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Intergenerational Caregiving Teams: Reconceptualizing Youth Caregivers in Kinship Care with Aging Adults to Inform Service Delivery

Andrea F. Kalvesmaki, PhD^a , Kate Nederostek, MGS, CDP, Gerontologist^b, Alyssa Craven, SSW^b, Francesca Perkins, MA^c and Encarni Gallardo, MBA, CPM^c

^aDivision of Epidemiology, Department of Internal Medicine, University of Utah School of Medicine, Salt Lake City, Utah, USA; ^bDivision of Aging & Adult Services, Utah Department of Health & Human Services, Salt Lake City, Utah, USA; ^cChildren's Service Society of Utah, Salt Lake City, UT, USA

ABSTRACT

Informal, family caregiving arrangements are a critical part of the overall health and social care system. However, many family caregivers remain underrecognized and as a result, underserved in programming and policy. These caregivers include the rising number of aging adults caring for children through kinship arrangements, traditionally known as “grandfamilies” – and children who are in their care supporting an aging adult with age-related illness, injury, or disability, known as “youth caregivers.” The Aging GRANDfamilies Expanding Healthcare Access Partnership Project (AGE HAPPY) reconceptualizes youth caregivers in kinship care arrangements with aging adults as “intergenerational caregiving teams” and provides emerging evidence of their existence as well as mutual challenges and benefits for intergenerational well-being. The project provides a blueprint for a community-academic-policy partnership designed to recognize this unique population, use lived-experience and community member input to reform service delivery opportunities, and advocate for policy to support and improve the well-being of aging adults with youth caregivers in intergenerational caregiving teams.

Informal and family caregivers are an integral part of health-care systems and communities (Administration for Community Living, 2022; Bose et al., 2021). The definition of “family caregivers” has evolved to align with family structure changes. This includes acknowledging aging adults providing kinship care as vital care partners when parents cannot care for children (Pilkauskas & Dunifon, 2016), and conversely, children who are younger than 18, defined as youth caregivers, supporting disabled or aging family members to live independently (Administration for Community Living, 2022; Kavanaugh & Stamatopoulos, 2021). Until recently, most family caregiving research has focused on adult parents raising children with disabilities, illness, or other complex needs. However, understanding about how children provide pivotal care for parents, grandparents, siblings and other family members has increased through public health crises such as HIV (Robson et al., 2006) and the COVID-19 pandemic (de Marco, 2021), events like the post-9/11 conflicts (Kalvesmaki, Miller, et al., 2025) and increased international migration (Evans, 2011). Similarly, the opioid epidemic in and outside of the United States (U.S.) has caused a burgeoning new family structure called “grandfamilies,” in which children under the age of 18 are being cared for by an aging adult who is either kin (as in a genetically connected grandparent, aunt, or uncle) or unrelated (as in a foster or adoptive older adult) (Dolbin-MacNab

& O'Connell, 2021; Pilkauskas & Dunifon, 2016). According to recent U.S. Census data, up to 10% of U.S. children live within a “grandfamily” structure with no parent present (Grandfamilies.org, 2017). Yet, these grandfamily and youth caregivers remain underrecognized, underserved, and not well understood.

Caregiving impacts on youth

Youth caregiving research is an emerging area of study in the U.S. and abroad (Kavanaugh & Stamatopoulos, 2021; Leu et al., 2023). Of the research that exists, youth caregivers report similar stressors to those of adult caregivers, namely increased overall mental and physical stress, increased mental health issues, reduced sleep, and reduced social support (Caregiving Youth Research Collaborative, 2023; Stamatopoulos, 2018). However, due to their age and stage in life, youth caregivers may also struggle to remain academically productive (Armstrong-Carter et al., 2022) and may disengage from school altogether due to caregiving stress and the need to provide economically for their families (Bridgeland et al., 2006). Identifying youth caregivers may indicate other issues related to social determinants of health (SDOH) for families. Emerging research on youth and young adult caregivers of aging adults has shown that these older adults are more likely to have lower income, lower health literacy, lack reliable

transportation, and may have other unmet needs related to aging (Kalvesmaki, Garcia-Davis, et al., 2025; Miller et al., 2024). Youth caregivers caring for these aging adults also have unmet needs related to education, social support, and economic stability (Miller et al., 2024; Miller & Wolff, 2024). Additionally, youth caregivers who are underage can face limitations and hurdles to supporting aging adults including lack of experience, financial dependence, educational responsibilities, or employment pressures (GAO, 2025).

While many of these impacts are primarily negative, of the literature that exists, youth caregivers also report positive experiences and emotions related to caregiving. In the first reported study of youth caregivers of U.S. military personnel and veterans (Malick et al., 2022), youth reported a sense of pride in caring for a parent with a disabling condition. Some of these youth also reported a desire to go into service as a future career—in health careers or military duty (Malick et al., 2022). Importantly, early research exploring the potential adverse effects of caregiving on youth of parents with disabilities uncovered a surprising aspect of caregiving that had not been foreshadowed—it fostered a deeper relationship between parent and child with multiple aspects of positive family and personal well-being noted (Olsen & Clarke, 2003). The authors suggest that unlike the process of “parentification” in which adults place unrealistic demands on children making them grow up too quickly, the roles of a child and youth in the home for families of persons with disabilities create a family systems approach to caregiving (Kalvesmaki, Miller, et al., 2025; Olsen & Clarke, 2003). In youth caregiver research to date, many families express concern that they are asking too much of children (e.g. (Malick et al., 2022; Olsen & Clarke, 2003), which youth caregiving research scholars suggest may be explored further as the precise opposite of the expected impact of parentification (Caregiving Youth Research Collaborative, 2023; Kalvesmaki, 2025; Kalvesmaki, Miller, et al., 2025; Kavanaugh et al., 2016; Kavanaugh & Stamatopoulos, 2021).

Intergenerational care is intergenerational Well-being

Expanding the cultural understanding of who family caregivers are and whom they are caring for has the potential to improve health and well-being for all caregivers across all ages. With the rise of grandfamily caregivers in recent years, and the increasing number of young people <18 years of age caring for aging adults, reconceptualizing this intersectionality as “intergenerational caregiving teams” provides a context within which to conduct research, reframe caregiving efforts, and recognize this specific population through program support and advocacy. The reconceived title from kinship families to “intergenerational caregiving teams” acknowledges the bi-directional nature of care present in these families. Kinship adult caregivers step in to provide foundational love and support in a young person’s life—often at a critical time when other support may be non-existent. This directional flow provides care to the youth, and a foundation for the future. Conversely, the adult providing this care may develop needs related to aging or other circumstances (e.g. an accident or health diagnosis) and the flow of support may reverse toward

the opposite direction. For instance, aging adult grandfamily caregivers provide critical baseline support for children and young people in their care including economic stability, shelter, food, health, and education security often into and through early adulthood (Hayslip Jr et al., 2019; Pilkauskas & Dunifon, 2016). On the other spectrum of the intergenerational caregiving team, youth caregivers help support aging adults’ technological literacy, provide emotional support, and promote intergenerational solidarity (GAO, 2025). Considering that many grandfamilies are comprised of adults and children separated by at least one generation with the child’s parent (typically the aging adult’s child) absent (Dolbin-MacNab & O’Connell, 2021), these intergenerational caregiving teams may be more of each other’s lifelines for support than is possible to anticipate as no literature to date examines this phenomenon and the long-term roles each person plays. Figure 1 provides a reconceptualization of kinship family arrangements as intergenerational caregiving teams. By recognizing and defining “intergenerational caregiving teams,” caregiving activities and the impact of these activities on the individuals within these family caregiving teams can be better understood and conceptualized.

The concept of intergenerational caregiving teams builds on recognizing aspects of intergenerational caregiving such as grandparents raising or caring for grandchildren (Administration for Community Living, 2022), and recent acknowledgement of the tasks youth take on to support aging adults in and outside the home (GAO, 2025; Miller et al., 2024). Research examining how volunteer work that spans generations (e.g. aging adults volunteering to support young children, or vice versa, children and teens volunteering with aging adults) indicates that aging adults who receive support from youth exhibit increased well-being and improved communication especially during age-related decline, and youth who provide support to aging adults improve in communication and career-related skills, attitudes toward aging, as well as deeper and more diverse friendships (Andreoletti & Howard, 2018; Blais et al., 2017). The concept of “intergenerational caregiving teams” attempts to extend and encapsulate the concept of intergenerational caregiving by acknowledging the care may be better understood as bi-directional and mutually beneficial, especially as are represented within grandfamilies.

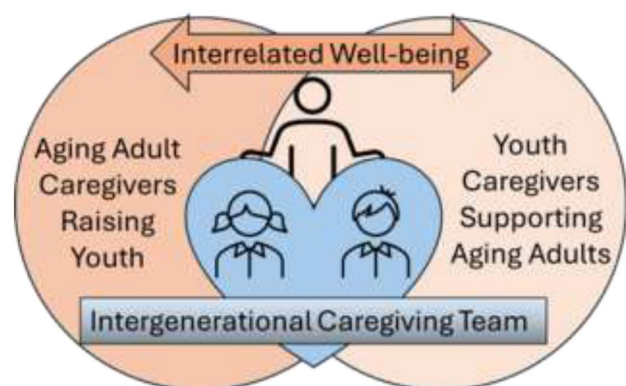


Figure 1. Intergenerational caregiving teams.

Empirical examinations of grandfamilies, including how caregiving affects older adults' well-being, impacts to social determinants of health (SDOH), and long-term impacts on children in care remain limited (Dolbin-MacNab & O'Connell, 2021). As world populations increasingly age, the number and importance of youth caregivers of aging adults is expected to increase (Kavanaugh & Stamatopoulos, 2021; Miller & Wolff, 2024). Grandfamilies are also expected to increase as substance use and opioid addiction remain an ongoing national and global epidemic (Hayslip et al., 2019). As such, greater understanding of kinship care arrangements and its impacts on health and well-being for children and aging adult "intergenerational caregiving teams" is increasingly critical to understand.

Materials and methods

The *Aging GRANDfamilies Expanding Healthcare Access Partnership Project (AGE HAPPY)* brings together a dynamic team using a community-based participatory research (CBPR) approach (Sánchez et al., 2021; Wallerstein, 2021) to (1) reconceptualize and identify intergenerational caregiving teams, (2) assess the needs of these family caregivers in order to have data necessary to provide effective interventions and supports, and (3) craft policy in support of these caregiving teams. CBPR methods that engage community and academic partners to understand health disparities have been successful at launching new initiatives in hard-to-reach communities (Holkup et al., 2004), identifying new ways of addressing complex health issues (Bogart & Uyeda, 2009), and engaging young people's voices and opinions in research on the hidden nature of youth caregiving (Smyth et al., 2011; Stamatopoulos, 2018).

The research partners for the AGE HAPPY project are a leading 501(c)(3) organization providing support to grandfamilies in a largely rural western state, an academic from the largest state university who specializes in youth and family caregiving research and community engagement methods, and a leader of multiple aging and caregiving programs in the state government. The goals of this project are to advance knowledge, understanding, and support of intergenerational caregiving teams. This paper outlines the protocol for this partnership as a template for organizations and researchers to partner in advancing human health and greater cultural understanding of an overlooked and underserved population.

Aims and proposed methods

This mixed-method pilot study will use a complementary combination of community-academia research partnership (CBPR) (Wallerstein, 2021) and PRISM/RE-AIM Frameworks (Cooper et al., 2021; Jolles et al., 2024) to develop an assessment to understand and meet the needs of intergenerational caregiving teams.

Aim 1. Convene a community advisory board (CAB) of up to 20 GRANDfamilies participants to discuss the needs of aging adults raising children, types of support provided by these children for the adult(s), and current and anticipated

needs. Using a co-creation model of community collaboration for health equity (Bogart & Uyeda, 2009; Chanchien Parajón et al., 2021; Holkup et al., 2004; Wallerstein, 2021) we will obtain a diverse sample of lived-experience data from aging adults with children under age 18 to identify common and unique aspects of aging adult needs, potential roles children and young people assume in supporting activities of daily living (ADLs) and instrumental activities of daily living (IADLs) of the aging adults or other family members, and/or concerns for needs that may emerge over time (e.g. onset of aging-related disabilities or conditions). We expect to hold up to five CAB meetings to generate knowledge about the needs of aging adults and youth caregivers, which will inform the development of an assessment used to then collect information from intergenerational caregiving teams and inform service development and delivery. Meetings will be held online using Microsoft Teams to maximize participation from members in different locations across the state. Meeting data will be generated using AI notetaking and transcription, facilitator summary notes, chats, and other meeting options such as short pop-up surveys. These data will be templated and analyzed using rapid qualitative methods for intervention development and implementation (King, 2012; Lewinski et al., 2021; Schexnayder et al., 2023). Templates will be structured to support an analysis of data aligned to the PRISM/RE-AIM model, which combines implementation science with community-research frameworks to identify contextual factors that can be used to design and implement interventions (Jolles et al., 2024). Data aligned with the PRISM/RE-AIM model can then be structured into questions to collect information from intergenerational caregiving teams across relevant domains which in turn, guide the delivery and/or development of services.

Aim 2. Using input from the CAB, develop an assessment to be tested by GRANDfamilies participants and inform an intake form to support service pathway development. The assessment questions generated in Aim 1 will be field tested with current GRANDfamilies participants through a large-scale survey approach. Current GRANDfamilies participants will be mailed a packet of information that include the purpose of the project, a QR code to complete the assessment online, and a printed copy of the assessment questions if they would prefer to respond via paper and mail. The online and paper assessment will include the questions informed by the AGE HAPPY CAB and include an open-ended item asking for additional information or feedback to improve the questions. Results from the survey of all current GRANDfamilies will be monitored for a minimum of 50 responses. Descriptive statistics will be used to summarize demographic and scaled results. Rapid qualitative methods (as described for Aim 1) will be used to summarize open-ended items. The CAB will be asked to review the results for representativeness of needs. A CAB meeting will be held to finalize the assessment that can then be included as part of an overall GRANDfamilies intake form.

Aim 3. Create an implementation and service development plan and pilot test the new assessment to ensure service delivery that meets the needs of the communities engaged in GRANDfamilies across the state of Utah. Our team will

prepare an implementation plan and service pathway development plan with partners in the Utah Department of Health and Human Services (UT DHHS) and Salt Lake County Aging and Adult Services (AAS). The revised GRANDfamilies intake form with the aging adult needs assessment will be piloted with approximately 50 families in various Utah counties to ensure service delivery connections are fully established, providing data for ongoing funding through legislative appropriations and community development funds in the state. The implementation plan will be based on the Adoption and Implementation portion of the PRISM/RE-AIM framework (Jolles et al., 2024) and will include training, implementation pilot testing, and evaluation of the initial pilot phase (approximately 8–10 wk), supporting the ability to move into the ‘maintenance’ phase of implementation following the pilot testing phase.

Results

Reconceptualizing grandfamilies’ service needs

Current intake forms and assessments for grandfamily programs across the U.S. focus primarily on the needs of the children in care, while evaluations assess grandparent training and competencies *rather than identifying service needs*. Lack of assessing older adult caregiver needs means next to nothing is known about the caregivers’ health, financial stress, emotional well-being, access to support, and aging-related disabilities that may require support from children in their care. To understand these concerns, our team is assembling a community advisory board (the AGE HAPPY CAB) of up to 20 older adults in the local GRANDfamilies program who have identified that their children are also caregivers for aging adults.

The AGE HAPPY CAB currently has two members. One grandfather, over the age of 65, reported how his 13-year-old adopted daughter supported the care of his wife (now deceased) through her Alzheimer’s journey. The child supported the grandfather through the three years of the disease progression (which occurred when the child was 10 until 12) by staying with her while he ran errands, bringing her back after wandering away from home, and overall supporting his emotional journey of loss. Another member of the CAB is an aging grandmother who has fostered and adopted more than twenty children over the course of her life. She has a fifteen-year-old son who supports the care of his disabled brother in critical ways that allow her the time and space to clean, cook, and provide for the family. These individuals, along with others, are reframing the understanding of caregiving teams with young people in kinship care. The AGE HAPPY CAB is recruiting additional members from a variety of backgrounds (diverse experiences, rural/urban locations, and various supports available) to identify how these families function to support their combined well-being and fulfill gaps in service needs. Identifying needs from community members who will benefit from any changes to policy or programming is an integral part of CBPR research and has been successful in supporting various populations in achieving health-related goals, including youth, rural adults, and

other hard-to-reach communities (Bogart & Uyeda, 2009; Holkup et al., 2004). Moreover, the engagement of individuals within underserved and misunderstood communities can provide hope to others who may be struggling with complex social, economic, and health issues that remain elusive to address and/or support (Chanchien Parajón et al., 2021). Following the youth and family’s caregiving outcome model (Kalvesmaki, Miller, et al., 2025), the well-being of aging adult caregivers and their youth caregiver partners are tightly intertwined and related to the caregiving tasks conducted by each part of the team.

Developing a new protocol for intergenerational caregiving teams

Needs identified by aging adults in the AGE HAPPY CAB will be used to inform a new protocol and approach to service provision. Information from the community members on service, support, and other SDOH needs for aging adults will be added and tested through the local chapter of the GRANDfamilies program. This chapter has already won national recognition for their ability to support thousands of families annually in a primarily rural state with a diverse population, including members from refugee, international, and American Indian communities. For a leader in the field of grandfamily support services, developing a new intake form that includes the ability to identify the needs of both children and aging adults—and developing new protocols for service connection to address these needs—has the potential to revolutionize the fields of aging and child service provision.

The community-academic partnership for AGE HAPPY also includes state government leaders connected to these communities as well as leadership for the implementation of the National Family Caregiver Support Program aligned to national priorities for caregiver support (Administration for Community Living, 2022). As the project unfolds, the partnership is expected to expand and become a model for CBPR research on including individuals within a community, community service organizations, and government leaders capable of connecting communities to resources quickly, along with academic partners to assess the implementation

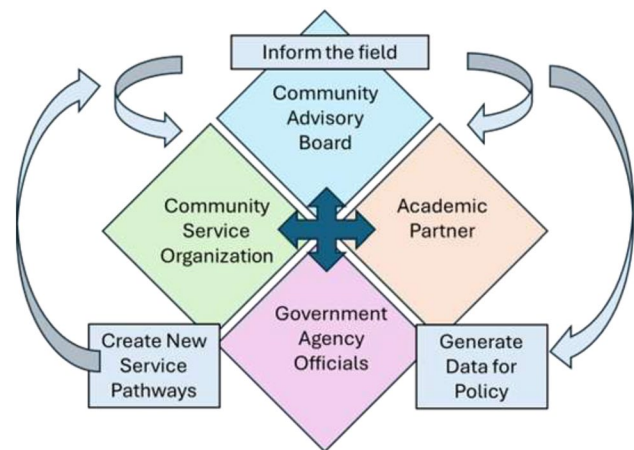


Figure 2. Community-academic-policy partnership model.

of the project. This concept expands traditional CBPR from a community-academic model to incorporate government as a critical member of the partnership (see Figure 2).

Discussion

Understanding and supporting intergenerational caregiving teams is vital for moving the field of intergenerational health, well-being, and relational motivations forward. This under-recognized population may hold the keys to truly understanding the benefits of intergenerational relationships and moreover, the intertwined roles of family caregivers over the lifespan. The AGE HAPPY project has the potential to reform how aging adults caring for young children are recognized and supported, which in turn, will create healthier families and more robust communities in which all forms of family are celebrated. Data from the project will (1) address research, data, and policy gaps for family caregivers of all ages and (2) improve the ability of local service agencies in providing more tailored and personalized support through expanded data collection. In addition, with clearer data on caregiver challenges, service agencies may more effectively advocate for policy changes, funding, and community resources at local, state, and national levels, directly benefiting kinship families. This partnership project has already begun to impact state and national awareness of the interrelated caregiving roles in kinship families by providing a template for community-academia-policy partnerships to benefit multiple communities around the world.

Moreover, by reconceptualizing the bi-directional relationship of care between aging adults and children in kinship caregiving arrangements as intergenerational caregiving teams, issues related to mental health may be more readily addressed. Caregiving can take a toll on mental and physical health regardless of the age, experience, and knowledge caregivers glean over time related to their support roles (Yates et al., 1999). When caregivers remain underrecognized, they remain underserved, leaving blind spots in service delivery that could potentially alleviate burden (Administration for Community Living, 2022; Bose et al., 2021). Youth caregivers in particular, are an emerging population that may be more present in an aging person's life than previously anticipated (Miller & Wolff, 2024), and as such, may become vital long-term care partners as part of the overall system of caregiving (Kalvesmaki, Garcia-Davis, et al., 2025). An awareness of the interrelated, mutually beneficial roles intergenerational caregiving teams may play in each other's lives could help shape mental health interventions and services provided both in and outside the home, providing benefits beyond an individual and extending into the greater community. In fact, tests on caregiver intervention supports that have included assessing the impact on additional family members have shown a reduction in anxiety and mental health issues even when those family members are not part of the intervention (Shepherd-Banigan et al., 2020). How much more impactful could the interventions be when caregiving teams are first recognized, and then supported? This is the overall goal of AGE HAPPY.

Implications

The reconceptualization of kinship caregiving arrangements as intergenerational caregiving teams, along with our project's design to collect lived-experience from individuals within these caregiving teams will provide foundational data that will be used by community, academic, and policy partners to improve health outcomes for aging adults and children in their care. Data collected in this project will support our ability to advocate more effectively for policy changes, funding, and community resources for kinship families and intergenerational caregiving teams, especially by recognizing that aging adults may both provide and receive benefits from children in their care and vice versa.

Importantly, we hope this protocol will result in an ecologically validated assessment that can transform how care is provided to kinship families, aging adults, and youth caregivers. In addition, the community-academic-policy partnership outlined has the potential to provide a template for health service supports (including mental health nursing, in- and out-of-home medical care, and other caregiving interventions to partner with community organizations and state agencies in providing wrap-around support that can strengthen individuals, families, and communities.

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Author contributions

CRedit: **Andrea F. Kalvesmaki**: Conceptualization, Methodology, Writing – original draft, Writing – review & editing; **Kate Niderostek**: Conceptualization, Writing – original draft, Writing – review & editing; **Alyssa Craven**: Conceptualization, Writing – original draft, Writing – review & editing; **Francesca Perkins**: Conceptualization, Writing – original draft, Writing – review & editing; **Encarni Gallardo**: Conceptualization, Writing – original draft, Writing – review & editing.

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ORCID

Andrea F. Kalvesmaki  <http://orcid.org/0000-0002-4282-0619>

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