

## debates and issues

### The challenge of identifying young carers in the US: how state laws put families at risk for separation

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**Keywords** young carers • disability • family relations • law and policy

To cite this article: Kalvesmaki, A.F., Miller, K.E.M., Armstrong-Carter, E., Lewis, F., Shih, R.A., Olson, E. and Kavanaugh, M.S. (2025) The challenge of identifying young carers in the US: how state laws put families at risk for separation, *International Journal of Care and Caring*, 9(1): 188–195, DOI: 10.1332/23978821Y2024D000000082

## Introduction

Around the world, the population of older adults and people with disabilities is increasing rapidly; carers are vital in the delivery of care for older adults and people with disabilities and are increasingly recognised in national and international policy (Daly, 2023). In the US, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act 2017 defines a ‘caregiver’ as an unpaid family member or other

individual of any age who ‘has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation’ ([Administration for Community Living, 2022](#)). Demographic shifts, including greater female participation in the workforce, delayed childbearing and smaller family sizes, necessitate greater attention to under-recognised carers, who fill roles that have been primarily assumed to be the purview of spouses and adult children. Globally, carers under age 18 (‘youth caregivers’ in the US; hereafter in this article, ‘young carers’) are gaining recognition, increasingly researched and the subject of policies enacted to support them and their families ([Leu and Becker, 2017](#); [Leu et al, 2023](#)). Yet, in the US, prevalence estimates and understanding of the well-being of young carers are relatively unknown due to limited data and a lack of policy recognition. This leaves a knowledge gap regarding a key population of carers and potentially misrepresents who provides care to families and communities.

Young carers are children/young people under age 18 who provide care to siblings and/or adults, including support with activities of daily living, such as personal care, feeding and supervision. Much extant research has focused on young carers in Europe and Australia. Yet, the experiences and consequences of young caring in the US remain vastly under-addressed. In a study ranking various countries in this emerging field, the US ranked in the fifth tier (out of seven), along with Finland and France, where young caring research is also still not influencing national policy to the level of providing crucial supports and protections ([Leu et al, 2023](#)). The reasons for the relative neglect of this population in the US are historically and politically complex and include the cultural, economic and normative social roles of children ([Olson and Edmonds, 2023](#)). In this ‘Debates and issues’ article, we describe the legal challenges facing families with young carers in the US and the unintended consequences of these. As US researchers of youth caregiving (young carers), we contend that routinely including and accounting for young carers within US policy remains underdeveloped ([Kalvesmaki, 2022](#)) and highlight why this situation may put children and families at risk.

While carers in the US broadly lack national systematic supports, such as training, education and financial support ([Eden and Schulz, 2016](#)), young carers (under 18 years) are additionally disadvantaged; often, they are not recognised as carers and are ineligible for existing state and national carer support services. Moreover, multiple US states have laws containing provisions that promote the removal of children from homes where a parent/guardian is disabled; guidance exists to protect parents with disabilities under US law, but there are no such provisions for young carers ([DeZelar and Lightfoot, 2019](#); [US Department of Justice, 2024](#)). These laws potentially undermine both the developmental need for children to remain with their families and the long-term health and well-being of families. Further, such laws may: (1) pose risks to children through potentially unnecessary family separation; (2) deter families from seeking support and/or participating in research; and (3) precipitate costly reliance on the state for care outside the home. They also pose barriers to the development of evidence-based support and targeted interventions.

## Recognising young caring in the US

Approximately 5.4 million children under the age of 18 are carers for an adult with an illness or disability ([AARP and National Alliance for Caregiving, 2020](#)), and more

than half (over three million) live in a veteran household ([Family Caregiving Advisory Council, 2021](#)). These estimates do not capture the full caring context for young people, however, as children may also be caring for other family members, including biological, adopted or fostered siblings, grandparents, or other family members. Taking this into account, estimates suggest that some ten million children in the US may be carers of a disabled family member ([Murphy, 2022](#)).

Research addressing young carers in the US has informed a growing body of evidence documenting the experiences and needs of young carers and programmes to support them ([Kavanaugh et al, 2016b](#); [Armstrong-Carter et al, 2021](#)). The American Association of Caregiving Youth ([AACY, 2024](#)) has a specific mission to support young carers, practitioners, clinicians and researchers within the field. With leadership from the AACY, an interdisciplinary network of scholars, researchers and practitioners from the Caregiving Youth Research Collaborative ([CYRC, 2023](#)) drafted a 'white paper' summarising extant young carer research in the US, identifying gaps and the need for training and services, and recommending next steps. This included a discussion of the multiple and varied organisations in the US that support families and provide programmes for young carers, many of which are disease (for example, cancer, ALS or Alzheimer's disease) or population (for example, military or veteran young carers) specific.

## Challenges in the US legal landscape

US research identifying young carers indicates a need to advocate for expansive law and policy change ([Kavanaugh and Stamatopoulos, 2021](#)). As the only nation that has not ratified the United Nations Convention on the Rights of the Child, and in the absence of national policies or laws that protect children providing care for a family member, the US stands in stark contrast to countries that have integrated children's rights into wider care policies and supports ([Kavanaugh et al, 2015a](#)). Although numerous policies exist to support adult carers in the US ([Kavanaugh et al, 2016b](#)), policies that might include or directly address supports for carers under age 18 are piecemeal or contingent upon budgetary and programmatic action ([Olson and Edmonds, 2023](#)). In the UK, for example, young carers have rights in law through provisions in the Children and Families Act 2014 and the Care Act 2014 ([Department for Education, 2014](#); [HM Government, 2014](#)); however, the US has no such legislation on the rights of children who are carers, instead focusing in its laws on children in the context of child protection or child welfare.

### *Child protection laws*

The US has a complex network of laws and policies related to child protection that may implicate families if a child is identified as providing care for a parent or guardian with disabilities. In 2010, a legal review found that 37 US states had laws or policies that included disability-related grounds for the termination of parental rights (TPR), including on the basis of physical disability alone, with no evidence of neglect ([Lightfoot et al, 2010](#)). By 2022, this had increased to 42 states ([National Research Center for Parents with Disabilities, 2022](#)).

While the removal of a child may be appropriate in instances of identified abuse or neglect, a parent's disability is not an indication of neglect. Removal of a child

is a worst-case scenario, as removal can damage attachment and interfere with the lifelong well-being of both parents and children (Olsen and Clarke, 2003). Many US state laws include biased and outdated language, such as ‘retardation’, to describe circumstances in which children may be removed from a parent or guardian (Lightfoot et al, 2017). Further, persistent racial bias has been identified in TPR cases, leading US scholars and activists to describe the ‘child welfare system’ as a ‘family regulation system’ in order to highlight harmful, rather than protective, outcomes within child protection (Washington, 2022). In a case review of parents/guardians with disabilities who had experience with TPR, it was found that state welfare workers frequently did not assess the disability needs of parents and escalated cases to TPR before parents/guardians could demonstrate their success in implementing parenting skills or other improvements deemed necessary (Lightfoot et al, 2017). In the same case review, approximately 50 per cent of the children removed from their homes also had disabilities (Lightfoot et al, 2017).

Parents/guardians with a range of disabilities (mental, physical and emotional) are disproportionately referred to child welfare and protection services compared to parents without disabilities (National Council on Disability, 2012). This separation of families is in direct conflict with US federal laws aimed to support persons with disabilities of any age, yet challenges to state statutes that allow the removal of children due to a parent’s/guardian’s disability status have not been successful (Lightfoot et al, 2010; Gupta-Kagan, 2022). States are beginning to change laws to align disability rights across federal and state levels, but progress is slow.

## Consequences of the US legal context

The complexity of US laws and the need to address protection for families with disabilities and their young carers have major consequences for the rights and well-being of young carers.

### *These laws and policies pose emotional and physical risks to children by potentially unnecessarily separating them from their families*

Parents/guardians fear identifying young carers to child protection services, feeling that disclosure could create additional risks. Families may be afraid to reach out for support, resulting in unmet needs and inappropriate pressures on young (or other) carers. As an example, in 2023, a school counsellor contacted one of the authors (Andrea Faith Kalvesmaki) for advice on how to support a teenage carer whose father had died and whose mother was seriously depressed, leaving the teenager caring for the mother and three younger siblings. The counsellor felt that help was needed from family services but feared that if the nature of the mother’s depression was identified, the family could be split up, ostensibly to ‘provide support’, based on the state law and fostering system. Similar accounts exist of parents/guardians with disabilities engaging with the social welfare system and encountering case workers untrained to focus on their disability and to view it as a risk for the abuse and neglect of children (Lightfoot et al, 2017). Care provided by children and young people in such circumstances is neither abuse nor neglectful and may be critical for overall family functioning; such families need whole-family support, not family separation. As care needs increase in the US,

separating families, irrespective of the carer's age, may have negative consequences for both the carer and care recipient (Kavanaugh et al, 2021; Malick et al, 2022). Parents/guardians with disabilities/illness are still parents (Olsen and Clarke, 2003) and feel gratitude when a child supports them (Kavanaugh et al, 2021).

Developing solutions for young carers thus requires a change in how child protection and health services respond. Across professions, the historical response to illness/disability has been to scrutinise and consider child removal. Social work, while not the sole profession involved in child protection, is often at the forefront and is now starting to adopt a more holistic approach to parents/guardians with disabilities (DeZelar and Lightfoot, 2019). Targeted training and guidance for social workers (and other professions) in child welfare and disability settings is needed on the complexity of families when young carers are present and how to engage and support families without taking a punitive approach like family separation/child removal.

### *These laws and policies deter families from seeking support and participating in research*

Researchers often struggle to recruit participants from vulnerable populations (children, youth, prisoners and so on). Recruiting young carers is additionally difficult given justified and deeply rooted concerns about personal and familial welfare and long-term outcomes (already described). In one study of young carers (US Department of Veteran Affairs, 2020), parents expressed concerns about risks to their federal family benefits or researchers reporting their family to child protection services if they allowed their child to take part. In a study comparing young carers' experiences in the US and UK, Lewis (2018) found that several additional months were needed to find research participants due to the hidden nature of young caring and a lack of awareness among recruiting partners (healthcare professionals, social workers, educators and so on). Recruiting young carers, including for crucial longitudinal studies, will remain difficult while families fear child removal/family separation.

### *Existing laws and policies are barriers to the development of evidence-based support*

There are few evidence-based young carer programmes in the US due to the risks families face in self-identifying and allowing their children to participate in research. This leaves US scholarship limited and piecemeal, with a large gap in how best to support these families. Carer research in other countries (the UK, Australia, Germany and others) provides insight into young carers' experiences there, compelling engagement with rights-centred approaches to understanding kinship care and new approaches to services and supports. These may provide a useful roadmap for the US, informing necessary changes in research, education and other professional services in order to begin building a collective understanding of the consequences of our limited understanding of young caring. This would provide an evidence base for wraparound support and services and inform policy approaches to protect their rights and well-being.

## Conclusion

In 2023, *A Minor Revolution* (Benforado, 2023) laid out an argument for protecting six key rights in the US for children who remain ‘invisible’ in law, including young carers of a parent or family member with a disability/illness, beginning with the right to attachment. To protect this right, current US state laws on child welfare in such contexts need to be reformed. A good start would be to outline the support structures required under disability rights laws to guide the administration of services that support child and parental well-being and the family unit. When young carers care for a parent/guardian or siblings with disabilities, they may also be supporting other family members in a variety of contexts. In this article, we have identified the unintended consequences of US laws that impact this field and the families and young people affected. Our goal has been to highlight these laws as indicative of a large-scale systemic problem that needs to be resolved to support families, their children and national and international recognition of young carers.

## Funding

This work was supported with resources and the use of facilities at the Veteran Affairs Informatics, Decision-Enhancement and Analytic Sciences (IDEAS) Center of Innovation, Salt Lake City, Utah.

Dr. Kalvesmaki is supported through the Utah Family Caregiving Collaborative and is part of the Family Well-being Research Network (FAMNET) Scholar Corps. The FAMNET Scholar Corps (Award U24HD107562) is funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Center for Complementary and Integrative Health, and the National Institutes of Health Office of Disease Prevention.

## Conflict of interest

The authors declare that there is no conflict of interest. The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs, Johns Hopkins University or the US government.

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