Caregiving Responsibilities and Work Requirements

When Caring for Others Becomes Grounds for Losing Coverage

Rosa Martinez, 43, works overnight warehouse shifts three nights weekly, earning just enough for Medicaid while caring for three other people. She's raising her sister's two children after her sister's overdose death two years ago, ages 4 and 7, neither formally in her legal custody because she can't afford guardianship attorneys. Her 71-year-old mother lives with them. The mother fell last year, recovered physically but developed worsening dementia. She can't be left alone. She wanders. She forgets the stove is on.

Rosa's schedule exists around her mother's limitations. She works nights when the children sleep, getting four or five hours rest between her 6 AM return and the 8 AM school run. The arrangement isn't sustainable. Her blood pressure has risen. Her depression, managed for years, has worsened since her sister's death.

The warehouse offers 32 hours weekly but Rosa can't accept them. Who would watch her mother during the day? Adult day programs have 18-month waiting lists. In-home care requires her mother to qualify for long-term services, which requires functional assessment, which requires doctor's appointments, which Rosa has tried to schedule three times but her mother became agitated and wandered off twice. Home health aides cost $25 hourly. Rosa earns $16.

When work requirements begin, Rosa faces a problem with no solution. She works 12 nights monthly, about 96 hours, meeting the 80-hour threshold. But her warehouse is closing, consolidating with a facility 40 miles away. She's applied to 17 other jobs, all daytime, all requiring availability her mother's care prevents. She can't document she's a caregiver because she's not her mother's legal guardian and hasn't obtained custody of the children. Her niece and nephew's school records list Rosa as guardian but that's not legal documentation. Child protective services determined the children were safe with her and closed the case, giving Rosa responsibility without documentable status.

The documentation gap will cost her coverage. The care reality preventing her from working more hours also prevents her from proving she has legitimate reasons for not working. When her Medicaid ends, so does her therapy, her blood pressure medication, and the knee brace making warehouse shifts manageable. Her niece's asthma medication costs $340 monthly without insurance. Her nephew's trauma therapy ends too.

Rosa represents approximately 2.8 million expansion adults whose caregiving responsibilities conflict with work requirements while preventing them from documenting those responsibilities in ways state systems recognize.

Demographics and Scope

The population of expansion adults with significant caregiving responsibilities defies precise quantification because caregiving intensity exists on a spectrum and formal documentation captures only a fraction of actual care provision.

Approximately 1.4-1.8 million expansion adults are primary caregivers for children under age 6, the threshold many states use for automatic exemption. Another 800,000 to 1.1 million care for children ages 6-12 who require substantial supervision but don't qualify under most age-based exemptions. Between 600,000 and 900,000 provide substantial care for elderly relatives, with "substantial" typically meaning assistance with Activities of Daily Living or Instrumental Activities of Daily Living. Approximately 400,000-600,000 care for adult children, siblings, or other relatives with disabilities.

Kinship caregivers represent a particularly invisible population. Between 300,000 and 450,000 expansion adults are raising relatives' children outside the formal foster care system. These arrangements often exist without legal formalization, making the caregiving invisible to verification systems that recognize only legal guardianship. The grandmother raising grandchildren may have no documentation beyond school enrollment forms listing her as emergency contact.

The sandwich generation faces compounding demands. ***Approximately 200,000-350,000 expansion adults care for both children and elderly relatives simultaneously.*** Rosa's situation represents this intersection. The care demands multiply rather than simply add, creating time constraints no single-burden exemption captures.

Women comprise approximately 75 percent of family caregivers across all categories. Among expansion adults, the concentration is likely higher because men in this income range more commonly work full-time jobs incompatible with primary caregiving. Work requirements without adequate caregiving exemptions disproportionately harm women, forcing choices between coverage and family care that men face less frequently.

The gender implications extend beyond immediate coverage effects. ***Women who lose coverage due to caregiving-related work requirement non-compliance face health deterioration that further limits future employment capacity. The*** mother who loses coverage while caring for young children, develops untreated depression, and cannot work when children reach school age represents compounding gender-based harm. Exemption policies that fail to recognize caregiving perpetuate gender inequities in both health coverage and labor force participation.

Cultural variation affects how work requirements impact different communities. In some cultures, placing elderly parents in nursing facilities carries significant stigma. Immigrant families may have stronger multigenerational household norms creating care expectations nuclear family-based exemptions don't capture. Native American communities often have extended family arrangements that don't fit standard definitions. Systems designed around nuclear family assumptions fail extended families where caregiving is distributed across generations and households.

Employment patterns among caregivers reveal the constraints they navigate. About 40 percent work at least part-time despite caregiving responsibilities, typically in jobs with flexible scheduling or evening and night shifts. Rosa's overnight warehouse work exemplifies this pattern: she works when the children sleep and when her mother's confusion is less acute. Another 30 percent worked previously but stopped due to caregiving demands. The remaining 30 percent have never worked consistently due to caregiving combined with health limitations and labor market barriers.

Caregivers themselves experience health consequences. ***Higher rates of depression, anxiety, chronic stress, and physical pain afflict those providing care.*** Rosa's depression began after her sister's death and intensified as her mother's dementia progressed. She needs the Medicaid coverage that work requirements may eliminate.

The economic value of unpaid family caregiving exceeds $600 billion annually. The grandmother raising grandchildren prevents state foster care costs of $30,000-40,000 per child annually. The adult caring for an elderly parent at home prevents nursing home costs of $90,000-120,000 annually, most of which Medicaid would fund. Work requirement policies that ignore this value treat caregivers as non-contributors when they provide services saving public programs billions.

Failure Modes: When Care Creates Documentation Impossibility

Work requirement systems fail caregivers through design assumptions that don't match caregiving reality. Documentation demands reasonable for employed workers become impossible barriers for those whose time is consumed by care.

The documentation deadlock operates with particular cruelty. Proving caregiving intensity requires documentation that caregiving demands make impossible to obtain. Rosa needs a physician's functional assessment documenting her mother requires substantial care. Obtaining this requires scheduling appointments, transporting her mother, sitting through evaluations, following up on paperwork. Each step requires time she doesn't have and patience from a care recipient who may not cooperate. The documentation Rosa needs to prove she can't leave her mother alone requires her to leave her mother alone.

Medical providers can document dementia but ***cannot easily document how many supervision hours someone requires or whether the family caregiver can work while providing care.*** Functional assessment tools used for nursing home eligibility weren't designed for this purpose. Rosa's mother might need only two hours of direct care daily, but she needs someone present 16 hours daily because her confusion creates safety risks.

The relationship recognition gap compounds documentation barriers. A biological parent caring for their child qualifies for exemptions by proving parenthood. An aunt raising her sister's children needs legal guardianship. A grandmother raising grandchildren needs custody orders. These legal distinctions don't reflect caregiving intensity. Rosa provides identical care to what the children's mother would have provided but faces higher documentation burdens purely because of relationship type.

Kinship caregivers face the most severe problems. A grandmother raising her grandson may have temporary custody through child protective services, legal guardianship through family court, or simply be the person the child lives with. Only some arrangements create documentation verification systems recognize. Obtaining legal guardianship costs thousands of dollars, requires attorneys, and takes months.

The care intensity assessment challenge defeats attempts to recognize caregiving beyond legal relationships. How many hours qualify as "substantial"? Does supervision count if you're not providing direct physical care? A parent of a child with severe autism might spend three hours daily on direct care but need 24/7 availability because the child elopes. The three hours don't capture work incompatibility.

Age-based exemption thresholds create arbitrary cliffs disconnected from care reality. Exempting parents of children under 6 assumes elementary school provides sufficient supervision. Neither assumption holds universally. Kindergarten runs 6 hours daily, not 8. Summer break eliminates school-based supervision entirely. For special needs children, age thresholds disconnect entirely from care reality. A child with severe autism may require more intensive supervision at age 10 than a typically developing child at age 2.

State Policy Choices: Recognizing Care or Ignoring It

State decisions about caregiver exemptions reveal underlying assumptions about whether unpaid care constitutes social contribution and whether administrative convenience should trump caregiving reality.

Age-based automatic exemptions represent the simplest approach. A member with a child under age 6 receives automatic exemption upon submitting the child's birth certificate and proof the child lives with them. Georgia's initial Pathways program had no caregiver exemptions. The 2025 refinement added exemptions for parents of children under six, acknowledging the original design was impossible for many.

The policy choice centers on which age threshold to use. Age 1 recognizes infant care intensity but ignores toddler demands. Age 6 aligns with kindergarten entry but ignores that elementary school schedules don't match full-time work hours. Age 13 recognizes children need supervision until old enough to be alone safely but creates long exemption periods. Each threshold creates cliff effects at the age boundary.

Arkansas's approach of counting caregiver status as good cause for reduced requirements rather than complete exemption creates middle ground. A parent with children under 6 might face 40-hour monthly requirements rather than 80 hours. This avoids the binary of full exemption versus full requirements but requires more complex administration.

Disability-based automatic triggers leverage existing eligibility determinations. States can automatically exempt caregivers of individuals receiving disability-related services. A parent of a child with an Individualized Education Program receives automatic exemption. A caregiver of an adult receiving Medicaid long-term services receives automatic exemption. If the state has already determined someone needs special education services or Medicaid LTSS, it has implicitly determined that caregiving involves more than typical demands.

Ohio's automated data matching demonstrates how disability-based triggers work administratively. The state matches Medicaid enrollment files against special education records, LTSS enrollment, and SSI recipient files. When a match indicates someone is caring for a person with documented disabilities, the caregiver receives automatic exemption without application.

Simplified attestation for eldercare reduces documentation burden without eliminating verification. The caregiver submits a form attesting they provide 40 or more hours weekly of assistance to a household member over age 65. The care recipient's physician signs a one-page form attesting the care recipient requires substantial assistance. This requires two attestations but not detailed functional assessments.

Kinship care recognition must accept multiple documentation forms beyond legal guardianship. States can accept school enrollment records, pediatrician attestation, child welfare case records, or simple attestation by both caregiver and the child's parent if available. The key is not requiring the single most formal documentation type when functional care happens without formalization.

Respite-based partial exemptions create middle ground between full exemption and full requirements. A caregiver whose elderly mother attends adult day program 20 hours weekly has time that could potentially accommodate part-time employment. Reduced hour requirements of 40 monthly rather than 80 recognize that some work is possible while caregiving limits work capacity. This approach requires coordination between Medicaid LTSS programs that might fund respite and work requirement systems, and it requires respite to actually exist reliably. The caregiver on an 18-month waitlist for adult day services cannot benefit from respite-based partial exemptions.

The Accountability Question

Caregiving exemptions generate objections from fiscal conservatives, labor market advocates, and those concerned about fairness to workers without caregiving responsibilities. These perspectives deserve engagement.

The choice argument frames caregiving as private decision rather than social contribution. Parents chose to have children. Adults can choose not to care for elderly parents. Kinship caregivers chose to take relatives' children. Why should choices create exemptions?

The choice frame fails on multiple levels. Many caregiving situations don't involve meaningful choice. Rosa didn't choose caregiving by preferring it to alternatives. She faced impossible alternatives: take the children or watch them enter foster care. The choice between watching your mother wander into traffic and accepting caregiving isn't really a choice.

Even chosen caregiving creates social value mutual obligation frameworks should recognize. The grandmother raising grandchildren prevents state foster care costs. The adult caring for an elderly parent prevents nursing home costs. Treating this as private choice ignores public benefit.

The child care availability argument notes subsidies exist and schools provide free education. But child care subsidy programs have waitlists. Head Start serves children 3-5 during school hours only, typically 6 hours daily during the school year. Parents working full-time need 8 hours daily plus commute time plus summer coverage.

The extended exemption concern worries that exempting parents until children reach age 6, 8, or 13 creates multi-year workforce gaps. These concerns have merit but overstate risk. Data shows most caregivers who receive exemptions return to work once care demands diminish. The alternative to exemption is not work but coverage loss. The mother who cannot find employment compatible with infant care doesn't start working when she loses Medicaid. She loses coverage, her health deteriorates, and she ends up with worse employment prospects than if she had maintained coverage.

The fairness question asks why workers without caregiving responsibilities must meet requirements while caregivers receive exemptions. Unpaid family caregiving prevents public costs that employed workers' taxes would otherwise fund. The gender dimension matters: 75 percent of caregivers are women. Exemption policies not recognizing caregiving force women disproportionately to choose between coverage and family care.

Fraud concerns about unverifiable care have some basis. People facing coverage loss have incentives to claim exemptions whether or not they qualify. But fraud prevention mechanisms exist without requiring documentation that legitimate caregivers cannot obtain. States can verify that children exist in school enrollment records. They can verify that elderly care recipients exist in Medicare records. They can require physician attestation for medical care needs. They can conduct random audits. The financial benefit of fraudulent exemption is continued Medicaid coverage, not cash payments. The incentive to commit fraud is lower than for cash benefit programs.

Stakeholder Roles in Supporting Caregivers

Managed care organizations can identify members likely to need exemptions through claims analysis. A member whose child has multiple claims for occupational therapy, speech therapy, and behavioral health likely has a child with disabilities creating intensive care demands. Proactive outreach prevents coverage loss from members not knowing exemptions exist.

The MCO role extends beyond exemption identification. Care coordinators should understand that caregiving members face different constraints. Appointment scheduling must accommodate that caregivers cannot leave care recipients unattended. Home visits may be more effective than office-based appointments. MCOs serving both caregivers and care recipients can coordinate across members.

Providers serving families with care demands need understanding of how exemption documentation works. Pediatricians and geriatricians should receive simple one-page attestation forms completable in 30 seconds during routine visits. The physician who sees Rosa's mother quarterly could provide the attestation she needs if the form were simple enough.

Home visiting programs provide ideal verification support contexts. Public health nurses or community health workers already visiting families can help caregivers gather documentation during visits that don't require arranging coverage for care recipients. Early intervention programs serving children with developmental delays, hospice programs, and chronic disease management programs all create opportunities for integrated documentation support.

Employers offering flexible scheduling, remote work, or non-traditional shifts enable caregiving-compatible employment. Healthcare employers hiring certified nursing assistants often employ workers who are themselves family caregivers. These employers understand dual caregiving roles and may offer shift flexibility. Warehouse and logistics employers recognize that night shifts attract workers with daytime caregiving responsibilities.

Community-based organizations serve as natural navigation partners. Early childhood programs like Head Start can integrate work requirement navigation with existing family support. Head Start family advocates already help families access benefits, coordinate services, and navigate bureaucracies. Adding work requirement exemption support extends existing relationships**.** ***Area Agencies on Aging*** serve elderly populations and their caregivers, providing caregiver support programs, respite care, and adult day services. These agencies understand eldercare demands and can help caregivers document care needs while connecting them to respite services. ***Kinship care support organizations*** address grandparents raising grandchildren and other relative caregivers who standard services often miss. These organizations can provide legal assistance for guardianship at reduced cost and documentation support using alternatives to legal guardianship. ***Faith communities with caregiver support ministries*** provide both practical support and verification through community attestation.

Child care subsidy programs should integrate with work requirement navigation. If a state determines that a caregiver doesn't qualify for exemption because child care is available, that determination should automatically trigger child care subsidy screening. The connection between "you must work" and "here is how to access child care enabling work" should be seamless rather than requiring caregivers to navigate separate bureaucracies.

Rosa's Situation as Structural Pattern

Rosa Martinez will likely lose her Medicaid coverage when work requirements begin. She cares for three people, works when she can, and cannot document her caregiving in ways the system recognizes. Her warehouse is closing. Her mother has dementia. Her sister's children have no legal guardian.

Her situation illustrates why categorical thinking about caregiving fails. She is simultaneously a parent figure for two children, an eldercare provider, and a worker maintaining near-full-time employment. No single exemption category captures her reality. The child under 6 exemption might cover her niece but not her nephew. The eldercare exemption might cover her mother but requires documentation she cannot obtain.

The sandwich generation phenomenon affects hundreds of thousands of expansion adults caring for both children and aging parents. Exemption systems should recognize compounding burdens rather than treating each caregiving role as separate administrative checkbox.

Rosa is not choosing between work and care. She is choosing between her mother's safety and her own health coverage. Between raising her sister's children and documenting she's raising them. The mother with dementia will wander into traffic if unsupervised. The children will enter foster care if Rosa stops providing care. These are not options she can actually select.

Systems recognizing caregiving's economic value, accepting simplified documentation, and building grace periods around transitions will maintain coverage for people providing socially valuable care that prevents costlier institutional alternatives. The grandmother raising grandchildren saves the state $30,000-40,000 annually in foster care costs per child. The adult caring for an elderly parent at home saves $90,000-120,000 annually in nursing home costs. These savings dwarf the cost of exemption administration.

Systems that treat caregiving as excuse rather than reality will terminate coverage for people who will stop working not because they're unwilling but because care recipients would be neglected in their absence. The coverage loss won't create employment. It will create health crises for caregivers whose deteriorating health undermines their ability to provide care.

Rosa is not non-compliant. She is caring for her family in circumstances that leave no room for the administrative burden compliance requires. The system could recognize this. The question is whether it will.

References

1. AARP Public Policy Institute. (2023). *Valuing the Invaluable: 2023 Update*. Washington, DC: AARP.
2. National Alliance for Caregiving & AARP Public Policy Institute. (2020). *Caregiving in the United States 2020*. Washington, DC: National Alliance for Caregiving.
3. Bauer, J.M. & Sousa-Poza, A. (2015). Impacts of Informal Caregiving on Caregiver Employment, Health, and Family. *Journal of Population Ageing*, 8(3), 113-145.
4. Children's Bureau. (2024). *Kinship Care: A Report from the U.S. Department of Health and Human Services*. Washington, DC: Administration for Children and Families.
5. Feinberg, L.F., Reinhard, S.C., Houser, A., & Choula, R. (2011). *Valuing the Invaluable: 2011 Update*. Washington, DC: AARP Public Policy Institute.
6. Kasper, J.D., Freedman, V.A., Spillman, B.C., & Wolff, J.L. (2015). The Disproportionate Impact of Dementia on Family and Unpaid Caregiving to Older Adults. *Health Affairs*, 34(10), 1642-1649.
7. Van Houtven, C.H., Coe, N.B., & Skira, M.M. (2013). The Effect of Informal Care on Work and Wages. *Journal of Health Economics*, 32(1), 240-252.
8. Wolff, J.L., Spillman, B.C., Freedman, V.A., & Kasper, J.D. (2016). A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. *JAMA Internal Medicine*, 176(3), 372-379.
9. Skira, M.M. (2015). Dynamic Wage and Employment Effects of Elder Parent Care. *International Economic Review*, 56(1), 63-93.
10. Reinhard, S.C., Feinberg, L.F., Houser, A., Choula, R., & Evans, M. (2019). *Valuing the Invaluable: 2019 Update*. Washington, DC: AARP Public Policy Institute.
11. U.S. Census Bureau. (2021). *Multigenerational Households: 2012-2021*. American Community Survey Brief ACSBR-012.
12. Medicaid and CHIP Payment and Access Commission (MACPAC). (2024). *Report to Congress on Medicaid and CHIP*. Washington, DC: MACPAC.
13. Georgia Department of Community Health. (2025). *Pathways to Coverage: Implementation Manual for Work Requirements*. Atlanta: Division of Medicaid.
14. U.S. Government Accountability Office (GAO). (2019). *Medicaid Demonstrations: Evaluations Yielded Limited Results* (GAO-19-315). Washington, DC: GAO.
15. Laughlin, L. (2013). *Who's Minding the Kids? Child Care Arrangements: Spring 2011*. U.S. Census Bureau.

Syam Adusumilli, Chief Evangelist, *syam.a@groundgame.health*

16. Schulz, R., & Sherwood, P.R. (2008). Physical and Mental Health Effects of Family Caregiving. *American Journal of Nursing*, 108(9 Suppl), 23-27.
17. Pinquart, M., & Sörensen, S. (2003). Differences Between Caregivers and Noncaregivers in Psychological Health and Physical Health. *Psychology and Aging*, 18(2), 250-267.
18. Generations United. (2021). *State of Grandfamilies 2021*. Washington, DC: Generations United.
19. Child Welfare Information Gateway. (2022). *Kinship Care*. Washington, DC: Children's Bureau.
20. National Academies of Sciences, Engineering, and Medicine. (2016). *Families Caring for an Aging America*. Washington, DC: National Academies Press.