Policy Brief | Bridging Policy and Practice 2026 – Mashriq Series

Left to Carry It Alone:

The Hidden Cost of Caregiving for Persons with Disabilities in Displacement and Return (Syria, Jordan, Lebanon)



Executive summary

Across Syria, Jordan and Lebanon, support for families of persons with disabilities arrives in cycles, while care does not. A voucher runs for three months and stops. A rehabilitation programme ends when a project closes. Continued access to rehabilitation and other essential services often depends on whether families can afford transportation and manage the distance to services. Yet care continues every day, and the gap is often absorbed by one woman in the household, unpaid, largely invisible, and rarely asked what kind of support she needs.

This brief argues that this is a structural feature of the response, not a private family matter: the interviews suggest that the sustainability of return and reintegration for persons with disabilities depends on unpaid caregiving that is neither recognised, resourced nor counted, placing both caregivers and the people they support at compounding risk.

The brief draws on 18 interviews HI teams conducted in Syria, Jordan and Lebanon in August and September 2026. A small purposive sample cannot measure how common a problem is. It can show how a mechanism works, and the same mechanism appears in Syria, Jordan and Lebanon, across refugee, displaced and returnee households and across rural, urban and shelter settings. The brief builds on the HI factsheet *Disability Inclusion in Syria: Bridging Promise and Practice* (June 2026) [9] and the HI regional policy brief *Returning to Syria: Supporting safe and inclusive returns from Jordan and Lebanon* (Bridging Policy and Practice 2026) [10].

Four findings stand out.

- **Care is assigned, not chosen.** In half of the interviews, a woman provided most or all of the daily care, and in half the role fell to her because no other adult was available or willing to share it. Several women described expectations tied explicitly to motherhood or marital status, suggesting that care is often treated as a woman's responsibility rather than a shared one.
- **The cost lands on the caregiver first.** Caregivers reported chronic pain from daily physical support such as lifting and carrying their family member with disability. Half said caregiving had reduced or blocked their ability to earn an income, and most described taking on debt or cutting food and other spending to pay for care.
- **Caregivers are invisible to the support system, and at times to themselves.** No caregiver who was asked knew of any respite, training, or peer support designed for them. Asked what she needed for herself, one answered through her children.
- **Services are valued, then they end.** Caregivers in all three countries described assistance that had stopped, been suspended, or never arrived. When a service ends, the caregiver becomes the service: doing therapy exercises at home, carrying a child to appointments, and staying beside a person who cannot be left alone.

The brief makes six asks: to count caregivers, because what is not counted is not planned for or funded; provide predictable rather than cyclical cash; fund respite and mental health support for caregivers; protect continuity of rehabilitation, health care and education; address documentation and housing barriers; and ensure that caregivers are part of the consultation and decision making processes, alongside persons with disabilities and organisations of persons with disabilities (OPDs).

1. Introduction: Why caregiver invisibility drives exclusion

Caregiver invisibility is a structural gap, not a private family matter, because it decides whether persons with disabilities can reach rehabilitation, school and protection at all.

Humanitarian and recovery data treat the household as an assumed source of unpaid care. Caregivers appear as an extension of the person they support, not as a population with needs, losses and risks of their own. As a result, no plan, budget or indicator asks what caregiving costs, who bears it, or what happens when the caregiver can no longer continue.

This brief starts from testimony. It draws on interviews with caregivers and persons with disabilities in Syria, Jordan and Lebanon, and reads them against the standards set out below. Individual voices are quoted to illustrate each mechanism. The findings are presented as themes across the three countries, not as a summary of each interview.

> "They focus on providing services to the person who has the problem, but they do not pay enough attention to the person who is providing the care." A caregiver in Jordan

The wider picture matters. In Syria, Jordan, and Lebanon, humanitarian and recovery planning identifies persons with disabilities, where it identifies them at all, as individual beneficiaries, and treats the household as the source of their care. Within that household, the burden of daily care falls mainly on women and girls. In Syria this is documented at scale [9]; in Jordan and Lebanon it emerges from the interviews. What the interviews show is a substantial amount of unrecognised labour that the response relies on and does not count.

The standard against which the findings are read

The **Convention on the Rights of Persons with Disabilities (CRPD)** protects the right to live in the community with the support services needed to do so (Article 19), to education (Article 24), to habilitation and rehabilitation (Article 26) and to an adequate standard of living and social protection (Article 28), and it recognises the particular exposure of women and girls (Article 6) [5]. It also requires States to ensure the protection and safety of persons with disabilities in humanitarian emergencies (Article 11) [6] and to collect statistics and data, disaggregated as appropriate, to identify the barriers they face (Article 31) [7]. The **IASC Guidelines** on the Inclusion of Persons with Disabilities in Humanitarian Action (2019) include disaggregating data to monitor inclusion among their four priority actions [8].

In 2023 the **UN Human Rights Council** adopted a resolution on the centrality of care and support from a human rights perspective, which calls for unpaid care to be recognised, valued, reduced and redistributed and affirms the rights of caregivers as well as those who receive care [1][2]. A response that delivers these rights to persons with disabilities by drawing silently on a caregiver's unpaid time is not delivering them in full. It is transferring the cost.

2. Methodology and limitations

The brief draws on 18 interviews carried out by HI teams in Syria, Jordan and Lebanon between late August and late September 2026, with caregivers and with persons with disabilities and their families, in host community, refugee, displaced and returnee settings, in cities, rural areas and collective shelters. Interviewees included mothers, an aunt and an adult daughter caring for children and an older parent, and persons with injuries or health conditions who depend on relatives for care. Interviews covered household and gender roles, the daily burden of care, access to services, income, wellbeing, coping and recommendations.

Interviewees were chosen purposively to span a range of caregiving relationships and impairments. The interviews are used to show how mechanisms work, not to measure how common they are, so where the brief gives a number, it refers to the interviews as a whole and only where the question was asked. Secondary sources are used to corroborate findings, not as a stand-alone evidence base.

Limitations

- The sample is small and purposive. The findings illustrate mechanisms and should not be read as measuring prevalence, or as representing caregivers in any one country.
- Most interviewees were reached through HI or partner services, and interviews were conducted by HI staff. Positive accounts of services may reflect this, and caregivers outside services are likely to be underrepresented and probably worse off.
- All caregivers interviewed were women. Findings on gender are suggestive, and the experience of male caregivers is not captured.
- Depth varies. Not every question was asked in every interview, so denominators differ and are stated where numbers are given.
- Interviews were conducted in Arabic and are quoted from English translations.
- Informed consent and the option of anonymity were the agreed protocol for all interviews. All names are removed here, and identifying details have been kept to a minimum. The cover photograph is used with the informed consent of the persons shown, including for publication alongside the testimony in Section 4.

3. Who carries the burden

All the caregivers interviewed were women, and in most households one woman carries the care alone. The HI factsheet [9], drawing on the 2025 Multi-Sector Needs Assessment, reports that women serve as primary caregivers in over 95% of Syrian households; when caregivers are themselves displaced, injured, or killed, persons with disabilities can be left entirely without support. In half of the interviews, a woman provided most or all of the daily care. In half, the role fell on her because no other adult was available or willing to share it.

Care is assigned, not chosen. Few caregivers described a decision. They described a default that follows family status and gender, and that the rest of the household treats as settled. "As a woman and a mother, most of the caregiving is expected from me," said one mother in Jordan, even though her husband lives at home. A divorced woman caring for her mother explained that,

in her brother's view, since she is divorced, she does not have "other major responsibilities or commitments," while he and his wife live far away and share none of the work. In Lebanon, one mother spoke of "this unspoken expectation that I, as the mother, must be the sole caregiver," and another said her husband helps, "but not like I do." In Aleppo, a mother of a girl with severe impairments described the default without illusion: "I am her mother, so I will continue to care for her and stand beside her, no matter how exhausting it becomes. But a mother cannot carry everything alone."

Care passes down to daughters and young women. When a mother cannot carry the load, a daughter often does. Caregivers described a girl of fourteen stepping in for her mother in Jordan; an eldest daughter providing daily help and emotional support in a Beirut shelter, and, in Aleppo, another girl of fourteen "taking on a lot of responsibility at home" because of her mother's pain, just as school was about to start. Separation intensifies this pressure. A mother in Aleppo whose other children live in Türkiye said that when her health deteriorated, her daughter, aged twenty four, "had to leave her studies and return to Syria to help and support me." Young women without children of their own also take on substantial caring roles: a woman of twenty five in Syria is raising her sister's son and fears that marriage will end the arrangement and harm the child. The household secures the care it needs, but the cost is transferred to a young woman’s life, opportunities and choices about her own future.

Willing care is still unrecognised care. Some caregivers presented the role as a choice and saw caregiving as a normal part of their lives. One aunt who has provided daily care for nine years described her life as normal, yet she spends about six hours a day providing it, reports back and neck pain, feels sad about the child's situation and has no one to turn to for emotional support. Willingness does not make care visible, nor does it remove its physical, financial and emotional costs.

The same gendered pattern of care emerged across all three countries, among refugee, displaced and returnee households, and across urban, rural and collective shelter settings. Its recurrence across these different contexts suggests that it is not specific to one setting or displacement status but reflects a broader structural pattern in how care responsibilities are assigned.

The pattern takes different forms by context. In Syria, care sits with mothers, daughters and female relatives, and distance to services multiplies it. In Jordan, care is stable, daily and solitary in a protracted refugee setting. In Lebanon, it is carried in collective shelters, often amid repeated displacements and with little privacy or personal space.

Return changes where care is carried, not who carries it. In Syria, caregivers described the same pattern as in Jordan and Lebanon: rehabilitation far from home, sessions cancelled by power cuts, an assistive device requested and not received, and care passing to a daughter when her mother’s health fails. In one case, a daughter of twenty four left her studies and returned to Syria to support her mother. These accounts suggest that return does not reduce the care burden by itself. Caregivers who returned described services that were farther from home and harder to afford, and support networks of neighbours and relatives that had to be rebuilt from scratch.

4. What the burden costs

Caregiving costs income, health and social connection, and repeated displacement compounds each of these.

Income and livelihoods. Half of the caregivers interviewed said that caregiving had reduced or blocked their ability to earn. Some caregivers can take only short daily jobs. Others cannot work at all because someone must stay with the person they support at every hour: "I would have loved to go and work to support her and her education, but I can't because there has to be someone staying with her constantly." One mother left a job as a translator when her son's condition became too demanding, and a mother in Aleppo cleans for a living to support her daughter: "I am not ashamed of the work I do. I work because I want to provide for my daughter." Costs rise as income falls. Caregivers named medicine, diapers, special diets, transport and therapy, met through debt, unpaid rent and skipped meals. Most described debt or cuts to food and other spending. "If we buy food at the beginning of the month, by the middle of the month we do not have money left," said one mother. Another said, "I do not even have one dinar to buy bread for the house." A hospital trip costing about 10 JOD in Jordan, or a 30 minute physiotherapy session at USD 25 in Lebanon, is out of reach for a household without a steady earner.

The same collapse follows when a breadwinner is injured. A survivor of a landmine explosion in Deir ez-Zor, who had worked as a daily labourer and provided for his household, paid about USD 500 for emergency treatment that he could barely afford, and his wife now takes occasional work harvesting to bring in income. "Since acquiring my disability, I see my life completely differently," he said. "I used to work, provide for my family and even help other people. Now, I am the one who needs help." Chronic conditions add a recurring cost on top. A person in Aleppo described needing to buy medication every week, "which is sometimes very difficult to afford," and another noted that even basic nutrition is out of reach for many families, who struggle to afford protein or enough nutritious food.

Loss of employment is where the effect of caregiving is most direct. In the interviews, caregiving was repeatedly the direct reason mothers could not work or had left work. Livelihoods and cash programming that assume unpaid care is freely available will not reach these women unless the care burden is addressed first.

Physical health. All the caregivers reported pain, mostly in the back, neck and shoulders, and a quarter described broken sleep. Caregivers lift, carry and turn children and adults who cannot move alone, often without a stroller, an adapted bathroom or a wheelchair. One mother carries two children weighing 13 and 14 kilograms to appointments and has been told she may have osteoporosis. Another takes a painkiller "just to get a half hour of relief" so that she can get the children up and fed. Some have health scares of their own that they cannot stop to treat: one mother left a hospital before her treatment was finished because her child's insulin was due. The smallest tasks carry the toll. "Even taking her to the toilet can be difficult because she is at risk of falling, so I need to be there to support her," said a mother in Aleppo. It accumulates quietly over years rather than appearing in any clinical record.

Mental health. All the caregivers described emotional strain, most often sadness, loneliness, helplessness and fear for the future. "I am always afraid of what would happen to my daughter if

something happened to me," said one. Another said, "I feel broken by the situation. There is no assistance, and I feel helpless. I do not know where to go or what to do." A mother in Aleppo put the same worry in terms of dependence: she wants to know that her daughter's future does not depend "only on how much I am able to carry each day." Some caregivers hide their own exhaustion to protect the person they care for, because that person may take it personally and blame themselves. Support helps those who receive it: after the mental health and psychosocial support sessions, one caregiver said, "I was 90% broken before; now I am at 70%."

Caregiver burden refers to the complex stress experienced by people who provide ongoing care to family members or loved ones. The American Psychological Association defines caregiver burden as the stress and other psychological symptoms experienced by family members and other non professional caregivers in response to caring for individuals with disabilities, disorders or diseases [11]. This strain does not stay with the caregiver. Psychological distress and emotional exhaustion can undermine a caregiver's ability to sustain supportive interactions with children and other family members, with potential effects on children's emotional wellbeing and on household functioning. As the testimonies above show, caregivers carry fear and exhaustion that they often conceal to protect the person they care for. When a service for the person with a disability ends, the consequences therefore do not stop at that one gap. They pass through the caregiver's health and wellbeing to everyone who depends on them.

Isolation. Worry keeps some caregivers at home because leaving the person they care for without support is not an option. All caregivers described stigma, including bullying directed at the child with a disability and remarks aimed at the mother. One caregiver said that for long periods no one stood by her: "not my family, not my husband's family, and not even my husband." Isolation is further reinforced by the loss of the informal networks that normally absorb the overflow of care. One mother in a Beirut shelter said no one helps her, and described the two women she met during the war as her main company: "If we do not talk to them during the day, my day does not feel complete."

Repeated displacement. Each move breaks the links that make care possible: the therapist, the visiting medical team, the school, the neighbour who helps. Caregivers in Lebanon who had moved between shelters said they no longer knew what services existed: "Since we came here, we do not know what is available." In Syria, families describe displacement lasting more than a decade. In Jordan, families have carried care alone since 2013. Collective shelters add their own strain: there is no private space and no accessible water, sanitation and hygiene (WASH) services.

5. When caregiving breaks down

When a caregiver is overwhelmed, displaced or unsupported, the person with a disability loses rehabilitation, schooling and safety, and the interviews already show each of these losses.

When a service ends, the caregiver becomes the service. All the Lebanon and Jordan caregivers interviewed described a rehabilitation service that had ended or had never reached the household. Rehabilitation does not stop being needed; it moves into the home. "We cannot always go to physiotherapy. The cost, transportation, and everything have become difficult, so I do some of it here," said a mother in a Beirut shelter, who added that other residents "think I am playing with her." A mother in Jordan carries out her daughter's exercises between sessions, and a mother in

Aleppo does the same after twelve sessions at a centre. An aunt in Raqqa, who lives two and a half hours from the rehabilitation centre, asked to space out her sessions and to learn how to do the therapy at home.

Health needs are inadequately met. One mother in Jordan could not obtain a neurologist appointment for her daughter after a seizure the week before her interview, and the girl has never had comprehensive rehabilitation. In Aleppo, a mother applied for a hearing device in 2025 and said, "we have not yet received one." In Lebanon, access to hospital care depended on legal status. A mother whose child developed lung and kidney infections linked to conditions in a collective shelter described how the child was refused at the hospital admission desk because the family held no legal papers. The refusal came at registration, before any assessment or treatment, so the barrier was the documentation required to enter the service, not the absence of the service itself. The child was treated only after the mother found a way around the requirement, and the family later received USD 200 in assistance from a local organization toward the admission costs. The mother explained that lacking legal papers or citizenship creates continuous administrative barriers that impede access to formal structures and institutional care.

Housing conditions shape both health and care. A mother in a Beirut shelter linked her child's lung and kidney infections to conditions in the shelter, which offered no private space and no accessible water, sanitation and hygiene services. Caregivers named unpaid rent among the debts they carry, and repeated moves between shelters broke links to services and kept one boy out of school for three years.

Continuity fails for reasons beyond funding. In Aleppo, a rehabilitation session "had to be postponed because there was no electricity in the neighbourhood, including at the centre," and the woman and her son went home without receiving the service, despite the fact that her son had a day off from work for this reason. A landmine survivor who travelled from Aleppo to Damascus to receive his prosthesis now needs it adjusted as his body changes, and each hospital visit means finding money for transport: "Whenever I need to return to the hospital, we have to think about how we will save enough money for transportation and the other costs." Services run in project cycles, and when a cycle closes, the therapy, the device follow-up and the assessment stop unless the household can pay privately.

Schooling stops. All the interviews involving a child with a disability described a child who was out of school or had no school able to accommodate her. In Syria, a girl left school after an amputation, and the school was far away. Siblings lose years too: one boy has lost three years while his family moved between shelters, and his younger brother may lose a fourth. In Jordan, two girls with significant cognitive difficulties do not attend school, and one mother said she had been unable to find specialised schooling for her daughter as a refugee.

Safety depends on the caregiver's presence. All the caregivers interviewed said they could leave the person they support alone only briefly, and named the risks plainly: falls, missed medication, delayed meals, and fear or distress when left alone. One mother described a period when she felt she could not go on, but "when I look at them, I cannot say, 'This is where I stop.' I have to force myself to continue, beginning there for my child."

The interviews record fear more than a complete breakdown. That is telling in itself: caregivers do not allow themselves to become unavailable, and the cost of that resilience is borne in their own

bodies and finances. Support for the person with a disability cannot be sustained if the person who makes it work is treated as free.

> "I cannot sleep thinking what will be after me? What if I am sick, or when I will die? There is no place, no system, no networking. What will be after me?" A caregiver in Syria

6. Who is hit hardest

The burden is heaviest where care overlaps with other forms of exposure. Five groups stand out in the interviews.

- **Women who are the only adult available.** Women who are divorced, or whose partner is ill, working away, or unable to share the load, are sole caregiver and sole earner at once. In some extended households, several people need care at the same time and a single earner holds everything together.
- **Caregivers of children with high support needs.** Lifting, night waking and constant supervision, with no one to relieve them, wear down health first. One mother cannot use the bathroom without waiting for another adult.
- **Young caregivers.** Women in their early twenties described carrying long-term care with little experience and little help. "I was still a child raising a child," said one. In Syria, daughters have left school or university to care for an ill parent.
- **Caregivers far from services.** Distance turns every appointment into a cost and a day of lost work, and it is greatest in rural areas, where a family may live 2.5 hours from the nearest hospital offering therapy for a young child, and a car trip costs 200 Turkish lira (about USD 4). Caregivers in Aleppo noted that travel to the centre is itself an expense they must weigh against food and medicine.
- **Caregivers whose families lack secure documentation or status.** Missing identity or birth documents, a father's nationality passed to children, and fear of returning each narrow the routes to services and add a source of worry. A mother in Lebanon whose children hold their father's Syrian nationality asked authorities to help them obtain citizenship, after a hospital refused to take care of the children, which she attributed to their nationality.

These pressures multiply. A caregiver who is young, alone, displaced and undocumented has the fewest options, and is least likely to appear in any dataset.

7. What is already being tried, and why it falls short

Assistance reaches many of these households, but it is intermittent, aimed at the person with the need, and silent on caregiving as a need in its own right.

In focus: three months on, one or two months off

All three caregivers in Jordan had received iris scan verified assistance or vouchers, and all three described it as stopped or suspended. One explained that it can pause for one or two months and resume for about three, depending on case assessment. "It has affected us a lot," said another. "There is no iris scan assistance anymore, and even the services that used to come from time to time are no longer available."

What all three asked for was continuity before any increase in amount. "What would make the biggest difference is having continuous support, not support that only comes for one or two months." The care they provide has no off months.

Cash and promises. In Lebanon, caregivers described vouchers and allowances they had heard of but never received, including a monthly voucher of USD 125 and a ministry allowance of about USD 100 linked to the disability card, and others that ended without explanation. "Organizations come, take our names, and write down lists, but nothing ever reaches us," said one mother, while noting that the few that followed up were valued. In Aleppo, caregivers noted that even where assistance exists it comes with waiting lists.

Services work, and end. Where caregivers had reached a service, they spoke well of it. Several described specialists or organisations in positive terms: close by, quick to access, patient. In Aleppo, people registered at a new rehabilitation centre and were confirmed within days; users spoke warmly of physiotherapists who explained the exercises and taught them to continue at home, and one woman who could not lift her arm after a shoulder injury said she could move it again after ten sessions. The problem is not the quality of what is delivered. It is that most of it is time-limited, and it cannot compensate for interruptions caused by power cuts, cost, or the end of a project.

Access is uneven. Psychosocial sessions in one shelter were offered to selected residents, and others were not told. A mother in Jordan applied to several associations without success and said, "I do not feel that people in situations like ours are given priority."

The response does not count caregivers. None of the caregivers who were asked knew of any respite, caregiver training, or peer group. "They focus on providing services to the person who has the problem," said one, "but they do not pay enough attention to the person who is providing the care." The invisibility reaches into how caregivers see themselves. Asked what she needed for herself, one mother answered: "I don't have anything specifically for myself. Because I am everything for them."

Caregivers appear in response data only as an assumed part of the household. UNHCR has called since 2011 for explicit procedures to identify persons with disabilities at registration [3], and its 2023 guidance integrates the Washington Group Short Set into its registration system for this purpose [4]. Recording caregiving status alongside disability would make caregivers visible in the data that services and planning draw on. Where services do exist, caregivers often do not know what is available or how to reach it: "I do not know where to go or what to do," said one. The bottleneck is not only supply, but the design, communication and accessibility of what exists.

Faith and family fill the gap. Wherever the question was asked, caregivers mentioned faith first among their sources of support and coping, followed by sisters, daughters and neighbours, with organisations after them. This is the most consistent finding after the cost of care, and it is not evidence that the burden is manageable. It is what caregivers have built for themselves in the sustained absence of an adequate response.

What works is visible. Caregivers pointed to what helps: physiotherapists who taught them to continue exercises at home, a rehabilitation centre in Aleppo that confirmed registrations within a few days, and the few organisations that followed up on their promises. The barrier is often not the absence of a service but the absence of a trusted bridge to it. This points toward a concrete, low cost intervention: trained peer or community navigators attached to rehabilitation and shelter settings.

All the interviews describe no mechanism that treats a caregiver's time, health, or income as something to protect. That is the gap this brief asks partners to close.

8. Recommendations

Caregivers were consistent about what they wanted: continuous financial support first, then rehabilitation, schooling and documentation for the children, and recognition for the work they do. The brief therefore recommends that donors, governments, UN agencies, INGOs and NGOs, and OPDs recognise caregivers as a distinct category within disability inclusive programming and financing, and act on six asks: count caregivers; make cash continuous; fund respite and support for caregivers; keep rehabilitation, health care and schooling going; address documentation and housing barriers; and give caregivers a seat. The recommendations below show what each duty bearer can do.

To donors

- **Fund respite and support for caregivers.** Provide multiyear, flexible funding for short-term respite care, peer support groups and psychosocial support for caregivers within rehabilitation services and shelters, and for training caregivers to safely support home exercises, without substituting for professional rehabilitation services.
- **Make cash support continuous.** Fund predictable cash for households with a member with a disability, so that assistance does not stop and restart in cycles.
- **Keep rehabilitation, health care and schooling going.** Provide bridge funding so therapy, device follow-up, and assessment do not end with a project cycle, and cover transport and fees.
- **Count caregivers.** Add a caregiver line to disability inclusive financing frameworks and fund the data collection this requires.

To governments and ministries

- **Make cash continuous.** Ministries of social affairs should prevent recurring gaps in social assistance for households with a member with a disability and include care time in targeting.

- **Keep rehabilitation, health care and schooling going.** Ministries of health and education should expand inclusive and specialised schooling, including for refugee children, and guarantee access to hospitals and schools regardless of a child's nationality or missing papers.
- Address documentation and housing barriers. Speed up issuance of identity documents, and prioritise households that include persons with disabilities for accessible housing and rent support.
- **Count caregivers.** Ministries of social affairs should make identification of disability and caregiving status a routine part of registration and social assistance targeting.
- **Fund respite and support for caregivers.** Ministries of social affairs and health should include respite care, peer support and psychosocial support for caregivers in national disability and social protection services, working with the OPDs and NGOs that already provide them.
- **Give caregivers a seat.** Include caregivers and OPDs in consultations on disability and social protection policy, with transport and childcare covered.

To UN agencies and coordination bodies

- **Count caregivers.** Add a caregiver line to sector plans and needs assessments, and build on the Washington Group Short Set already integrated in UNHCR registration to make identification of disability and caregiving status a routine part of registration. Embed caregiver indicators in planning and monitoring under the Regional Refugee and Resilience Plan (3RP) and the Humanitarian Needs and Response Plan (HNRP). Proposed minimum indicators: hours of unpaid care per day and who provides it, by sex and age; change in the caregiver's income or employment; caregiver access to respite, psychosocial support or training; months of uninterrupted assistance over the past year; and school and rehabilitation access for the person supported.
- **Make cash support continuous.** Move toward continuous cash and voucher assistance, including iris scan verified assistance, for households with a member with a disability, so that pauses and suspensions do not interrupt support, and include care time in targeting and livelihoods design.
- **Keep rehabilitation, health care and schooling going.** Use sector and coordination platforms to track assistive device requests to closure and to flag service interruptions, such as power cuts, that cancel sessions.
- **Address documentation and housing barriers.** UNHCR and protection actors should support families without secure documentation or status to obtain identity documents and to reach hospitals and schools.
- **Give caregivers a seat.** Include caregivers and OPDs in consultation and feedback processes for the 3RP and HNRP, with transport and childcare covered.

To INGOs and NGOs

- **Fund respite and support for caregivers.** Provide respite, peer groups and psychosocial support inside rehabilitation services and shelters. Train caregivers in home exercises, extending what physiotherapists already begin in session. Consider trained peer or community navigators who help caregivers find and reach the services that exist, and make sure caregivers know what is available.

- **Keep rehabilitation, health care and schooling going.** Plan project closure so that therapy, device follow-up, and assessment are handed over or bridged. Cover transport and fees where funded, guarantee reliable power and scheduling so sessions are not cancelled, and supply assistive devices, including wheelchairs, walkers and hearing aids.
- **Count caregivers.** Collect who provides care, for how many hours and at what cost, by sex and age, and record caregiving status alongside disability in assessments and monitoring.
- **Give caregivers a seat.** Include caregivers in consultations and feedback, with transport and childcare covered, and use caregivers' own words, with consent.

To OPDs

- **Give caregivers a seat.** Include caregivers in OPD membership, consultations and feedback, with transport and childcare covered, so that their experience shapes OPD positions and advocacy.
- **Fund respite and support for caregivers.** Where OPDs are resourced to do so, host or support peer groups for caregivers.
- **Count caregivers.** Bring caregivers' own accounts, with consent, into the consultations and planning processes OPDs take part in, so that caregiving is named in the data and plans that services draw on.

9. Conclusion: a call to action

Return, reintegration and inclusion for persons with disabilities are unlikely to hold unless the people who provide daily care are recognised, resourced and counted. Support in these three countries comes in cycles. Care does not. Today the system leans on caregivers without naming them, and the weight falls on women who are already carrying loss, debt and pain.

The interviews are consistent across the three countries: where caregivers are invisible, the people they support lose rehabilitation, schooling and safety, and the cost is absorbed by women's bodies, incomes and futures. Seeing, counting and supporting caregivers is the first step to protecting everyone in the household.

Donors, governments, UN agencies, INGOs and NGOs, and OPDs can act now:

- First, add caregivers to needs assessments, financing frameworks and regional and country refugee response planning.
- Second, make cash and rehabilitation continuous for households that depend on care.
- Third, fund respite and psychosocial support for caregivers, and invite them into OPD and consultation processes.

These steps are practical and within reach of existing mechanisms. They protect caregivers and through them, the rehabilitation, education and protection of every person they support.

Sources

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Cover Photo Caption: Ibrahim S., 62, sits beside his wife A. at their home in Deir ez-Zor, Syria. Following a landmine explosion that resulted in the loss of his right leg, he faces ongoing mobility challenges, while his wife helps support the family financially.