivers alike, while the exclusion of people with disabilities from society affect refugees differently, leading to isolation, exclusion from language classes and potentially risk of undocumented employment or moving back to countries at war. Member States should:

- **Provide accessible and adequate housing:** Recognize refugee families with disabilities as a vulnerable group in housing policy. Governments should prioritise them for social housing or housing subsidy programs and enforce accessibility standards so that accommodations meet disability needs (e.g. ground-floor units or buildings with elevators). Where private rentals dominate, authorities can offer incentives or renovation support to landlords to adapt apartments for persons with disabilities. Expanding accessible housing stock and dedicated shelter options will address the fact that housing is a top unmet need among these refugees.

- **Simplify access to benefits and services:** Simplify access to benefits and services by reducing administrative burdens and streamlining procedures. This includes providing information and application processes in accessible formats and languages, and assigning caseworkers to guide families through social welfare, healthcare and disability benefit applications. Lengthy delays or complex procedures (such as waiting months for rent or care allowances) can be devastating for these families – therefore, governments should streamline procedures (one-stop shops, fast-track processing for urgent needs) and guarantee timely disbursement of support. Sufficient interpretation and counselling services must be available so that caregivers can communicate their needs effectively and understand their entitlements.

- **Support caregivers' inclusion in the labor market:** Take measures to help Ukrainian caregiver refugees who are able to work find suitable employment. Flexible work arrangements, part-time opportunities, and remote work options should be promoted by public employment services and encouraged among employers, so that carers can balance work with care duties. However, flexible work arrangements alone are insufficient. Expanding access to alternative care services, personal assistance, respite care, and independent living support is essential to enable caregivers to genuinely participate in the labor market. Without strengthening community-based disability services, employment measures risk shifting the care burden rather than reducing it. Anti-discrimination efforts are needed to prevent bias against parents (often mothers) of children with disabilities in hiring. Member States should fully implement the EU Work-Life Balance Directive – including carers' leave and flexible working rights – and extend awareness of these rights to refugee employees. Facilitating accessible and rapid recognition of Ukrainian qualification, together with ensuring that language training is freely available, flexible, and effectively tailored to caregivers' time constraints, will significantly enhance their ability to access employment that matches their skills and professional experience.

- **Invest in community-based services and respite and work on inclusion of people with disabilities in society at large:** Strengthen the local support systems that complement family care. Member States should use public funding (and EU funds) to expand **community services** such as day care centres, inclusive education programs, in-home nursing support, and respite care facilities for persons with disabilities. Greater provision of quality long-term care services in the community will directly reduce the burden on family caregivers. Additionally, authorities should ensure emergency respite options are in place – for example, temporary care placements or mobile support teams – to relieve caregivers during crises or periods of exhaustion. Providing psychological support and counseling to caregiver refugees can also mitigate stress and prevent burnout. Overall, a **holistic national strategy** is needed to enable independent living for all including refugees with disabilities (through services, assistive devices, personal assistance, etc.), which in turn eases the pressure on all informal carers.

6.3 To Civil Society and Service Providers

Civil society organizations (CSOs), non-governmental organizations (NGOs), and local service providers are often on the front lines addressing gaps in official support. Their close contact with refugee communities and persons with disabilities positions them as key actors to improve outreach and service delivery.

Civil society and service providers should:

- **Proactively reach out to caregiver refugees:** Identify and engage Ukrainian caregivers of persons with disabilities who may not be visible in mainstream refugee assistance. This can involve deploying mobile teams or community volunteers to find families in need, working with refugee reception centers, and partnering with disabled persons' organizations to ensure no caregiver is left in isolation. By establishing trust within these communities, NGOs can better understand their needs and connect them to available services. Targeted outreach and peer support groups will help bring hidden caregivers into contact with support networks and empower them to voice their needs.

- **Provide information and training:** Develop accessible information resources and training programs tailored to this group. Service providers should ensure that caregivers receive clear guidance (in Ukrainian and easy-to-understand formats) on how to navigate local healthcare, education, and social services for their family. NGOs and disability organisations can also train their staff and volunteers on the specific challenges faced by refugee caregivers – including trauma-informed approaches, cultural mediation, and disability rights. Building capacity among frontline workers will improve the quality and inclusiveness of support. Additionally, empowering caregivers through workshops (for example, on self-care, coping strategies, or vocational skills) can enhance their well-being and confidence in managing integration challenges.

- **Coordinate with local authorities and communities:** Strengthen partnerships between civil society and public institutions to address the multifaceted needs of these families. NGOs, municipalities, social services, and healthcare providers should coordinate case management, share expertise, and refer cases to ensure comprehensive assistance (covering housing, social care, education, employment, etc.). Regular coordination meetings or local task forces can be set up to include refugee representatives and disability advocates in problem-solving. Civil society should advocate at local and national levels for inclusive policies, using evidence from the ground to inform authorities. By fostering networks among stakeholders – as this project has aimed to do – service providers can create a more seamless support ecosystem, whereby municipal services, charities, and community groups each play a role in integrating caregivers and the persons they care for.

6.4 Next Steps

Looking forward, continued efforts are necessary to ensure sustainable inclusion of Ukrainian caregivers of persons with disabilities in the EU. Key **next steps** include:

- **Improve data collection and research:** Address the current data gap by systematically collecting disaggregated data on disability and caregiving status among refugees. Both EU and national authorities should invest in mapping the population of refugees with disabilities and their care needs. Allocating specific resources for needs assessments (as recommended by the EESC) will provide an evidence base to design better policies. Enhanced data collection – respecting privacy – should feed into regular reports to track how many caregivers are reached by services, what their unmet needs are, and where additional resources are required.
- **Establish monitoring and accountability mechanisms:** Develop indicators and frameworks to **monitor the implementation** of these recommendations and the well-being of caregiver refugees over time. At EU level, progress on supporting informal carers can be incorporated into the monitoring of the European Care Strategy and the European Semester's country reports (e.g. under social policy and inclusion benchmarks). A mid-term review of commitments (for instance, evaluating the Barcelona targets on childcare or long-term care strategies) should specifically consider the situation of refugee caregivers. Civil society should be involved in watchdog activities, and the EU Fundamental Rights Agency or other bodies could include this topic in their assessments. Regular monitoring will help maintain momentum and allow for adjustments to policies as needed.
- **Integrate caregiver needs into strategic planning:** Ensure that upcoming **national and EU strategies** explicitly address this group. For example, Member States updating their National Disability Strategies or Long-Term Care plans should include provisions for refugees and asylum seekers with disabilities and their carers. At EU level, the Disability Rights Strategy 2021–2030 and the action plan on integration should reflect the lessons from the Ukraine crisis, promoting inclusive disaster response and refugee reception practices aligned with the CRPD. Likewise, the new EU Migration and Asylum Strategy should contain dedicated measures for persons with disabilities. By embedding caregiver considerations into mainstream policy documents and funding programs, stakeholders can move from ad-hoc emergency responses to structural inclusion of these families.

- **Plan for long-term inclusion:** Recognising that many Ukrainian refugees may remain in the EU for an extended period of time, plan beyond the immediate emergency. This means creating pathways for long-term integration: for instance, enabling caregiver refugees to transition from temporary protection to a more secure legal status, continuing education for children with disabilities, and ensuring continuity of care as needs evolve with age. It is essential to put in place longer-term planning now so that the special needs of people with disabilities and their carers are consistently addressed and essential care is guaranteed over time. EU institutions should work with Member States on a forward-looking strategy (potentially a "caregivers´ inclusion roadmap") that links humanitarian assistance with development of permanent support structures. Such foresight will help avoid cliff-edges in support if temporary schemes end, and will contribute to the social cohesion and dignity of both Ukrainian refugees with disabilities and their caregivers in the European Union.

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