Supporting Grandparents Raising Grandchildren (SGRG) Act

Initial Report to Congress

Prepared by: Advisory Council to Support Grandparents Raising Grandchildren With assistance from: Administration for Community Living, an operating division of the U.S. Department of Health and Human Services













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The Advisory Council to Support Grandparents Raising Grandchildren

With the passage of the <u>Supporting Grandparents Raising Grandchildren (SGRG) Act</u> in July 2018, Congress authorized the establishment of a council (the Advisory Council) to support grandparents and other kin caregivers who are raising children, including grandchildren. The charge was to identify, promote, coordinate, and disseminate information, resources, and the best practices available to help grandparents and other older relatives meet the needs of the children in their care while maintaining their own physical and mental health and emotional well-being.

The report that follows outlines progress of the Advisory Council to date and proposes 22 recommendations for changes to formal and informal systems that will benefit grandparents and other kin caregivers of children who cannot remain in the homes of their parents. The Advisory Council is composed of grandparents, professionals working in the field of supports and services to grandparents and the children they care for, and representatives of the federal agencies that serve these populations.



Advisory Council Appointees

The following 13 non-federal appointees are grandparents, advocates, educators, and child welfare professionals. Their biographies are available on the <u>Advisory Council to Support Grandparents Raising Grandchildren website</u>.

- Jaia Peterson Lent, Advisory Council co-chair and deputy executive director of Generations United
- Ethlyn McQueen-Gibson, D.N.P., M.S.N., R.N.-B.C., Advisory Council co-chair and associate professor and director of Gerontology Center of Excellence at Hampton University



- Martha R. Crowther, M.P.H., Ph.D., associate dean for research at the University of Alabama, College of Community Health Sciences
- Patrick Donavan, supervisor with Muskingum County (Ohio) Adult and Child Protective Services
- Gail Engel, grandparent and founder of Grand Family Coalition
- Sarah Hedden, B.S., M.S.W., J.D., attorney with the Kinship Care Legal Services Program at the Center for Elder Law & Justice in Buffalo, New York
- Bette Hoxie, former director of Adoptive and Foster Families of Maine, Inc. & the Kinship Program
- Toni Kleckley, M.A., D.Th., grandparent and founder and executive director of Trans4mation Now Inc., and the Grandparents Educating Minds program
- Yvonne S. Lee, M.S.W., professor at West Virginia State University
- Linda Miller, R.N., director of the Iowa Department on Aging
- Sharon Olson, grandparent and past president of the Minnesota Kinship Caregivers Association
- Sarah L. Smalls, grandparent and family resource coordinator for Formed Families
 Forward
- Charlotte Stephenson, grandparent and advocate

Federal Representation

The SGRG Act specifically called for participation from the Secretaries (or their designees) of the U.S. Department of Health and Human Services (HHS) and the Department of Education (ED). It also called for participation from the Administrator of the Administration for Community Living (ACL), the Director of the Centers for Disease Control and Prevention (CDC), and the Assistant Secretary for the Administration for Children & Families (ACF), all within HHS. In addition to those agencies named in the SGRG Act, federal representation on the Advisory Council includes participation from:

- AmeriCorps
- The Consumer Financial Protection Bureau (CFPB)
- The Health Resources and Services Administration (HRSA)
- The National Institute on Aging (NIA), National Institutes of Health (NIH)
- The Office of the Assistant Secretary for Planning and Evaluation (ASPE)
- The Office of the National Coordinator for Health Information Technology (ONC)
- The Substance Abuse and Mental Health Services Administration (SAMHSA)



Administration for Community

Letter from the Principal Deputy Administrator of the Administration for Community Living (ACL)

There are more than 2.7 million American children being raised within the loving homes of kin and grandparent caregivers (U.S. Census Bureau, 2019). These kinds of families are called kinship families or grandfamilies. Even though they are not a new phenomenon, they are growing increasingly common across the nation. While each family is different, one characteristic they all share is the presence of a kin or grandparent caregiver who is providing support, love, and stability to vulnerable children—often outside the child welfare system.

These new families form in response to a range of challenges, such as the opioid epidemic, death, incarceration, serious mental illness, or other causes. When parents can no longer care for their children, there is no one better suited to step in than grandparents, extended family, and close "family-like" friends—in other words, the people whom the children already know and love. But providing that care can come at a cost to the caregivers' own physical, mental, and financial health and well-being.

The Congressionally mandated Advisory Council to Support Grandparents Raising Grandchildren (the Advisory Council) spent two years understanding how to better support kinship families and grandfamilies. Even though they are professionals working in the child advocacy field and grandparents raising children themselves, they talked to the experts and they listened to focus groups. They also launched a formal Request for Information (RFI) that yielded over 1,900 comments from more than 300 respondents across the nation. Prominent among these responses was a trove of moving testimonials from kin and grandparent caregivers about their day-to-day troubles and triumphs.

As this report makes clear, the Advisory Council overwhelmingly heard that the legal and child welfare systems in this nation are not designed to address the needs of these families. Nor are the caregivers adequately supported by federal, state, and local policies. As a result, many lack access to basic supports and services. They struggle to house, feed, and clothe themselves and the children in their care. Almost half of the children living in "grandmother-only" households live in poverty, and Black, African American, and Native American communities are over-represented in these families. For many families, the disproportionate inequities they are already grappling with each day are only compounded as they navigate complex legal systems, a maze of disconnected financial and social services, and social stigma. The ongoing COVID-19 pandemic has exacerbated these challenges, creating new urgency and momentum to address the needs of kinship families and grandfamilies.

These unmet needs go straight to the heart of ACL's mission. Forty percent of kin and grandparent caregivers are older adults, and 25% have disabilities (U.S. Census Bureau, 2019). Often, they are caring for children who experience disabilities. ACL is



committed to advancing programs and policies that support opportunities for older adults and people with disabilities of all ages to thrive in their own communities. The President's American Rescue Plan, signed into law in March 2021, directed ACL to establish the nation's first National Technical Assistance Center on Grandfamilies and Kinship Families. This effort directly aligns with the mission of the Advisory Council.

The needs of caregivers of all types are at the forefront of public policy, including the priorities of the Biden-Harris Administration. The President's Build Back Better Plan calls for significantly increased funding for accessible child care and preschool, nutrition and housing assistance, and supports for caregivers, including family caregivers—all of which have the potential to transform the lives of many kinship families and grandfamilies. Together, these investments, along with the National Family Caregiving Strategy being created pursuant to the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act and to be released in early 2022, will transform how the nation supports a population of caregivers, who—until now—have received little in the way of appreciation and recognition for their selfless contributions to the well-being of generations of children.

With the release of this groundbreaking report, we now have an unprecedented opportunity to achieve—and go far beyond—the goals Congress mandated in the Supporting Grandparents Raising Grandchildren Act. I want to express our deepest gratitude to the members of the Advisory Council for their hard work on this report. As this report shows, we have our work ahead of us if we are to truly support the millions of kin and grandparent caregivers in the United States of America. We have a unique opportunity to bring that vision to life, and we are committed to seizing it.

Alison Barkoff Principal Deputy Administrator Administration for Community Living U.S. Dept. of Health & Human Services



Acknowledgements

This report would not have been possible without the generous support, assistance, expertise, and advocacy of a wide range of stakeholders committed to assisting the millions of kin and grandparent caregivers across the nation who step in to care for children who cannot remain with their birth parents.

Many voices came together in the development of this document. Notably, the members of the Advisory Council, with assistance from ACL, shaped this document from inception to outline through discussion and review. The Advisory Council appointees shared key insights gleaned from years of experience raising grandchildren and working in the child welfare and advocacy fields. In addition, a working group of members drafted text for the rationale statements that support each of the Advisory Council's recommendations below. The Advisory Council also wishes to extend its appreciation to Charlotte Stephenson for her dedication in reviewing and vetting resources submitted through the RFI into the needs and challenges of kinship families and grandfamilies.

In addition, representatives from multiple federal agencies served on the Advisory Council and contributed expertise and insight to the Advisory Council discussions. The value of this became especially evident as the Advisory Council explored the feasibility of its proposed recommendations and during clearance of the document. Federal members also provided valuable information on existing programs and resources in the federal government to support grandparents raising grandchildren.

The Advisory Council recognizes the hundreds of members of the public and representatives of advocacy groups who responded to the RFI. Many of the comments received were deeply personal and served as a constant reminder to the Advisory Council of the urgency to develop practical solutions to address the needs of kinship families and grandfamilies. Approximately 50 of those comments are included in this report. Also included are key comments from members of the Advisory Council. Multiple subject matter experts within ACL provided critical input and guidance on this report, including the ACL regional administrators, ACL grantees, and staff within ACL's Office of American Indian, Alaskan Native, and Native Hawaiian Programs (Title VI) and the Center for Policy and Evaluation.

Finally, it is important to note that this report is the result of many years of effort by a wide range of stakeholders and other advocates. The passage of the SGRG Act was the result of years of dedicated advocacy on the part of grandparents and other kin caregivers and organizations including Generations United, the American Bar Association Center on Children and the Law, Annie E. Casey Foundation, Casey Family Programs, the Children's Defense Fund, and the American Academy of Pediatrics. Without these advocacy groups and the tireless work of legions of family members,



social workers, child welfare professionals, and community organizations, this critical report and its recommendations would not have been possible.

Important Note on Terminology Used in this Report

The Advisory Council recognizes that federal and state legislation, the child welfare system, and state and local jurisdictions use a variety of terms to describe the families that are the focus of this report. These terms include **fictive kin, kin, kinship** caregivers, families of choice, person acting as a parent, non-parent caregiver, person acting in a parental relationship, etc. Similarly, inconsistencies exist among other aspects of the nomenclature related to kinship families and grandfamilies. For the purposes of this report, the Advisory Council agreed on the following terms:

- Adverse childhood experiences (ACEs): Many kinship families and grandfamilies come together in response to violence, abuse, neglect, disasters, death, substance use disorders, or other emotionally harmful experiences. When the experiences occur during childhood, they are known as adverse childhood experiences (ACEs). Research has found that although most children exposed to ACEs are resilient, a significant minority of children exposed may go on to experience chronic health problems, mental illness, and substance use problems in adulthood. ACEs can also negatively impact education, job opportunities, earning potential, and longevity. Notably, research "suggests that the impact of these adverse childhood experiences on adult health status is strong and cumulative" (Felitti, et al., 1998).
- Child welfare system: This report uses this term defined by the Children's Bureau within the U.S. Department of Health and Human Services as "a group of services designed to promote the well-being of children by ensuring safety, achieving permanency, and strengthening families." The primary responsibility for child welfare services rests with the states, however, the federal government supports states through program funding and legislative initiatives (Child Welfare Information Gateway, 2020).
- Note: Within this report, for the purposes of expediency, the Advisory Council uses the term "inside the system" to describe families with children who have been placed in the child welfare system, usually known as "formal" families (Child Welfare Information Gateway, 2020). The term "outside the system" is used here to describe families with children who are not in the child welfare system, also sometimes known as "informal" families.¹
- Grandchildren and/or children: Throughout this report, these terms describe the care recipients in kinship families and grandfamilies. This term applies to minor children and adult children with disabilities whose primary caregivers are kin and grandparents. The Advisory Council uses these terms for expediency, recognizing



- and acknowledging that some care recipients in these families are nieces, nephews, great-grandchildren, godchildren, siblings, cousins, and/or beloved family friends.
- Kin and grandparent caregivers: The Advisory Council uses this term when it is necessary to specify <u>the adults</u> who have primary responsibility for grandchildren or other children who cannot remain with their parents.
- Kinship families and grandfamilies: To signal support for the diversity of families raising grandchildren today, the Advisory Council adopted the widest possible definition for the families who step up to raise children who are unable to reside with their parents. Typically, "kinship family" refers to families where individuals are related by heredity, marriage, friendship, or adoption. The term "grandfamilies" is a type of kinship family where children live with grandparents or other adults with whom they have a family-like relationship. The Advisory Council uses "kinship families and grandfamilies" as an inclusive term in this report to describe all members of the blended and extended families raising grandchildren, godchildren, nieces, nephews, siblings, and dear family friends. This term includes families in caregiving arrangements such as when a child is placed with a state's child welfare system, those in which a child is placed in the custody of the caregiver by child welfare authorities, and those families who have taken responsibility of rearing children outside the child welfare system.
- Trauma-informed care: As a result of exposure to some type of trauma or traumatic event, both children and adults may need interventions grounded in the knowledge and understanding of trauma and its implications. This report uses a <u>definition</u> developed by the Substance Abuse and Mental Health Services Administration's (SAMHSA) Trauma and Justice Strategic Initiative to define trauma-informed care: "A program, organization, or system that is trauma-informed realizes the widespread impact of trauma and understands potential paths for recovery; recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatization" (Substance Abuse and Mental Health Services Administration, 2014).



Executive Summary

"Grandparents and relatives are amazingly resilient and strong members of our community, they are often overlooked, but from my years of experience in social work, this is THE group that can help transform child permanency in our communities."

-Response to 2019 RFI about the needs and priorities of kinship families and grandfamilies.

Families are the central and enduring influence in children's lives, shaping their development, identity, values, and sense of security (Schor, Edward; American Academic of Pediatrics Task Force on the Family, 2003). Throughout history and across cultures, grandparents have been at the heart of this experience. They are a recognized source of wisdom, practical assistance, and unconditional love for children. They nurture family connections and foster cultural identity while providing trusted practical support to parents and children alike.

When tragedy strikes and parents can no longer care for their children—whether due to the opioid epidemic, death, incarceration, serious mental illness, or other causes—there is no one better suited to step in and raise the children than grandparents, extended family members, and close family friends. Unlike the caregivers and providers in traditional foster homes and institutional settings, kin and grandparent caregivers already know and love the children, they understand the losses and grief the children face, and, as a result, are better suited to help them continue to grow and learn within the warm embrace of a loving family.

Collectively, known as "kinship families or grandfamilies," these families are not a recent phenomenon. Throughout history and across cultures, grandparents—especially grandmothers—have stepped in to raise children (Minkler & Fuller-Thompson, 2005). The difference now is that the need for loving support of children is growing. The number of children who cannot live with their parents continues to increase across the nation. In drafting the Supporting Grandparents Raising Grandchildren (SGRG) Act, Congress found that "between 2009 and 2016, the incidence of parental alcohol or other drug use as a contributing factor for children's out-of-home placement rose from 25.4 to 37.4 percent" (The Supporting Grandparents Raising Grandchildren Act, 2018). Against the backdrop of that increase, millions of grandparents, relatives, and close family friends are stepping up to raise children who cannot remain with their parents for other reasons, such as deployment, death, incarceration, and economic adversity. These caregivers are making tremendous sacrifices to care for and protect the vulnerable children they love outside the formal systems designed to care for children, and largely on their own. In doing this without support, they incur significant personal and financial costs and put their physical and mental health at risk, since there are few supports and services in place designed to assist these families.



Congress established The Advisory Council to Support Grandparents Raising Grandchildren (SGRG) (the Advisory Council) to address these critical and intertwined issues. Congress charged the Advisory Council with identifying, promoting, coordinating, and disseminating information, resources, and best practices to help grandparents and "older relative caregivers" of children meet the health, educational, nutritional, and other needs of the children in their care, while at the same time maintaining their own physical, mental, and emotional health and well-being. This vision includes all kinship families and grandfamilies, regardless of whether they are providing care as a foster parent inside the foster care system or outside the child welfare system. Just as it is important to provide supports to birth parents to keep children safely with them whenever possible, it is equally imperative to provide kinship families and grandfamilies with the supports and services they need so that all members of the family can thrive.

When children cannot remain in the home of their parents, they typically begin a journey on one of two possible paths. A minority of children enter the foster care system. Their caregivers may be their own relatives who are licensed as foster parents (kinship care), they may be non-relative licensed foster parents, or the children live in some other arrangement (e.g., a group home).

In most cases, however, the children do not move into the foster care system. Instead, their grandparents, close relatives, or family friends step in and raise the children, often without support, for a period of time and sometimes indefinitely, without the benefits, support, and assistance of the child welfare system.

Accurate data about the prevalence of these families is extremely limited, and most estimates are believed to be an undercount. According to the five-year estimates from the 2019 American Community Survey (ACS), 2,741,869 children were living with grandparents who were responsible for most of their basic needs. More than a third of these children (991,929) lived with grandparents who were responsible for their basic needs and had no parent present in the household (U.S. Census Bureau, 2019). The majority of these families exist outside the foster care system, meaning they do not receive supports and services and/or financial assistance to raise the children.

The ACS prevalence data is likely an undercount reflecting the challenges inherent in developing survey tools that reflect the diversity of these families. For example, the ACS does not collect information about relatives other than grandparents who are caring for children. Similarly, it does not account for close family friends who step in to prevent a child from being placed in foster care, nor does it measure the unknown number of grandparents (or kin) caring for grandchildren over the age of 18 who live with disabilities. For every kinship family and grandfamily counted by the U.S. Census Bureau, there are likely many others who are unrecorded and unsupported. In fact, analysis conducted by Annie E. Casey Foundation's Kids Count Data Center



suggests that 4% of all children in the U.S. (or 2,791,000 children in 2019) lived "in households where a grandparent provides that child's primary care" (Annie E. Casey Foundation, 2019).

"The majority of the systems serving kinship families and grandfamilies were not designed with these families in mind. Outreach efforts often miss the families. Kinship families and grandfamilies often spend down their savings to pay for health care or other services for the children, only to later find out they could have qualified for other assistance."

-Jaia Peterson Lent, Co-chair of the Advisory Council to Support Grandparents Raising Grandchildren

Understanding the actual prevalence of children living with grandparents and other kin is critical because a significant and growing body of research has shown that children both inside and outside of the foster care system have better outcomes when they live with family (Generations United, 2016). However, while today's grandparents and other relatives are an energetic and vital generation, ready and able to protect the children they love, the children often need more support than a kin or grandparent caregiver can provide alone. Many of the children in need of homes have experienced multiple adverse childhood experiences, or ACEs. Some of the children in need of homes have experienced trauma or witnessed traumatic events such as overdoses, domestic violence, and even deaths. Others have experienced maltreatment (Generations United, 2017). A significant number suffered exposure to harmful substances before birth, putting them at risk for lifelong problems including developmental delays, behavioral disorders, and mental health disorders.

According to the CDC, "women and racial/ethnic minority populations are at a greater risk for having experienced four or more types of ACEs" (Centers for Disease Control and Prevention, 2021). For more information on ACEs, refer to the following publications:

- Patterns of adverse childhood experiences and substance use among young adults: A latent class analysis
- The effect of multiple adverse childhood experiences on health: a systematic review and meta-analysis
- Effect of the type and number of adverse childhood experiences and the timing of adverse experiences on clinical outcomes in individuals with bipolar disorder

Research has found that although most children exposed to ACEs are resilient without long lasting effects, cumulative exposure to ACEs can reverberate through a person's life and can be linked with chronic health problems, serious mental illness, and substance use disorders in adulthood (Felitti, et al., 1998). During childhood and





adolescence, children with multiple ACEs may exhibit behaviors consistent with post-traumatic stress disorder (PTSD). These issues require professional interventions, which should include evidence-based care such as trauma-focused cognitive behavioral therapy or other relevant treatments for relevant illness and symptoms to help these children grow and thrive. Sometimes, mental health symptoms follow children into the classroom, requiring specialized education plans, school supports, and occupational therapy. For many kin and grandparent caregivers, the cost of the mental, behavioral, and educational supports their children need are out of reach.

It is not only the children who need support. In order to care for traumatized children, the kin and grandparent caregivers themselves have to set aside tremendous sadness and grief over lost relationships with their adult children and the secondary trauma and emotional challenges that comes with exposure to what the children have experienced.

They require culturally appropriate services and supports grounded in the principles of trauma-informed care to assist them in understanding and appropriately responding to the behaviors of the children, handling the secondary trauma they may experience, and managing their own stress. To access these services, they also need a range of financial and practical assistance. This assistance would help them maintain their health and well-being while navigating the bureaucracy, bias, stigma, shame, legal contests, and an endless stream of unanticipated expenses associated with raising a child, often later in life, while living on a fixed or limited income.

For a detailed discussion of the findings of the RFI, refer to Section IV, Discussion of Challenges and Systemic Gaps Identified in the Request for Information.

While the prevalence of kinship families and grandfamilies is growing in all communities across the nation, communities of color are disproportionately impacted by this issue. Even though Black or African American individuals represent just 13% of the U.S. population, they make up nearly a quarter of all children in households where a grandparent is responsible for the needs of the child. Similarly, American Indian and Alaska Natives make up only 1.3% of the U.S. population, but their representation in households where a grandparent is providing for most of a child's needs is more than double that rate (U.S. Census Bureau, 2019). When kin and grandparent caregivers take on the demanding and important task of raising a child, they need culturally appropriate support, assistance, and public acknowledgement of their tremendous sacrifices.

In developing a slate of recommendations to address these complex issues, the Advisory Council worked to integrate the voices and perspectives of a wide range of stakeholders, especially kin and grandparents. This report includes their voices. To understand the landscape of existing programs to support kin and grandparent caregivers, the Advisory Council worked with the Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council on the development of



an inventory of federal programs and other useful information to support caregivers, including kinship families and grandfamilies. ACL also issued a formal Request for Information (RFI) in December 2019 seeking information on the challenges and unmet needs of kin and grandparent caregivers. The RFI yielded a trove of heartrending stories reflecting the concern kin and grandparent caregivers have for the future well-being of the children and their struggles to navigate complex legal, financial, and medical systems.

Many of these issues are multifaceted and intertwined. This is particularly true for financial and legal issues which—depending upon the situation of the family—often serve as the basis of a dense and complex web of unaddressed issues such as access to food and nutrition, education (including special education), respite care, mental health, substance use disorders, health, and health care. Without appropriate support, these issues lead to increased stress and less time for self-care and respite among already overwhelmed kin and grandparent caregivers. That in turn puts them at risk for poor health outcomes, depression, and caregiver burnout. Preventing these risks is in the interest of everyone as millions of children depend on these caregivers every day.

The information in the RFI analysis and the development of the inventory and best practices resource enabled the Advisory Council to outline remaining critical gaps in the existing systems of services and supports to kinship families and grandfamilies. Those gaps formed the basis on which the Advisory Council developed recommendations for changes to the systems of supports for kinship families and grandfamilies to enhance the well-being of all children and their caregivers. The recommendations also complement and support the recommendations developed by the RAISE Family Caregiving Advisory Council for how the federal government, states, tribes, territories, and communities—in partnership with the private sector—can better "Recognize, Assist, Include, Support, and Engage family caregivers." Those recommendations are outlined in the RAISE Family Caregivers Act Initial Report to Congress.

Both sets of recommendations will inform the development of the National Family Caregiving Strategy, which is being developed by the Advisory Council in collaboration with the RAISE Family Caregiving Advisory Council. When fully developed, the strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers—including kin and grandparent caregivers. It will promote greater adoption of person- and family-centered care in all health care and long-term service and support settings, increase use of evidence-informed tools, information, education, training supports, referral, and care coordination to increase support for caregivers and expand access to respite options. Finally, and this is especially important for kinship families and grandfamilies, it will increase financial security and reduce workplace discrimination faced by caregivers, including kin and grandparents raising grandchildren.



I. Introduction

"My day consist[s] of jumping out of bed starting breakfast, getting kids up and dressed. Kids are then fed, hair and teeth brushed. Jump in the car, drop one at school at 8 and the twins at 9. Hurry home start laundry and wash dishes and pick up. At 1:30 pm return to school to pick up the 5-year-olds. Get home make lunch and do any required school work and more household chores. At 3:30 pick up 7-year-old, fix snacks, do homework, start dinner. A short bit of playtime then dinner and dishes. Then it is bath, and bedtime... By the way I am 70 and a disabled vet, and a widow."

-Response to the RFI

Family is the single most important influence on a child's life. From the first moments, babies depend on parents and family to nurture and protect them. As they grow, children depend on their adult caregivers for their basic needs, and for shaping their development, identity, values, and sense of security. Throughout history and across cultures, grandparents have played an important role in this experience. They are a recognized source of wisdom and unconditional love for children. They nurture family connections and foster cultural identity while providing trusted support to parents and children alike.

In recent years, a significant body of academic research has also proven the wisdom of the ages: grandparents are a force for good. Children with grandparent figures in their lives have better health, education, and behavioral outcomes than children who lack this source of unconditional love (Pulgaron, Marchante, Agosto, Lebron, & Delamater, 2016) (Buchanan & Rotkirch, 2018).

Grandparents across the nation provide vital support for American families, serving as a financial safety net for their adult children and offering practical assistance along the way, such as child care. When unexpected tragedies happen and parents can no longer care for their children, there is no one better suited to step in as primary caregiver than grandparents and those extended family members and close friends who know and love the children.

Collectively known as "kinship families or grandfamilies," families led by grandparents (or other relatives and close friends) are not a new phenomenon. Rooted in historical patterns, custodial "grandparenting" has long been a strength of the African American community (Minkler & Fuller-Thompson, 2005). Black or African American grandmothers in particular have played a critical role in keeping families together despite historically high rates of poverty and in response to the practice of separating families during slavery (Minkler & Fuller-Thompson, 2005). During the great migrations of the early 20th century, many southern grandmothers cared for children while their parents traveled north in search of employment (Minkler & Fuller-Thompson, 2005).



In Native American communities, elders—even those not biologically related to the child—traditionally assist in the raising of children and the passing on of sacred traditions and language. The cultural norms of elders and grandparents are consistently held in high esteem across Tribal Nations (Brave Heart, 2007). Older adults are viewed as cultural transmitters, oral historians, and wisdom keepers (Minkler & Fuller-Thompson, 2005). Although practices and traditions vary by community, these extended connections have helped preserve cultural identity and family bonds for generations (Generations United, 2020e). This is perhaps most clearly described by the poet Raymond Young Bear, who was raised by his grandmother on the Meskwaki Tribal Settlement in Iowa. In his poem, Grandmother, Young Bear describes how, through her devoted care, she passed on to him the knowledge and understanding of his culture and identity "like the light of someone stirring ashes from a sleeping fire at night."

Notable Individuals Raised by Kin and Grandparent Caregivers

- Olympic gymnast Simone Biles
- Actress and comedian Carol Burnett
- Poet Langston Hughes
- Rapper Curtis Jackson
- TV presenter Vanna White

To read a collection of inspiring stories about children raised by kinship families and grandfamilies, refer to <u>Grand</u> <u>Successes: Stories of Lives Well Lived</u>.

American Indian grandparents demonstrate resilience and strength in caring for their grandchildren despite the fact that many also experience resultant trauma from their own lived boarding school experiences. U.S. Bureau of Indian Affairs policy created a military-style boarding school system to "civilize" and assimilate American Indian children from 1891 through the mid-1980s (Archuleta, Child, Lomawaima, & Heard Museum, 2009).

Across American culture, the rearing of children by grandparents and extended family is a longstanding practice; examples abound of individuals raised in kinship families and grandfamilies who have made significant contributions to our society. Oprah Winfrey, Willie Nelson, and Jamie Foxx are just a few notable individuals who were raised by grandparents. Barack Obama, who was raised from age 10 by his grandmother, wrote that she was "the one who put off buying a new car or a new dress for herself so that I could have a better life. She poured everything she had into me."

Children raised by kin and grandparent caregivers have also long been a familiar trope of children's literature. Both Peter Parker (i.e., Spiderman) and Dorothy Gale of the Wizard of Oz were raised by loving aunts; Star Wars' Luke Skywalker was brought up by his step-uncle.

What Causes Kinship Families and Grandfamilies to Form?

In recent years, kinship families and grandfamilies have risen to national attention, due in part to the opioid crisis, which has contributed to a striking growth in the number



of kinship families and grandfamilies, particularly among white Americans (Anderson, 2019). States with higher rates of opioid prescribing also have higher rates of people over age 30 raising grandchildren, according to the U.S. Census Bureau (Anderson, 2019). However, the opioid epidemic is just part of the story.

Kinship families and grandfamilies form in response to a wide range of circumstances including substance use disorders, parental incarceration, economic instability, military deployment, serious mental illness, death, and adverse immigration actions. Because of the events that lead to the formation of kinship families and grandfamilies, many of the children involved are at a high risk of emotional disturbance, juvenile justice involvement, and failure to thrive in school.

The difference between kinship families and grandfamilies of the past and those emerging today is that the number of children in need of loving kinship or grandparent caregivers is greater than ever before and the systems to support families in need do not recognize or understand the unique needs of these families.

For more on how the opioid epidemic has created and challenged kinship families and grandfamilies, refer to Spotlight on the Impact of the Opioid Epidemic.

Prevalence of Kinship Families and Grandfamilies

"While it appears that the data regarding the number of children being raised by grandparents differ by source, there is an overwhelming belief that these numbers are underestimated."

-Response to the RFI

Accurate data about the prevalence of these families is extremely limited, and most estimates are believed to be an undercount. According to the five-year estimates from the 2019 American Community Survey (ACS), **2,741,869** children were living with grandparents who were responsible for most of their basic needs. More than a third of these children (**991,929**) lived with grandparents who were responsible for their basic needs and had no parent present in the household (U.S. Census Bureau, 2019). It is important to note that these figures are most likely an undercount, in part because the available data collection instruments are not designed to reflect and account for the diversity and unique circumstances of kinship families and grandfamilies.

The ACS survey data collected by the Census Bureau is derived from 295,000 addresses each month and provides a robust pool of demographic information. However, based on other surveys and data sources analyzed for this report, the actual number of kinship families and grandfamilies likely exceeds the estimates provided by the ACS. Additionally, the findings of the ACS data may be further limited because it may not include many kinship families and grandfamilies who do not self-identify as



such for a number of reasons including privacy concerns, a perception that the family's situation is temporary, or for cultural reasons.

For every child counted by the census, there are likely many others who are unrecorded and unsupported. For example, analysis of multiple data sources conducted by Annie E. Casey Foundation's Kids Count Data Center has estimated that the percentage of children in the U.S. whose care is provided primarily by grandparents is 4% of the overall child population, or **2,791,000** children in 2019. (Annie E. Casey Foundation, 2019). That figure is nearly three times higher than the ACS figure for grandparents raising children without a parent present.

These figures may also be undercounts because of the challenges involved in tabulating other types of kinship relationships (e.g., aunts, uncles, cousins, siblings, families of choice) that are a part of this population. In addition, they do not include adult children with disabilities whose independence and quality of life are supported by grandparents, kin, or close family friends.

The Advisory Council recognizes that understanding the statistical prevalence of kinship families and grandfamilies is a crucial step in developing systems that support their needs. As a result, the Advisory Council developed a set of three inter-related recommendations to enhance research, data, and the promotion of evidence-supported practices for this population.

Meanwhile, the circumstances under which these families exist have become increasingly challenging. Just as data collection tools are not designed for kinship families and grandfamilies, the child welfare system is not designed to recognize and support their needs. While there is increasing recognition of the importance of providing supports to birth parents to keep children safely with them whenever possible, it is equally imperative to provide kinship families and grandfamilies with the supports and services they need so that all members of the family can thrive, regardless of the circumstances that lead to their formation.

"Inside" and "Outside" the System (...and Why This Matters)

"Because I intervened before CPS [child protective services] became involved, I do not receive the same assistance that grandparent/kinship caregivers receive. I am desperate for help. I receive \$271 for TANF [Temporary Assistance for Needy Families], and \$308 food assistance each month. That is it. I have two chronic and at times, debilitating autoimmune disorders (rheumatoid arthritis and scleroderma) that limits my earning potential greatly, not to mention issues with affordable child care, [it] ... makes me fuming angry and sad at the same time."

-Response to the RFI



Kinship families and grandfamilies live in an enormous range of circumstances. The Advisory Council recognizes there are an infinite range of possible circumstances within the lives of the families across the nation. Nonetheless, for the purposes of the present discussion, this report uses a binary framework that refers to families that exist within the foster care system as "inside" the system and those supporting children "on their own" with no involvement from children welfare systems as "outside" the system. In reality, there can be overlaps between categories due to variations in programs and system administration across states and communities and as families change over time.

Generally, when children cannot remain with their parents, they typically encounter one of two paths. In the minority of cases, they enter the foster care system where they are placed in the legal custody of the state. Their foster care caregivers (i.e., foster parents) may be their own relatives who have been licensed as foster parents (sometimes this is called "kinship care"), they may be foster parents with whom the children do not have a relationship, or the children may live in some other foster care arrangement. On September 30, 2019, a day for which the Administration for Children & Families (ACF) provides a representative statistical snapshot, there were an estimated 423,997 children in foster care. Thirty-two percent of those children lived with relatives serving as licensed foster parents, and 46% lived with nonrelatives. The remaining children lived in institutions, trial homes, group homes, pre-adoptive homes, supervised independent living, or had run away (Children's Bureau, Administration for Children & Families, 2021).

Most children, however, do not enter foster care for a variety of complex reasons which are discussed later in this report. Instead, their grandparents, relatives, or beloved family friends step in (often on short notice) to take responsibility of the child, typically with little preparation or training, financial assistance, or social support.

Sometimes the process for this is an alternative to foster care called "diversion," whereby a case worker will "place" a child with a relative rather than place the child within the custody of the state. Diversion may include voluntary placements, private custody or guardianship in a private third party proceeding, where they either have consent of the parents or must prove unfitness or abandonment. For these kin, legal representation is practically nonexistent (Wallace & Lee, 2013). After the child is placed with his or her relatives, the state has little to no involvement, and the family receives no monthly subsidy payment and no assistance with accessing other financial supports or child welfare and health services (Malm, Sepulveda, & Abbott, 2019). This practice varies considerably by state and jurisdiction, which makes prevalence difficult to determine. Some analysts suggest that "100,000 to 300,000 children are diverted from foster care to live with relatives each year" (Malm, Sepulveda, & Abbott, 2019).

In other instances, a grandparent may notice that his or her adult child is not able to provide adequate care for the grandchild for some reason. In response, they step in



to provide care. This can happen when a parent is incarcerated or dies. It can also happen when a parent neglects a child due to addiction or lacks the financial means to raise a child.

In either of the above cases—diversion practices on the part of case workers or kin and grandparent caregivers stepping in proactively—taking responsibility for a child can happen at a few hours' notice or slowly over time. It can last for months, years, or indefinitely depending on the circumstances of the family and the needs of the child. These children, living outside the foster care system, make up the vast majority of children in kinship families and grandfamilies today.

A 2020 report released by the Government Accountability Office (GAO) using a combination of American Community Survey data from 2018 and data from HHS's Adoption and Foster Care Analysis and Reporting System found that of an estimated 2,733,000 children in 2018 who were living with kin and grandparent caregivers, only 139,000 were in foster care with a kin or grandparent caregiver². The rest of the children living with kin and grandparent caregivers, (94% or 2,594,000 children) were living outside the foster care system. There are very few formal supports and services in place to assist these families, nor is there public recognition of the tremendous challenges they face and the sacrifice caregivers are making to assist, love, and protect the children.

This lack of recognition and support is important to this discussion because a significant and growing body of research has shown that children do better when they live with family. Caregivers are stepping up to become primary caregivers to children, often on short notice, and this generosity places their financial, physical, and emotional well-being at risk.

Why Kinship Families and Grandfamilies Need Recognition and Support

"I am a single, 49-year-old divorced grandmother raising my grands, ages 5 and 7, with zero parental support. I am ... suffering alone, in silence, and I am but one of many others, with situations nearly mirroring mine."

-Response to the RFI

While kin and grandparent caregivers hail from every corner of the nation and represent all demographics, they are more likely than other families to live in poverty. Forty-three percent of the children who lived with a "grandmother-only" in 2012 lived in poverty; these children are disproportionately Black or African American (U.S. Census Bureau, 2019). In fact, according to the American Community Survey, ethnically and culturally diverse populations are disproportionately represented in kinship families and grandfamilies. While Black or African American individuals represent just 13% of the U.S. population, they make up nearly a quarter of all children in households where a





grandparent is responsible for the needs of the child. Similarly, American Indian and Alaska Natives make up only 1.3% of the U.S. population, but their representation in grandparent-led households where the grandparent is providing for most of their needs, is more than double that rate (U.S. Census Bureau, 2019).

The available data on grandparents responsible for grandchildren suggests that underserved racial and ethnic populations are disproportionately taking responsibility for grandchildren. While the opioid epidemic has illuminated the experiences of white families raising grandchildren, this population is less likely to be represented in kinship families and grandfamilies. Table 1 shows a side-by-side comparison of overall population estimates for 2019 using the five-year population estimates of the children being raised by grandparents. As previously noted, ACS data presents, at best, an incomplete picture because it only includes "grandparents" who are responsible for most of the needs of their own grandchildren and does not include other relationships or adult children with disabilities.

Table 1. Side-by-side comparison of estimated racial and ethnic representation in grandparent-led households according to 2019 American Community Survey 5-year estimates.

Race/ethnicity	2019 U.S. Census Bureau Estimates of Self-Identified Racial Categories ³	2019 Estimates of Racial and Ethnic Representation Among Children in the Care of Grandparents ⁴	2019 Estimates of Racial and Ethnic Representation Among Grandparent Heads of Household Also Mostly Responsible for Grandchildren ⁵
Non-Hispanic White	60.3%	41.4%	53.1%
Hispanic and Latino (of any race)	18.5%	24.0%	19.6%
Black or African American	13.4%	24.8%	20.2%
Asian	5.9%	1.6%	3.5%
Two or more races	2.8%	8.3%	2.1%
Native Americans and Alaska Natives	1.3%	2.7%	2.2%
Native Hawaiians and Other Pacific Islanders	0.2%	0.3%	0.3%

Caregivers in kinship families and grandfamilies are also more likely to live with disabilities than the general population. According to ACS data, about a quarter of the heads of household in families led by a grandparent live with a disability (U.S. Census Bureau, 2019).



Adverse Childhood Experiences

"My son was murdered in 2010, and with the children in my care we all were completely devastated. When they came back to school, people who knew about the situation were sympathetic but did not know how to comfort the kids. There was no specialized staff member who knew how to approach children of homicide."

-Response to the RFI

A subset of the children in kinship families and grandfamilies need more support than a kin or grandparent caregiver alone can provide. This is often due to exposure to **adverse childhood experiences**, or ACEs, during the events that led to the formation of the new family. Research has found exposure to ACEs can reverberate over the lifespan. It is linked with chronic health problems, serious mental illness, and substance use disorders in adulthood. Some of the children in need of homes have experienced trauma or witnessed traumatic events such as overdoses, domestic violence, and death. Others have experienced abuse and neglect. A significant number suffered exposure to harmful substances before birth, putting them at risk for lifelong problems including developmental delays, behavioral disorders, and mental health disorders.

As a result of their exposure to ACEs, some children may experience symptoms of post-traumatic stress disorder or other mental illnesses. Respondents to the RFI noted behaviors in the children in their care that could be signs the child has been exposed to trauma. Examples noted by RFI respondents include attachment disorders, food hoarding, separation anxiety, difficulty sleeping, and self-harm. These issues require professional interventions, including extensive clinical and educational supports to help these children grow and thrive. Often these issues follow them into the classroom, requiring specialized education plans, school supports, and occupational therapy. For many kin and grandparent caregivers the cost of the mental, behavioral, and educational supports their children need are out of reach.

Even though becoming a licensed foster parent comes with financial assistance, many kinship families or grandfamilies do not choose this option for a variety of reasons. Some prefer not to give custody of the child to the state. Others are not given the option or are discouraged from becoming licensed foster parents. For example, caseworkers may emphasize that becoming a licensed foster parent is an extensive process without giving balanced information about the financial support that comes with licensure. Licensed foster parents have to comply with requirements such as background checks, mandatory visits with birth parents, personal assessments, and home safety inspections. Other families who step in before the child welfare system becomes involved lack information about how to become licensed foster parents.

The small percentage of families that are part of the foster care system receive some benefits. Those who are not fully licensed do not receive the same foster



care maintenance payment as licensed families. The benefits families receive vary considerably by state. Generally, they can include modest reimbursement subsidies for the child's daily needs, clothing allotments, transportation allotments, Medicaid insurance, and tax credits, in addition to support from case workers and access to educational and supportive services.

However, the majority of kinship families and grandfamilies do not have access to these supports and services. And while a legal relationship to the child is not required to access public benefits, affordable housing, or claim tax credits for the child, the lack of such a relationship can pose barriers and there are few available sources of trusted information.

On top of this, rearing a second family — often with no time for advance planning — is challenging in today's environment. Regardless of whether they are inside or outside the system, kin and grandparent caregivers over all ages are more likely to experience "negative changes in health behavior, depression, and self-rated health" (Hughes, Waite, LaPierre, & Luo, 2007).

A lack of awareness and inclusion across the broader society, in turn, makes it difficult for caregivers of children outside of foster care to complete straightforward but critical tasks such as registering the child for school and accessing medical records. The children often miss out on essential services and supports — like health care, dental care, counseling, nutrition assistance, and even educational programs. Public awareness is limited; when it comes to the few supports currently available, for example, Kinship navigator programs or support groups, kinship families and grandfamilies are often misunderstood and experience stigma.

To address these complex and interconnected issues, Congress authorized the <u>Supporting Grandparents Raising Grandchildren Act</u> (Public Law 115-196). One of the key charges of the SGRG Act is to convene an advisory council to develop recommendations to provide the nation's kin and grandparent caregivers "better coordination and dissemination of information and resources available to support them in their caregiving responsibilities."

This initial report to Congress by the Advisory Council includes 22 recommendations for changes to the formal and informal systems of supports for kinship families and grandfamilies to enhance the well-being of all children and their caregivers. In addition, it:

- Shows the unique strengths of kinship families and grandfamilies, and the challenges they face.
- Documents kin and grandparent caregivers' unmet needs, including those identified in a formal RFI issued by ACL in December 2019.



- Outlines critical gaps in the existing systems of services and supports to of kinship families and grandfamilies.
- Describes current best practices, federal and non-federal resources, and other useful information for grandparents and other older relatives raising grandchildren.

Refer to <u>Section II. Passage of the Supporting Grandparents Raising Grandchildren Act</u> for more information on the efforts of the Advisory Council and the outcomes of their work.

Toward a National Family Caregiving Strategy

"Kinship caregivers become overwhelmed without support. Most kinship families are fearful of the system and will not ask for help. This leads to the potential for placement disruptions and entry into the foster care system.

This can be traumatic for all involved."

-Gail Engel, grandparent and member of the Advisory Council to Support Grandparents Raising Grandchildren

Kinship families and grandfamilies are a specific type of family caregivers. In recent years, thanks to the efforts of a broad constituency of advocates and families, there is increasing awareness of the need to better recognize and support family caregivers. The RAISE Family Caregivers Act, which became law in January 2018, directs the Secretary of Health and Human Services to develop a National Family Caregiving Strategy. The strategy will set a course for the implementation of consistent actions that federal, state, local, and tribal governments, health care providers, and long-term services and supports providers will take to ensure the needs of caregivers, including kin and grandparent caregivers, are addressed in a holistic and coordinated manner.

The first steps of developing such a strategy involve understanding and documenting the existing federal supports in place to assist these families and identifying gaps and areas of duplicated effort. Federal members of both the Advisory Council and the RAISE Family Caregiving Advisory Council, developed an inventory of federally funded programs, including those that address the needs of kin and grandparent caregivers. This inventory, along with the work of both councils will allow policy makers to analyze and assess the landscape of available programs to better ensure efficient distribution of resources and prevent program duplication, a key component of the strategy.

For more information on ACL's implementation of the requirements of the RAISE Act and the forthcoming development of the National Family Caregiving Strategy, visit the RAISE Family Caregiving Advisory Council webpage.



Spotlight on the Impact of the Opioid Epidemic

Substance use disorders can be a challenge for any family, but for kinship families and grandfamilies, it may have a compounding effect. Substance use disorders, including alcohol, opioids, and other drug misuse, can be a causative factor for kinship families and grandfamilies. The presence of substance use disorders in the lives of these families creates additional challenges both for the adults and for the children who were potentially exposed to harmful chemicals in utero or experienced trauma related to substance use.

"It's hard watching my child go through her addictions. It's even harder watching my granddaughters being split apart and their lives flipped upside down because of the lack of empathy for kids in their situation."

-Response to the RFI

According to the CDC, more than 750,000 Americans have lost their lives from overdoses since 1999. The overdose crisis is evolving, and rates of overdose have increased exponentially since at least 1980, driven by distinct waves involving different drugs (and drug classes) at different times (Jalal, et al., 2018). Since 2013, overdose deaths have been driven mainly by opioids—first by prescription opioids, then by illicit heroin, and more recently by illicitly manufactured fentanyl and fentanyl analogs. In 2020, of the reported 94,134 overdose deaths in the U.S., 70,456 involved opioids. Provisional data indicates that the COVID-19 pandemic has only exacerbated the overdose crisis (Centers for Disease Control and Prevention, 2020).

Ripple Effect

"When my son was in treatment, there was not services to assist with the kids left behind and for myself. They just focus on the parent, and their classes. After they attend their classes and support meetings, they are released, and the kids go back. The kids are still traumatized by their parents' behavior and if there is a relapse, the whole circus starts up again. Then the grandparent has to pick up again and start the whole process over."

-Response to the RFI

While opioids are not the sole cause of these increases, their impact on kinship families and grandfamilies cannot be understated. According to the Altarum Institute, "the ripple effects of the opioid crisis are rapidly accumulating, resulting in—among other consequences—a dramatic uptick in the number of children being removed from the custody of their parents" (Stanik, 2018). Between 2012 and 2016, the nation saw a 10% increase in the number of children entering foster care. In some states, such as Minnesota, the increase was as much as 50%. Across the nation, states are required



to place children with relatives if possible. This has increased the number of kin and grandparent caregivers, many of whom receive little to no support or assistance. While the media covers stories about the causes of kinship families and grandfamilies, little attention is given to the myriad ways these new families struggle to stay afloat in the wake of such tragedies.

Recommendations for Better Supporting Families Affected by Substance Use Disorders

A 2018 update of the Generations United report <u>Raising the Children of the Opioid Epidemic: Solutions and Support for Grandfamilies</u> proposed a number of recommendations to support kinship families and grandfamilies in light of the opioid epidemic. These include:

- Encouraging states to offer a continuum of tailored services and supports for children, parents, and caregivers through the <u>Family First Prevention Services Act</u>.
- Ensuring a family-first approach, placing children with kin first whenever possible.
- Ensuring kinship families and grandfamilies affected by the opioid epidemic receive the support they need.
- Promoting the support of kinship families and grandfamilies through existing programs.
- Expanding legal options for kinship families and grandfamilies.
- Promoting best practices to support the needs of kinship families and grandfamilies.

"My daughter is an addict, started after the birth of her son that I am now raising. Her addiction started with pain pills, then to Suboxone, then alcohol, to cocaine and meth, and prostitution that led to rapes and trafficking, etc.

Her children, my grands, have been with me full time for a little over 2 years because of her addiction."

-Response to the RFI

Strengths and Benefits of Kinship Families and Grandfamilies

Despite the many challenges outlined above, decades of research have confirmed that kinship families and grandfamilies are a force for good in the lives of children who cannot remain with their parents. Researchers have documented increases in child safety, stability, permanence, and well-being among children raised by kin and grandparent caregivers (Annie E. Casey Foundation, 2012).



Children Thrive in Kinship Families and Grandfamilies

Children in foster care with relatives have more stable and safe childhoods compared to children in foster care with non-relatives (Generations United, 2016). They experience fewer school changes and behavioral and mental health problems. More importantly, because they are living with relatives, they also have a greater likelihood of remaining in the home as they transition to young adulthood, which prevents them from joining the ranks of the 23,000 children who "age out" of the foster care system each year (Generations United, 2016). Aging out of foster care is associated with homelessness among young adults, higher rates of unemployment, and an increased likelihood of becoming pregnant before age 21 (National Foster Youth Institute, 2017). Moreover, many families report that when children remain with their siblings and within their extended families, they experience a sense of identity and belonging that is frequently lost when a child is placed with non-relatives who cannot pass along cultural identity in the form of family memories, photographs, stories, food, music, and traditions.

Research finds that children in the care of kin and grandparent caregivers are less likely to try to run away than those in the care of non-relatives or residing in group homes; they are more likely to like the people they live with and more likely to report that they "always felt loved" (Generations United, 2016). This is important because the need for the affection and love that kin and grandparent caregivers bring cannot be understated. The children in kinship families and grandfamilies have experienced trauma, abuse, and/or neglect. Many of the respondents to ACL's RFI shared that the children in their care had learning disabilities, behavioral issues, depression, and severe anxiety because of their parents' actions. According to Generations United, "more than half of children involved with the child welfare system have experienced at least four ACEs, leaving them 12 times more likely to have negative health outcomes than the general child population" (Generations United, 2017). Even the experience of removal from the parental home, regardless of how unsafe it may have been, is traumatic for a child.

The love and care that kin and grandparent caregivers provide mitigates the stress of these childhood experiences. It helps children learn to cope with stress, develop a healthy stress response, and build resiliency. The unconditional love of a "parental figure" in the face of negative childhood experiences has been shown to have a protective effect on these children, building resiliency and helping them heal from the trauma that they may have experienced (Carroll, et al., 2013).

"Raising a child at 69 as a single parent is daunting. But I love him."

-Response to the RFI



Other Tangible and Intangible Benefits

Children are not the only people who benefit from kinship families and grandfamilies. Despite the challenges, the adults in these families experience immense satisfaction, pride, and meaning due to their efforts. The RFI yielded dozens of testimonials about the benefits and rewards of taking on full responsibility for raising a grandchild. These include joy, an increased sense of purpose, the opportunity to nurture family relationships, and the satisfaction of knowing they are keeping the child safe from harm. Taxpayers also benefit from the efforts of kin and grandparent caregivers. By stepping forward to raise children who would otherwise be placed in the custody of the state, kin and grandparent caregivers keep children safely with family and save taxpayers more than \$4 billion each year (Generations United, 2020f).

The contributions of kin and grandparent caregivers come at significant personal and financial cost. Kinship families and grandfamilies bring a tremendous amount of love and care to the raising of children. But love alone is not enough. Given the sacrifices kin and grandparent caregivers make and the undeniable needs of the children in their care, these families deserve recognition, support, and assistance to do what families do best: raise healthy children.



II. Passage of the Supporting Grandparents Raising Grandchildren Act

To heighten visibility and address the need for better support, information, and services to assist kinship families and grandfamilies, Congress passed the **Supporting Grandparents Raising Grandchildren (SGRG)** Act (Public Law 115-196) in 2018. The SGRG Act, signed into law in July 2018, authorized the establishment of a council made up of grandparents who are raising grandchildren and representatives from federal agencies. Congress charged the Advisory Council with supporting kinship families and grandfamilies through the **identification and promotion of information**, best practices, resources, and recommendations to ensure these caregivers meet the needs of the children in their care while at the same time are able to maintain their own physical and mental health, and emotional well-being. This vision includes all kinship families and grandfamilies, regardless of their relationship to the child and whether they are providing care inside or outside the foster care system. Because of the important role grandparents and elders play in Native communities, the SGRG Act also called for the Advisory Council specifically to consider the needs of members of Native American tribes.

Advisory Council to Support Grandparents Raising Grandchildren

"Serving on this committee is a fabulous experience. Watching as big and small goals are achieved makes all the work even more meaningful! The efforts of the dynamic and diverse personalities of this committee is proof of how things can work for the common good when politics and individual prejudices are set aside."

–Bette Hoxie, member of the Advisory Council to Support Grandparents Raising Grandchildren

As a first step to implementing the requirements of the SGRG Act, ACL published a call for nominations of non-federal members in the Federal Register on October 12, 2018. While the SGRG Act only called for two grandparent/older relatives and federal officials, ACL chose to broaden the membership of the Advisory Council to reflect the diversity and complexity of the needs of kinship families and grandfamilies. ACL received 74 nominations of highly qualified individuals from diverse backgrounds, including academia, the justice system, and human services. Staff from across ACL reviewed the nominations and recommended 18 nominees based on personal and professional experience with kin and grandparent caregiving and geographical distribution.

The Advisory Council selectees represented a cross-section of advocacy and child welfare groups, academic institutions, and governmental programs. Eight members have experience in advocacy, direct service, academia, and research. In addition, many members of the Advisory Council, including some of the professional advocates and federal representatives, are themselves caregivers who have a nuanced





understanding of the unique rewards and challenges of raising a grandchild in the current environment. Representatives of federal agencies with programs and initiatives that support kinship caregivers joined these non-federal members to form the full Advisory Council.

Advisory Council Deliberations

In August 2019, the Advisory Council met in person in Washington, D.C. and each non-federal member was administered the oath of office (5 U.S.C § 3331) to serve as a Special Government Employee. Since that inaugural meeting, Advisory Council members have pursued their work with a high degree of purpose. Following the COVID-19 outbreak, Advisory Council members were faced with the challenge of finding a safe way to continue to work, recognizing that some of the Advisory Council members were themselves older adults at greater risk of contracting the virus. To this end, members met virtually from March 2020 onward, adapting to this new way of conducting business to continue to focus on supporting kinship families and grandfamilies.

Mission of the Advisory Council

During the April 2020 full Advisory Council meeting, 150 members of the public joined the online platform to listen to the meeting and contribute via a public chat. During the meeting, the Advisory Council discussed the terminology it would use to describe. consistently and inclusively, the families raising children. The Advisory Council also solidified their vision statement and adopted a set of guiding principles that will shape their work to improve our nation's response to the needs of grandparents and older relative caregivers.

Former ACL Administrator and Assistant Secretary for Aging Lance Robertson, who also served as Advisory Council chair until January 2021, proposed a mission statement for the Advisory Council, which included text derived from the statute. Council members unanimously agreed to adopt the mission statement as follows:

"The mission of the Advisory Council to Support Grandparents Raising Grandchildren (SGRG) is to identify, promote, coordinate, and disseminate information, resources, and best practices to help grandparents and older relative caregivers of children meet the health, educational, nutritional, and other needs of the children in their care, while maintaining their own physical, mental, and emotional well-being. As part of this mission, all recommendations will consider the needs of members of Native American tribes and families affected by the opioid crisis."



Vision Statement and Guiding Principles

During the same meeting, the Advisory Council drafted a vision statement and adopted a set of guiding principles that informed the recommendations that follow in this report:

"The Advisory Council to Support Grandparents Raising Grandchildren will be a leader for identifying and sharing resources to support, educate, empower, and advocate for kinship families and grandfamilies. The council will increase awareness and understanding of the needs of these families to ensure they are treated with respect and dignity. By honoring cultures, values, and diversities, we will create a better future so that families can flourish."

The Advisory Council also collectively drafted, edited, and adopted a set of principles that have guided their work and the recommendations in this report. The agreed-upon guiding principles of the Advisory Council include the following five statements:

- 1. "We recognize and define kinship families and grandfamilies as families in which children reside with and are being raised by grandparents, or other extended family members, and adults with whom they have a close family-like relationship."
- 2. "Activities will promote greater adoption of person- and family-centered supports that place kinship families and grandfamilies at the center of every support system, while also acknowledging the challenge of possible conflicting goals."
- 3. "Efforts will aim to empower kinship families and grandfamilies to advocate for themselves to meet the needs of the child and family members. With improved access to resources, they may engage and contribute meaningfully in their communities."
- 4. "Recommendations should recognize and support kinship families and grandfamilies in a fair and impartial manner considering the physical, cultural, emotional, and financial impacts."
- 5. "The National Family Caregiving Strategy will include and amplify the voices of kinship families and grandfamilies."



III. Understanding the Unique Needs of Kinship Families and Grandfamilies

Kinship families and grandfamilies face all the same challenges that families across the nation face when raising children—but their needs are often amplified because there are few resources and structural supports in place to assist them, and many do not have a legal relationship to the children, causing barriers to accessing supports and services on their behalf. Many are retired or receive disability benefits and therefore have limited income to support themselves and their loved ones. Seldom are they financially prepared to raise children in their later years. Others are still working and trying to juggle the reality of suddenly caring for children while balancing their own needs. Meanwhile, regardless of their financial situation to start with, their expenses are significant. They need safe and adequate space to live, nutritious meals, clothing for school and play—in addition to health care, mental health support, tutoring, toys, transportation, phones, internet access for schoolwork, and timely access to information about health and safety. They also need to take care of their own health and wellness needs—that means taking a meaningful break, making time to socialize with friends, and having the flexibility to attend a medical appointment or access senior services without a child in tow. Some senior housing developments also prohibit children. Navigating the responsibility of raising traumatized children—while juggling all these requirements—is more than a full-time job. These needs have only intensified in the COVID-19 era. Understanding these unmet needs is a critical first step to supporting the children in these families.

Overview of the Existing Literature

In recent years, a body of research and analysis has emerged, extensively documenting the needs and challenges of kinship families and grandfamilies. This body of research mirrors the findings of the RFI, notably that kinship families and grandfamilies are disproportionately impacted by the opioid epidemic, child abuse and neglect, domestic violence, parental incarceration, financial instability, and serious mental illness; that the number of children in the care of grandparents and other relatives is likely much larger than official numbers suggest; and that these families, as a consequence, struggle to meet the basic needs of both the children and adults involved.

What follows is an overview of important studies and analysis of the causes and needs of kinship families and grandfamilies. It is not intended as a full literature review, but rather a framework of the major themes noted by researchers.

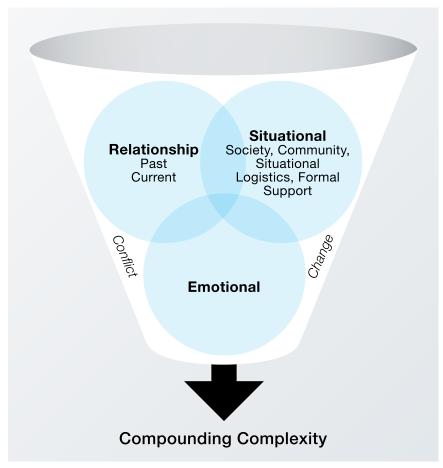
In 2020, researchers at George Mason University developed a framework for describing the unique experiences of members of grandfamilies using a family systems approach. The resulting paper, <u>Compounding Complexity: Examining Multiple Factors Leading to Challenges within Grandfamilies</u>, explains that grandfamilies





face a combination of three types of complexity: relationship complexity, situational complexity, and emotional complexity (Tompkins & Vander Linden, 2020).

Figure 3. How conflict and change contribute to compounding complexity for kinship families and grandfamilies (Tompkins & Vander Linden, 2020).



These three categories of complexity all occur amidst conflict and change. Conflict often arises from power dynamics between custodial grandparents and biological parents. Change also has a significant impact on these families and contributes to the complexity of their experiences.

In their interviews,
Tompkins and colleagues
uncovered complex
challenges in these
families. One case
demonstrates all
aspects of the Theory
of Compounding
Complexity:

"A grandfather, caring for his grandson, was

holding onto emotions of guilt, regret and remorse for not being able to prevent the illegal behavior of his daughter and feelings of resentment and disapproval toward his daughter for making bad choices and not putting her child first. The daughter expected her father to lessen the complexity of the situation by taking care of her child but still allowing her to parent from jail and pick up where she left off when she returned from prison (conflict). The grandson was fearful of living within the neighborhood that his mother lived in once she got out of prison (change). Thus, each family member had emotional responses to the situation and to the relationships involved which compounded the complexity of the situation."

The Compounding Complexity theory provides an explanatory framework to show that the challenges faced by kinship families and grandfamilies are more than the sum of their parts. When conflict and change are combined with situational, relationship,



and emotional complexity, the resulting stress is not merely additive, it compounds, suggesting that interventions to support these families must go beyond addressing the surface problem (for example, child care), but also take into consideration the lived experience of adults and children who are part of kinship families and grandfamilies and the recognition that they are a unique kind of family that require interventions flexible enough to address their circumstances.

Over time, each of those considerations affects other areas of the lives of kinship families and grandfamilies, creating a complex web that caregivers have to navigate just to ensure they and the children in their care have medical care, child care, safe housing, healthy food, and educational supports. Meanwhile, the caregivers need to find time for a meaningful and restful break. At the same time that these situational complexities are growing, the emotional complexities compound as kin and grandparent caregivers struggle to address their own stress amid mounting fatigue, and in an environment where mental health and educational resources are scarce. Add to this the sadness and grief many grandparents feel, not to mention the social stigma they experience, and it is no surprise that kin and grandparent caregivers experience higher levels of stress and illness than people in the general population.

Grandparents Raising Grandchildren: A Synthetic Review and Theoretical Model for Interventions, published in 2016 in the journal Family and Community Health, examined the causes and effects of custodial grandparenting through the use of a "stress-coping framework." It lists issues such as caregiver substance use, child abuse and neglect, intimate partner violence, and parental incarceration as contributing to already poor financial and health conditions, and so, the need for grandparents to step into the role of primary caregivers for their grandchildren (Choi, Sprang, & Eslinger, 2016). Overall, the review finds that the major causes (i.e., stressors) leading to custodial grandparenting are dysfunctional adult children as parents.

Evidence from available research has shown that while kinship care placements with grandparents is very popular and commonly preferred to foster care, these arrangements lack adequate psychosocial support and financial assistance from child protection agencies to properly address the well-being of these caregivers and the children they care for, compared to other out of home placements. The research found that the real impact of this disparity on the health and well-being of the children in these households, the caregivers, and the larger community remains undocumented (Choi, Sprang, & Eslinger, 2016).

The review identified the need to formulate formal, concrete financial services and recommended that attention should be given to the needs of culturally and ethnically diverse caregivers. While acknowledging the caregiving needs and experiences of grandmothers for the greater good of their grandchildren, this research also includes the needs and experiences of custodial grandfathers, who like grandmothers, also play





an important role in the caregiving of their grandchildren but have received very little or no recognition in the past body of literature on grandparenting and face a different set of caregiving challenges and service needs compared to grandmothers. Some of the important findings from the review include emotional, behavioral, and academic difficulties children in grandfamilies experience due to exposure to substance use, maltreatment, parenting instability, neglect, and loss, before placement with a grandparent. Also discussed are the *shifts* in the grandparent/grandchild relationship once grandparents become the primary caregiver. The review posits that this type of shift can lead to changes in relationships, finances, and physical and emotional health (Choi, Sprang, & Eslinger, 2016).

The GAO report <u>TANF</u> and <u>Child Welfare Programs – Increased Data Sharing Could Improve Access to Benefits and Services</u>, published in 2011, remains a valuable overview of one of the most often noted challenges experienced by kinship families and grandfamilies: lack of access to available financial support and services (U.S. Government Accountability Office, 2011). According to the report, "GAO was asked to examine the (1) trends and composition of the child-only caseload, (2) characteristics of caregivers and children in nonparent child-only cases, (3) factors influencing the level of benefits and services for children with non-parent caregivers, and (4) coordination efforts between state TANF and child welfare programs" (U.S. Government Accountability Office, 2011). The report found that while programs do exist to provide support to families, many kin and grandparent caregivers are not aware of these programs. The GAO report noted that increased "coordination among programs that provide financial assistance and support to these families is one way to ensure that caregivers are aware of available resources" (U.S. Government Accountability Office, 2011).

In a more recent GAO report, <u>Child Welfare and Aging Programs – HHS Could Enhance Support for Grandparents and Other Relative Caregivers</u>, released in 2020, the authors further explored the challenges faced by families when older relatives become caregivers of children. The report recommends sharing information and best practices with states about federal programs serving kin. It found that data sharing could enhance the delivery of services for older kin and grandparent caregivers under Title III of the Older Americans Act (OAA), which is administered by ACL, and Title IV-E of the Social Security Act, which is administered by ACF (U.S. Government Accountability Office, 2020).

The 2015 article, Challenges and Resilience in African American Grandparents Raising Grandchildren: A Review of the Literature with Practice Implications, reviews the literature on "caregiving challenges and resilience in African American grandparent caregivers within a socio-cultural context" (Tang, Jang, & Carr Copeland, 2015). Researchers estimate that African American grandparents are over three times more likely to raise their grandchildren, and as a result, make up a large proportion of kin



and grandparent caregivers. It explained that caregiving is stressful and has many negative personal, interpersonal, and economic consequences. Overall, grandparents experience a high level of financial risk, poor physical health, social isolation, role overload confusion, stress, and other related issues. Generally, financial constraints, health concerns, legal issues involving custody, and the ability to provide for their grandchildren are noted as the most stressful issues for many grandparents. It is also noted that incidents of depression, diabetes, hypertension, and insomnia are high among grandparent caregivers (Tang, Jang, & Carr Copeland, 2015).

Generations United has developed a number of reports and resources that have vastly expanded understanding of the needs of kinship families and grandfamilies. In <u>Love</u> <u>without Borders: Grandfamilies and Immigration</u>, Generations United outlines the challenges faced by families affected by immigration actions. The report shows that 1 in 5 children in kinship families and grandfamilies is raised in an immigrant grandfamily and that detainment and deportation are a factor in the creation of kinship families and grandfamilies (Generations United, 2018a). The report explains that children experience higher levels of trauma from living in dangerous and violent environments in their countries of origin, or due to their long and sometimes treacherous journeys to the U.S. In these types of situations, when children are separated from their parents, being cared for by a loving relative can act as a buffer from the effects of stress and trauma the children have endured. The report noted that between 2003 and 2013, the U.S. deported more than 3.7 million immigrants and 20% to 25% of these deportees were parents to U.S. citizen children (Generations United, 2018a).

The Generations United toolkit African American Grandfamilies: Helping Children Thrive Through Connection to Family and Culture details the rich history of kinship families and grandfamilies in African American culture and its implications for policy development. Among the benefits of kinship families and grandfamilies for African American families are improved well-being, preserved cultural identity, and a reduction in the disproportionate number of African American children entering the foster care system. The toolkit notes that despite the well-documented benefits described above, children and caregivers in kinship families and grandfamilies do not have access to the types and levels of support and services that are available to their counterparts in the foster care system. The toolkit notes that "while there is a tradition of African American kinship care, factors such as parental substance abuse and disproportionate incarceration have changed the landscape and needs of these caregivers and children. Given the substantial, expanded, and disproportionate number of African American grandfamilies, understanding how individuals and systems need to provide appropriate and effective services within the current environment is essential" (Generations United, 2020b).

A parallel toolkit, also developed by Generations United in partnership with the National Indian Child Welfare Association, <u>American Indian and Alaska Native</u>





Grandfamilies: Helping Children Thrive Through
Connection to Family and Cultural Identity notes similar
patterns exist for another ethnic group (Generations
United, 2020c). Available studies on the best ways to
help children thrive when they can no longer remain with
their parents have shown that they do best when raised
by relatives. This is especially true for American Indian
and Alaska Native (AI/AN) children because each of the
tribes is distinct in kinship structures, and cultural norms
have traditionally engaged the extended family on issues
of child rearing (Generations United, 2020c).

For more information on the unique needs of Native elders raising grandchildren, including case studies, refer to Section IV: Supporting Caregivers in Indian Country: Lessons from the ACL Title VI Programs.

In the 2017 update to its *State of Grandfamilies* report, titled <u>In Loving Arms: The Protective Role of Grandparents and Other Relatives in Raising Children Exposed to Trauma</u>, Generations United reported that over 51% of children in the child welfare system have had at least four ACEs, leaving them 12 times more likely to have negative health outcomes than children in the general population (Generations United, 2017). The report calls for reform of federal child welfare financing to support kinship navigator programs and increase use of "tailored, trauma-informed services and supports for children, birth parents, and caregivers to prevent children from entering or re-entering foster care." The report notes that children in the foster care system are five times more likely to suffer from anxiety, depression and/or behavior problems than children who are not in the system. However, children in foster care with relatives have more stability, better mental and behavioral health and are more likely to report always feeling loved (Generations United, 2017).

The ACL Request for Information about Kinship Families and Grandfamilies

"I'm sure I'm speaking for so many people out there who have worked all their lives, paid their taxes, and have done the right thing in order to be able to retire and enjoy life. ... but now we can't even do that because we can barely afford to buy food, clothing, and pay for shelter due to taking in our grandchildren and not receiving any extra help."

-Response to the RFI

While the sources above provide a basis of understanding, the Advisory Council also wanted to hear directly from kinship families and grandfamilies and the professionals who support them. ACL issued an RFI on December 7, 2019 via the ACL website and the Federal Register. The RFI invited respondents to provide information on the following overlapping areas:



- Information, resources, programs and/or best practices to help kin and grandparent caregivers meet the diverse needs of the children in their care.
- Information, resources, programs and/or best practices to help kin and grandparent caregivers maintain their own physical and mental health, and emotional and financial well-being.
- Information on gaps and unmet needs that kin and grandparent caregivers experience, especially when it comes to services and supports that could alleviate some of the challenges they face.
- Recommendations on how the nation can best support kin and grandparent caregivers, including any applicable legislative changes that respondents believe could make a meaningful difference in the lives of these families.

The RFI closed in February 2020 before the COVID-19 pandemic; therefore, responses did not touch upon the significant impact the public health emergency has had on kinship families and grandfamilies. Nonetheless, the 1,908 unique comments submitted by over 300 respondents provided a trove of first-person narratives describing in detail the reality of caregiving for children in the present moment.

Grandparent "Focus Group"

To further explore and understand the findings of the RFI, Community Catalyst, a Massachusetts-based organization contracted by the National Academy for State Health Policy and funded by The John A. Hartford Foundation, conducted an online focus group in September 2020 with more than a dozen kin and grandparent caregivers. The session was part of a larger series of caregiving-related focus groups to support the RAISE Family Caregiving Advisory Council in its future development of the National Family Caregiving Strategy. The focus groups were led by Pamela Nadash, Ph.D., a professor at the University of Massachusetts.

This "grandparent focus group" took place virtually on September 24, 2020, during the COVID-19 pandemic. Dr. Nadash kicked off the discussion by asking participants to identify a "silver lining" of the closures associated with the pandemic. Every participant described the challenges associated with school closures, reduced access to supports and services such as nutrition and special education, not to mention the risk of infection. This latter concern was especially pressing given that some of the participants were at greater risk of complications of the virus due to age or preexisting conditions. Despite these hurdles, each participant was able to also identify at least one positive outcome of the pandemic. One participant noted that the way children are raised today (as opposed to when she was raising her own biological children) feels "frenzied." She said that during the pandemic, thanks to school closures and cancellation of activities she was enjoying a quieter pace.



Participants then spoke at length about the difficulty of taking a break from their caregiving responsibilities. For example:

- Several noted they never left their grandchildren for safety or logistical reasons.
- Some of the logistical challenges faced by the grandparents reflect a general lack of public awareness of the circumstances faced by kinship families and grandfamilies.
- One participant, an older adult, described a medical provider telling her that children were not allowed in the office and she should leave her granddaughter in the car during the appointment. Given such an untenable choice, she did not attend her medical appointment.
- Another noted that her eight-year-old grandson goes "everywhere" with her. As a result, she and her husband have lost touch with friends.
- Still another participant shared that after a similar loss of social support system for the same reasons, he and his wife had found a new community for social engagement by joining a support group specifically for grandparents raising children.

These observations helped provide context for the responses to the RFI and deepened the Advisory Council's already rich understanding of the concerns of kinship families and grandfamilies, especially during the pandemic.

RFI Findings

"The children that were exposed to drugs are growing up with medical and educational issues."

-Response to the RFI

ACL received 1,908 unique comments in response to the RFI from over 300 respondents. Respondents included grandparents, family members, public and private stakeholders, and tribal organizations. Many shared deeply moving accounts of the day-to-day joys, hardships, and unforeseen circumstances that arise when raising grandchild or relative kin.

The major themes that emerged from the RFI responses were not surprising. They reflect the growing body of research showing that kin and grandparent caregivers experience significant financial strain in taking on responsibility of a child at a time in their lives when their peers are enjoying the fruits of retirement. In addition, they take on significant amounts of stress and concerns about the children in their care as they struggle to navigate complex legal, financial, and medical systems that are not designed to meet their needs. As if these were not enough, they also often have complicated—and sometimes contentious—relationships with the parents of the

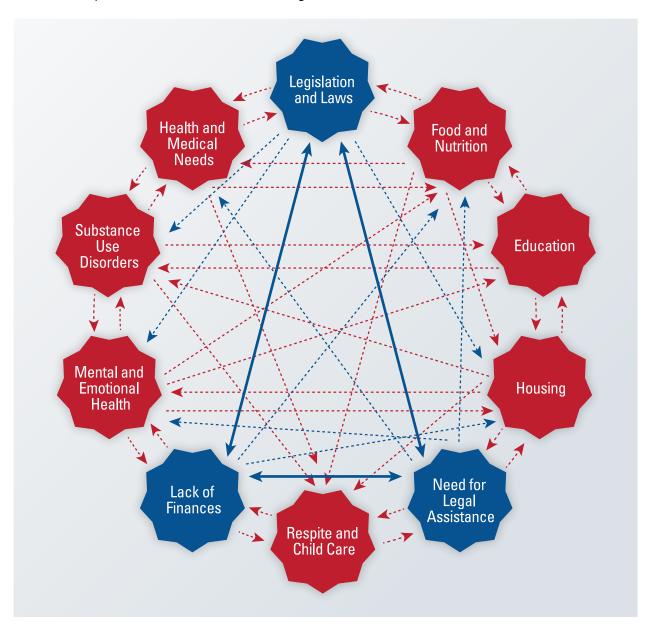


children in their care and unaddressed grief over the events that caused the formation of their new family.

"Many aged caregivers deplete any savings and even sell belongings to help with caring for grandchildren. In my case taking on 1 then another and both with special needs. (Cerebral Palsy and other has trauma needs) it was not a day that from 6:30am until 10:30pm I wasn't busy every moment feeling at times that I may not make it thru another day."

- Response to the RFI

Figure 4. The challenges faced by Kinship Families and Grandfamilies combine and compound to create a complex web that families must navigate to survive.







Many of these issues are multifaceted and intertwined. This is particularly true of the financial and legal issues which—depending upon the situation of the family—often create a ripple effect impacting housing, access to education, transportation options, availability of quality health care, nutrition, and mental health supports. Those issues, if not addressed, in turn lead to increased stress and less time for self-care and respite for already depleted kin and grandparent caregivers.

Still other respondents described how they were unprepared for the financial pressures and the consequences of taking on responsibility for a child or multiple children. These consequences ranged from significant changes in income and the ability to pay for housing, health care, and food, to seemingly small, but nonetheless important issues, such as the comment from one grandmother that her grandchildren had learned to play cards because she could not afford electronics, including mobile devices.

Another key trend throughout the RFI responses was that people frequently did not know where to go for support. This appeared to be true for both individuals new to raising a grandchild and those with years or decades of experience. There simply is no single resource that people can turn to for answers, advice, guidance, and support, leaving them to cobble together their own support systems based often on limited information—sometimes disinformation—and with few resources.

Recommendations to address this issue included developing an app, launching a call center, building a website, and other ideas to offer a central clearinghouse of trusted information so that grandparents do not have to "go it alone," as one respondent noted. Suggestions and comments were not limited to practical interventions, however. When asked if they believed kinship families and grandfamilies needed changes in federal legislation in order to thrive, the overwhelming response was in the affirmative; 80% of respondents selected "Yes" for this question.

> "We are the new poor. I give up medications to have money to take care of my two granddaughters."

> > -Response to the RFI

Respondents also noted the logistical complexities that lack of finances and limited access to social supports create. One respondent described what it is like to be on a waiting list for services for seven years. Another noted that she spends the time her grandson is at school driving from one food pantry to the next trying to pull together enough food to feed a growing teenager because she simply cannot afford enough groceries on her limited income. A third respondent described the pain of supporting a teen traumatized by her father's suicide a decade earlier.



A significant number of respondents represented ethnic and minority communities. Among respondents from Native communities, responses included reports that advocates, social workers, and health professionals frequently lack an understanding of the cultural norms experienced by Native people. Additionally, respondents noted challenges around the processes for applying for financial benefits and support services, like tutoring. There were suggestions for developing stronger partnerships and collaborations between tribal, state, and private organizations/agencies for the improvement of culturally relevant services to Native households.

The multi-faceted diversity of kin and grandparent caregivers was also noted in the RFI. For example, while the term grandparent denotes advanced age, many of the caregivers in these families are younger than age 60. Solutions designed for older adults were not appropriate for this sub-population. Similarly, interventions designed for metropolitan settings were inapplicable in rural settings. While this is true for most public health issues, when it comes to supporting kinship families and grandfamilies, recommendations and proposed strategies must be flexible enough to address the needs of an extremely diverse population. That includes people who live in every community across the nation and represent all ethnic and minority populations, are anywhere in age between 30 and 100 and includes all incomes (although a significant proportion live in poverty).



IV. Discussion of Challenges and Systemic Gaps Identified in the RFI

"Five years ago, when I started this journey, I got more info from a 10-minute conversation with a stranger from an Al-Anon group than I could get ANYWHERE!"

-Response to the RFI

The RFI specifically asked respondents to identify gaps and needs experienced by kinship families and grandfamilies. As noted above, slightly more than half of the respondents to the RFI were grandparents, relatives, and family friends raising children. While the issues faced by kinship families and grandfamilies are numerous, the following are the ranked order of concern as submitted by RFI respondents. Many people addressed the same issue across multiple categories, thereby increasing the frequency to greater than 300 (the number of respondents).

Table 2. Overview of Issues and Concerns as Reported by Respondents to the RFI conducted in 2019-2020.

Issues and Examples Cited by RFI Respondents	Frequency	Percentages
Finances (e.g., fixed income, additional expenses, insurance costs, unable to work)	581	20.91%
Legislation/Laws (e.g., laws more favorable to biological parents, child benefits not transferrable)	289	10.40%
Legal Assistance (e.g., high costs, expensive adoption process accessibility)	271	9.76%
Schools/Education (e.g., special needs not adequately addressed, lack of school system support)	266	9.58%
Substance Use Disorders (e.g., resources for biological parents, impact on children)	241	8.68%
Housing (e.g., affordability, limited space, repairs/maintenance, children not accepted at 55+ communities, custody orders preventing relocation,)	215	7.74%
Food/Nutrition (e.g., costs, nutritional value, special diets)	213	7.67%
Child Care (e.g., high costs)	195	7.02%
Respite (e.g., affordability, availability, quality)	156	5.62%
Physical Health (e.g., disabilities — children and caregivers)	145	5.22%
Mental/Emotional Health (e.g., stress, loss of social relationships, child trauma, separation, lack of support, grief)	105	3.78%
Medical/Health (e.g., caregivers place their health after children, lack of self-care, children's medical issues)	101	3.64%



While the RFI was not a scientific instrument, its findings reflect a growing body of research developed over two decades, which firmly establishes that kinship families and grandfamilies have unique and specific needs and one-size-fits all solutions designed for other populations may not be applicable. When kinship families and grandfamilies are formed, it typically involves some form of traumatic loss for the children as well as their caregivers. Inconsistent legal definitions and statutes often make it difficult for kinship families to have access to financial resources. Over time, these issues (trauma, lack of legal recognition, limited financial resources) interact and compound to affect all other areas of the family life including education, medical care, family relationships, child care, nutrition, and housing.

The sections below describe each of the key areas of concern identified by RFI respondents. These discussions are intended as an overview. For each issue, additional reading resources are provided.

Financial Challenges

"As a social worker assisting families (grandparents that have become the placement of children taken into the care and control of a Tribal court), I have found it is very difficult for some grandparents to get financial assistance (TANF & Medicaid for the children in question). This needs to be simplified at a higher level so that each state (and local counties) don't hinder this group from accessing much needed resources to take care of these children."

-Response to the RFI

Many Caregivers Find it Challenging to Support a Family on Limited Income

Financial unpreparedness for the cost of raising children, along with the financial uncertainty that comes with this responsibility, were among the predominant themes in responses to the RFI. Several respondents pointed out the urgency of their situations. One grandmother raising a teenage boy described the financial impacts of her decision to take in her grandson. Her remarks highlight the immediacy of the need for financial assistance for this population: "People lose their houses because we can't afford the cost of a child and no one seems to care that we'll risk losing everything just to keep them safe...We need support to be able to care for them. We can no longer wait!!! Our kids need the help now."

Kinship families and grandfamilies who step in to give care in times of crisis often feel they do not have a choice. Moreover, they do not have an opportunity to plan for the financial cost of this decision. In addition to addressing the needs of the children in their care, kin and grandparent caregivers also must make difficult choices to ensure that the children's needs are met while also preparing for financial security in later life.



"The kinship caregiver is put in a "catch-22" where they are having to decide between ensuring that the children in their care have what they need, and between holding down a job which in turn makes sure that the children in their care have what they need."

-Patrick Donavan, Supervisor with Muskingum County Adult and Child Protective Services (Ohio) and a member of the Advisory Council to Support Grandparents Raising Grandchildren

To understand the financial challenges that kinship families and grandfamilies face, it is useful to look at demographics. Custodial grandparents and older kin and grandparent caregivers typically have lower incomes and higher household expenses as compared to non-custodial grandparent caregivers. Approximately 1 in 5 kinship families and grandfamilies live at or below the poverty line, a rate that far exceeds the poverty rate among parent-led households (Generations United, 2020a). Black or African American kinship family and grandfamily households disproportionately experience financial need; children in these families are more than twice as likely to live at or below the poverty line as Hispanic/Latino or white children (Generations United, 2020a).

In addition, the direct and indirect financial costs of raising a child are considerable, and as noted above, families in these circumstances have little time to prepare. According to a report issued in 2016, by the Department of Agriculture, the annual cost of raising a child is between \$12,350 and \$13,900 each year (in 2015 dollars) (Lino et al, 2017). Multiple respondents to the RFI noted that because a significant proportion of kin and grandparent caregivers are raising children who are survivors of trauma or have disabilities, the true cost is often much higher once mental health, special education, and even dietary needs are factored in.

Limited Access to Financial Assistance Programs

"Getting a \$149 shelter benefit doesn't begin to even pay for the cost of taking care of a child. I can't afford to get kids into sports programs...I'm grateful we have food each day. These kids go through so many struggles and it is hard to not be able to give them the basic needs when I'm on disability and hearing folks say they would be better off if I let them go into foster care and have a chance to be adopted!"

-Response to the RFI

The majority of kin and grandparent caregivers are doing the same work as foster parents, yet they do not receive the same support or financial assistance that foster families have access to. When it comes to financial supports for kinship families and grandfamilies outside the foster care system, there are only a few avenues of support. Following is a list of the types of financial assistance available to kinship families and grandfamilies, however, it is important to note that access to these resources varies by program and many families are not aware that these programs exist or how to apply.





- Temporary Assistance for Needy Families (TANF), which replaced Aid to Families with Dependent Children in 1996, is designed to address a variety of outcomes of child poverty. One of the primary program goals is to keep children in their own homes or in the homes of relatives. Forty-one percent of child-only TANF units include children living with non-parental caregivers, usually grandparents (Golden & Hawkins, TANF child-only cases, 2012). However, if all children eligible for TANF were to receive support, the percentage would likely be higher. According to Annie E. Casey Foundation, only 12% of eligible children in kinship families and grandfamilies actually receive TANF support (Annie E. Casey Foundation, 2012).
- Supplemental Nutrition Assistance Program (SNAP) provides nutrition benefits to supplement the food budget of eligible families. According to the USDA, families apply for SNAP through SNAP state agencies and must meet resource and income limit requirements determined by the state. SNAP also offers special rules for older adults and people with disabilities. Annie E. Casey Foundation reports that "less than half of low-income kinship care households receive assistance from SNAP, despite the fact that most report food insecurity" (Annie E. Casey Foundation, 2012).
- The Social Security Administration administers benefit programs for which kin and grandparent caregivers or the children in their care may be eligible. For example, disability benefits provide a financial lifeline that protects more than 1.7 million children and the dependents of disabled workers who would otherwise face a high risk of either slipping into poverty due to reduced family income, dropping out of school, or both. It is payable to biological or adopted children, stepchildren, grandchildren, or step grandchildren. Retirement benefits provide monthly support to dependent children of retired parents and grandparents. The child benefits, in addition to their own retirement benefits, provide the support retired workers need to care for their dependent children when they retire, by partially supplanting lost wages. Some children in kin or grandparent families may qualify to receive survivor benefits or Supplemental Security Income for Children. However, individual cases vary, and families are advised to contact the Social Security Administration to see if a particular child meets certain eligibility criteria.

Each program comes with unique requirements, which create administrative barriers to participation. A major hurdle to accessing TANF, for example, is the requirement that recipients assign their rights to child support to the states. This requirement reduces access to benefits for kin who are fearful that when the state tries to locate the parent(s), the parent(s) will return to take the children, potentially placing the children at risk of harm. Some caregivers may fear that the pressure of child support enforcement may make it more difficult for a parent struggling with substance use or other challenges to recover and eventually be able to safely parent their children. States have flexibility and can waive the child support requirements for "good cause"



if the caregivers can demonstrate that seeking child support is potentially harmful, however many states do not offer this option or make it widely known (Beltran, 2014).

These barriers have consequences for the short-term and long-term financial welfare of kinship families and grandfamilies. For example, TANF is often kin and grandparent caregivers' only source of financial support for raising grandchildren; however, obtaining TANF can be an arduous process for many families. One reason for this is lack of understanding of the eligibility requirements at the local level; it is not out of the ordinary for a caregiver to be informally told by a caseworker that they are ineligible for TANF and therefore they do not complete the complicated application forms.

"Every family that takes on their grandchildren faces depleted income.

We all know the reality is that it IS expensive to raise children. If
your family chooses getting involved with foster care...there are some financial
benefit[s] as well as support. Those of us who choose to gain
custody ... receive no such financial support."

-Response to the RFI

For families who do receive them, TANF grants can provide a valuable, if limited, lifeline, which points to the need for policy reforms that make programs such as this easier for families' access. This is important because TANF assistance represents much more than just a monthly grant. Receiving TANF affects whether or not a family qualifies for a range of other supports. Under some state policies, recipients of cash assistance may also automatically qualify for Medicaid, child care, free school meals, education, and job training. That varies by state, however, and as noted, not all eligible families are able to access TANF.

For further discussion and an analysis of the financial complexities faced by kinship families and grandfamilies, including a list of resources, refer to the <u>Financial</u> Assistance - Summary & Analysis webpage on Grandfamilies.org.

Legal Concerns and Assistance

"For grandparents that take on the responsibilities of care when needed but do not have legal rights or custody but provide constant financial support, worry endlessly about the grandchildren when they are in the care of the addicted parent- there is nothing for us."

-Response to the RFI

Closely linked to financial pressures is the lack of consistent financial and legal recognition for kinship families and grandfamilies, along with limited legal assistance.



Legal Concerns Featured Prominently in the RFI Responses

Legal issues, including inconsistent legislation, were among the most prevalent responses from kin and grandparent caregivers and advocates in the RFI. Many respondents explained that because of their lack of legal custodial guardianship, they faced significant legal barriers to accessing financial assistance, enrolling children in school, advocating for educational services, or consenting to health care, including emergencies. While there are numerous state and federal laws that address care of children who cannot remain with their parents, these laws do not collectively meet the needs of kin and grandparent caregivers.

In fact, kin or grandparent caregivers who take responsibility for a child often face a bewildering maze of legal requirements and limitations that differ by state and depend on the family's circumstances (Wallace, 2016). Federal and state public policies are not designed to assist families who are not part of the child welfare system and therefore lack the necessary supports for grandparents and extended families raising children. "U.S. policy has not kept pace with the reality of the family and—as a result—those families who are most vulnerable often receive the least support" (Baker, Silverstein, & Putney, 2008).

Kinship Families and Grandfamilies Defy Existing Legal Categories

"There is an established legal process when children in the custody of the state are placed with relatives but those outside the formal system are left to find their own path to stability for the children they have been raising. These children often have the same experiences as those in formal foster care, the only difference is that a grandparent 'got there first.'"

-Sharon Olson, grandparent and member of the Advisory Council to Support Grandparents Raising Grandchildren

Unlike parents, kin and grandparent caregivers do not have automatic legal rights and responsibilities with respect to the children in their care. As noted, only a small minority of kinship families and grandfamilies (about 133,405 children) are part of the foster care/child welfare system, which accords them some specific rights and tax-free subsidies, which vary by jurisdiction. For the rest of the families, gaining legal recognition as the child's primary caregiver involves either petitioning the courts or persuading the child's parents to grant a power of attorney. Some kin and grandparent caregivers are reluctant to pursue this step. "Many caregivers find it difficult and intimidating to interact with adversarial court systems, especially when they have to bring cases against their own family members" (Annie E. Casey Foundation, 2012).

Because each state (and often times each county) has differing processes and procedures for defining and recognizing kin and grandparent caregivers, a continuum



of care arrangements has emerged—with kinship families and grandfamilies who are involved with the child welfare system at one end of the spectrum. At the other end of the spectrum are kinship families and grandfamilies who have no relationship with the child welfare system and no legal relationship to the child. Some states have laws that do offer an alternative legal authority, which can enable kin and grandparent caregivers to access much-needed medical services and enroll children in public education in their town or county, even if they do not have legal custody or guardianship. Because not all states have implemented such laws, their availability is inconsistent across the nation and even within certain states (Generations United, 2020a).

Variability in legal definitions also exist across states. For example, while some states are required to give preference to relatives over non-relatives in deciding where to place a child, the definition of "kin" varies significantly by state. As a result, access to child-only grants (i.e., TANF), Medicaid, and other programs can vary by jurisdiction.

Clarifying their legal relationship to the child is time consuming and expensive because it involves working with legal professionals. Approximately half of the children in kinship families and grandfamilies live with caregivers who have income below the federal poverty level, which was \$26,200 for a family of four in 2020. Few of these families can afford even a single hour of an attorney's time, not to mention the ancillary costs associated with custody applications, such as mediation, psychological evaluations, and miscellaneous fees such as filing fees and paying a third party to serve paperwork and subpoena financial records.

Legal support resources do exist in some jurisdictions. These include legal aid, law school clinics, Court Self Help, and lawyers for older adults. Yet, many kin and grandparent caregivers are not aware of these services or do not financially qualify. Others do not seek legal assistance out of concern for further jeopardizing family dynamics or because they expect that the custodial parents will return to care for the children.

Without Legal Recognition and Protections, Families are "On Their Own"

"Many times, the grandparent does not have any legal custody due to noninvolvement with child welfare. Causing difficulty receiving medical assistance, school enrollment. Financial qualifications are different."

-Response to the RFI

The inconsistency in legal recognition within and across systems and states has practical implications that add to the daily stress and challenges experienced by kin and grandparent caregivers. Despite the diversity of causes and composition of kinship families and grandfamilies, one thing they all have in common is the unexpected nature of becoming a kinship or grandparent caregiver. Rarely do families have resources to fall back upon in the face of such a life-changing event.



Amid this sudden life change, they find themselves caring for a child or multiple children while learning to navigate a complicated legal system within which they have few formal rights and lack the financial resources to obtain access to legal representation or seek legal custody. Without a recognizable and consistent form of legal custody that is flexible enough to meet the needs of these families and their circumstances, kin and grandparent caregivers are limited in their ability to access the supports and services that could make a meaningful difference in their well-being, quality of life, and financial security. At the same time, their day-to-day lives are complicated by the need to develop workarounds for inconsistent systems and outdated requirements. Even seemingly simple tasks like providing permission to participate in a field trip can be logistically challenging for some families.

This is important because a recurring theme of the RFI is that kin and grandparent caregivers in these situations were completely unprepared for the stress and financial insecurity they were taking on. Most have no idea what legal options exist in their states and for their unique circumstances, nor do they have time to educate themselves on the topic. Instead, they find themselves putting aside their own lives—retirement, work, sometimes other children—to care for a child that is more than likely traumatized by removal from the parent(s) and the events that led to that removal. The kin and grandparent caregivers who are not licensed foster parents must house, clothe, nurture, feed, protect, educate, and provide for medical care, often entirely at their own expense.

For additional analysis and discussion on legal arrangements available to grandfamilies and kinship families and the challenges they face in this area, refer to the <u>Care-Custody - Summary & Analysis webpage</u> at Grandfamilies.org.

Education (including Special Education)

"Our school district refuses to accept that kids like him need help as long as they do ok in school. Our school district told social security they think he's ok in school so we have been denied social security disability even though his medical [and] mental challenges in autism were all diagnosed by medical professionals and are all on the SSA [Social Security Administration] website as approved children's disabilities. His last diagnosis states he'll need lifelong support so who will raise him when I'm gone?"

-Response to the RFI

Education is a critical issue for kinship families and grandfamilies. Many of the children in these families have special education or behavioral support needs due to the trauma they have experienced. Yet many kin and grandparent caregivers struggle to ensure the children in their charge receive the educational supports they need. Public schools are often uneducated on trauma and how to manage children with behavior issues.





The National Survey of Child and Adolescent Well-Being (NSCAW II), a nationally representative sample of children involved with the child welfare system (CWS), found that 4% of young children placed in voluntary kinship care with developmental, cognitive, or language delays are significantly less likely to have an Individualized Family Services Plan as required by the Individuals with Disabilities Education Act, compared to 22% of similar children placed in nonrelative foster care (Casanueva, et al., 2020). Kin and grandparents often do not have access to or knowledge of the child's educational rights. Nor do they have the resources to hire professionals, such as advocates, counselors, and tutors, who can assist in addressing the educational needs of the child. Resources to evaluate and diagnose children exposed to trauma, fetal chemical exposure, and other issues are not easily accessible.

Legal Concerns Shape Education Access

To enroll a child in school, many jurisdictions require the caregiver to have a legal relationship to the child in his or her care. However, this practice varies considerably among states and across the nation (Generations United, 2014). Generally, the kin or grandparent caregiver needs to show they are responsible and have the legal right to make decisions for the child. Some state and school districts allow kin and grandparent caregivers to use other documents, such as a special power of attorney, to enroll a child in school while other states require a "Delegation of Power," which allows the enrollment of the child in school or access to medical care. It can also be limited to a specific period of time, which limits options for long-term caregivers.

Meeting proof of residency requirements, whether through obtaining birth records or a legal agreement, such as a power of attorney or legal custody, can be time consuming, is often expensive, and a considerable stressor in the lives of kinship families and grandfamilies. Due to tensions with birth parents, it can be a challenge for caregivers to obtain the child's birth certificate and immunization records. Without actual documentation, consent and access to student information is also compromised —including the right to make decisions in a medical emergency (Generations United, 2014).

Once kin and grandparent caregivers are able to enroll children in school, other challenges remain. For example, a significant proportion of the children need additional school-based supports and services such as special education or speech and language therapy. Others need extra assistance, such as counseling or other social emotional supports, as they adjust to a new environment. Numerous respondents to the RFI noted a perceived lack of awareness among educators of the psychological needs and a lack of trauma-informed support for children who have been exposed to trauma. Furthermore, despite the fact that the Individuals with Disabilities Education Act recognizes grandparents acting as parents, many kin and grandparent caregivers are denied inclusion and the opportunity to advocate for the child in the Individualized



Education Process if they do not have legal decision-making powers obtained through the court system (Generations United, 2020a).

"My grandson has ADHD. Many drug-exposed children do, along with learning disabilities."

-Response to the RFI

Mental Health Services

Educational needs and mental health are closely intertwined. School is most often the setting in which children receive mental health supports and children exposed to trauma often have additional need for academic assistance. Children who experience early adverse experiences and youth in foster care, in general, have elevated rates of both externalizing (e.g., ODD, conduct disorder) and internalizing (e.g., depression, anxiety disorders, PTSD) problems, depending on the age and age of exposures (Hambrick, Oppenheim-Weller, N'zi, & Taussig, 2016). A systemic review of interventions to address these issues found that some demonstrated benefit for both children and caregivers. Developing interventions that are effective for children in differing circumstances is critical because, left unaddressed, mental health issues could have long-term implications not just for the well-being of each individual child, but also for society (Gilad & Gutman, 2019). Children who have been exposed to crime and violence are at greater risk for behavioral problems that affect learning. Statistically, they are more likely to come into contact later in life with the criminal justice system, to engage in substance use, or to experience chronic health conditions. Researchers estimate that the cost to the nation of the outcomes of unaddressed childhood trauma are \$496 billion per year (Gilad & Gutman, 2019).

For additional discussion of educational challenges faced by kinship families and grandfamilies, refer to the <u>Education - Summary & Analysis webpage</u> on Grandfamilies.org.

Grief, Trauma, and Loss

"I've had my granddaughter in counseling since age 4, after her father's suicide... She is 14 now and just getting into addressing some major trauma issues. The in and out of their birth parents in their lives leaves them with many issues. The neglect they receive while in the care of their birth parents leaves them with many issues."

-Response to the RFI

Silent Witnesses

While most kin and grandparent caregivers experience immense joy as a result of their caregiving role, as noted above, the circumstances that lead to the formation



of kinship families and grandfamilies are often deeply troubling. Many of the children have been exposed to substances (often before birth), trauma, violence, and neglect. Some have been silent witnesses to domestic violence, overdoses, incarcerations, or witnessed the death of a parent. Some have seen their parents themselves become victims of crime. The stress associated with such events as death of a parent, child abuse and neglect, divorce, teen pregnancy, poverty, HIV/AIDS, and adverse immigration action each have well-documented impacts on the developing brains of children. Gilad and Gutman note in their analysis of the public health costs of unaddressed trauma in children that, "exposure to crime and violence during childhood causes heightened stress levels and overstimulation of specific brain structures, which can lead to chemical imbalances in the child's brain and abnormal neurological development" (Gilad & Gutman, 2019).

In 2012, the Attorney General's Task Force on Children Exposed to Violence declared exposure to violence, "a national crisis and a threat to the health and well-being of our nation's children and of our country" (Gilad & Gutman, 2019). That was nearly a decade ago, and still today, there are few community programs in place to support traumatized children and their caregivers and insufficient national awareness of the very real need.

That is important because with these experiences and stress also come social stigma and profound feelings of sadness, shame, and grief. The grief and shame are often compounded if the child's parent has died or been incarcerated or if the relationship with living adult children is compromised by the need to prioritize the safety and well-being of children. The adults in these families also need assistance and education in parenting children with behavioral or mental health challenges in order to be the parent/caregiver they need to be.

"The reality is this: the longer someone commits to staying in rehab and sober living establishments, the higher the likelihood for successful recovery. If the addicts could raise their children, the burden is lifted from grandparents."

-Response to the RFI

Responsibility for Children Also a Source of Stress

Caring for children leaves kin and grandparent caregivers with less time and money to pursue hobbies and engage in fulfilling activities, which can be a source of grief and loss. About a third of grandparents surveyed by the Altarum Institute reported no longer being able to participate in hobbies they once enjoyed, and a quarter said raising their grandchildren put a strain on their relationships with same-aged friends (Stanik, 2018).



"I have three grandchildren and all three of them are in several types of therapy. I have therapist that come to my home for 3 hours twice weekly and I also have a psychiatrist that I have to take them to see every month for therapy and medication. Two of my children have IEPs, so I have scheduled meetings with the school. I am in constant contact with the school through a Dojo app because of separation anxiety, PTSD and other dysfunctional issues due to abuse that the children went through before I was finally able to legally rescue all three of them."

-Response to the RFI

Respondents to the RFI and members of the Advisory Council also reported that a core need is assistance in adapting to a new family structure, specifically determining roles in the new family. Caregivers themselves are often facing grief and loss due to the death of their own child. Loss of their dreams of retirement are added on top of the stress of caring for a child with trauma. Kin and grandparent caregivers also express a need for assistance adapting to the role of caregiver, especially later in life.

For more on the grief and loss experienced by kinship families and grandfamilies and how to provide assistance, refer to the <u>Helping Children and Families with Separation and Loss webpage</u> on the Child Welfare Information Gateway website.

Housing

"Some of our members have needed to move into larger homes to be able to take in the relatives and this creates a financial burden since affordable housing is hard to find that takes in multi-generational families."

-Response to the RFI

While there is a small but growing number of housing developments specifically designed for grandparents and other relatives around the country, respondents to the RFI noted that securing adequate, affordable, and safe housing for their families is a key challenge.

Financial Issues often Drive Housing Challenges

Financial constraints are a significant factor in limiting the housing options for kinship families and grandfamilies. While statistically, a majority of older kin and grandparent caregivers own their own homes, in reality many of these families struggle to pay for expensive home repairs and maintenance, and cover mortgages and increasing taxes. On Tribal lands, American Indian and Alaska Native grandfamily caregivers and other residents face much higher incidents of plumbing, kitchen, and heating problems, structural deficiencies, and overcrowding than the general population. For those that are renters, the picture is equally dire; half of kin and grandparent caregivers raising grandchildren who rent their homes and have incomes at or below 50% of median



family income, spend more than 50% of their gross monthly income on rent and could benefit from any type of housing assistance. Many senior housing programs do not allow children and for those that do qualify, waitlists are often lengthy.

Limited Access to Assistance Programs

A number of housing assistance programs are available to qualifying kinship families and grandfamilies in the U.S. To date, Housing and Urban Development (HUD's) Office of Policy Development and Research (PD&R) estimates that approximately five million American households are receiving housing assistance through the different housing programs administered by HUD. However, eligibility for these programs is often hampered by unclear legal definitions for these families, especially those who lack legal custody, and they are not consistently available around the nation. Supportive housing for older adults or people with disabilities typically does not allow minors, so residents may be subject to eviction for bringing children into the household. Not all Regional Housing and Urban Development Offices, Housing Authorities, and other managers of subsidized housing recognize children as part of the caregiver's household unless the caregivers have legal custody. If kinship families gain recognition from subsidized housing managers, they typically join a long waiting list of families seeking larger units. Caregivers who live in a retirement community that does not allow children may lose a significant investment when they are forced to move so that the children may move in with them.

For caregivers who must relocate to accommodate a growing household, not only are larger residences more expensive, the cost of moving can itself be a barrier for families who are scrambling to reinvent their household budget to accommodate new members. This can prove especially difficult for older families living on a fixed or limited income, as an overwhelming majority do. Although innovative new supportive housing developments make a limited number of units available to kinship families, these are few and far between (Generations United, 2019).

"Financial assistance for needy families should be available to all grandparents raising grandkids. Affordable housing somehow... we have no Section 8 housing per say. We have one complex with reduced rent but at my low income on Social Security, I can't meet their requirement for ratio of income to rent."

-Response to the RFI

Child Care

One particular aspect of the financial concerns faced by kinship families and grandfamilies was so prevalent in the RFI that it warranted its own category for discussion. Child care, particularly the cost of child care, was mentioned 195 times in the RFI. This is likely because, in addition to limited support from TANF, and limited



access to housing and nutrition assistance, child care assistance is minimal for families that are not part of the child welfare system (Generations United, 2017).

Reliable Child Care is Costly...

Finding affordable child care is a challenge for families across the nation. According to the Economic Policy Institute, child care accounts for a significant portion of the budgets of working families, with some families in the median income range spending up to 33.7% of their income on child care. In addition, child care costs vary considerably across the nation. In 2015, a household with one child typically paid \$344 per month in rural South Carolina, while a similar family living in Washington D.C. would have paid \$1,472 (Gould & Cooke, 2015). For kinship families and grandfamilies, many of whom live on fixed or limited incomes well below the poverty level, quality child care, let alone trauma-informed care, is unaffordable. Even families that receive support through TANF typically do not receive assistance with child care. The 2011 GAO report examining TANF payments to kinship families and grandfamilies, noted that of families receiving TANF, only 5.7% also received assistance with child care (U.S. Government Accountability Office, 2011). This means that many kin and grandparent caregivers have limited opportunities to engage in the workforce or access respite services, leading to higher risks of poverty and burnout.

...And Growing More So

Without changes in policy and increased supports for the families, the situation is unlikely to resolve on its own. In response to the COVID-19 pandemic, child care costs are rising due to closures and increasingly stringent safety protocols for those that do stay open. One recent analysis found that operational costs for providers of child care rose 47% in 2020 (Workman & Jessen-Howard, 2020). These rising costs, if not addressed, will further negatively affect kinship families and grandfamilies.

Food and Nutrition

"We can't afford fruit, eggs, milk is scarce and there were days we had one big meal and just feed the kids."

-Response to the RFI

Children need good nutrition to maintain mental and physical health and achieve educational success. While some children receive free and reduced-price school meals, many go to school hungry. Children without adequate nutrition are more likely to suffer chronic illnesses. They have higher rates of hospitalization than children who have access to healthy food. They may have difficulty concentrating and are more likely to repeat a grade (Generations United, 2018b).



Obtaining and maintaining adequate food and nutrition is a challenge for both children and caregivers in kinship families and grandfamilies. Nearly a fifth of U.S. children (almost 16.7 million) "live in households where they lack consistent access to enough nutritious food for a healthy life. About 4.5 million (1 in 12) adults age 60 and older are now at risk of hunger or food insecurity" (Generations United, 2018b).

Researchers estimate that rates of food insecurity among "multigenerational families are at least twice as high as families without resident grandchildren" (Ziliak & Gundersen, 2016). This is especially true for the 21% of kin and grandparent caregivers who are living below the federal poverty line and the 24.9% who have a disability; both poverty and disability status are risk factors for food insecurity (Ziliak & Gundersen, 2016). In fact, the challenge of obtaining adequate food and nutrition is such a pressing concern for kinship families and grandfamilies that in addition to ranking nutrition as a key need, a number of respondents to the RFI wrote moving and lengthy descriptions of the daily struggles they face to adequately feed growing children.

Many respondents to the RFI described how they often sacrifice their own needs, including life-saving medication and food, to ensure they can feed the children in their care. An advocate described a typical scenario: "Most of the caregivers are sacrificing their own health to provide food, clothing, and stable housing for those in their care. One client I spoke to doesn't take all her insulin shots so the children can eat." For caregivers who are older adults this has implications for their long-term ability to provide care. Older adults who do not have access to adequate and healthy meals are more likely to get sick and be in poorer health. Inadequate nutrition impedes their ability to carry out daily activities and can compromise their quality of life, while also contributing to rising health care costs (Generations United, 2018b).

SNAP and Other Federal Nutrition Programs

Findings from a nationwide survey conducted by Generations United with funding from The Atlantic Philanthropies and AARP, found that 74% of those who sought assistance with obtaining nutritious food for their family members in the preceding months, did so through government programs like <u>Supplemental Nutrition Assistance Program</u> (SNAP), the <u>Fresh Fruit and Vegetable Program</u>, the <u>National School Lunch Program</u>, the <u>School Breakfast Program</u>, the <u>Supplemental Nutrition Program for Women</u>, <u>Infants, and Children</u>, and the <u>Emergency Food Assistance Program</u> (Generations United, 2018b). However, some families who qualify for these programs face difficulties accessing them because of complex eligibility requirements, misinformation about those requirements, and complicated application forms. Many families turn to houses of worship, food pantries, soup kitchens, and emergency shelters for food and nutrition, a challenge that has been made more complex by the increasing number of families relying on these resources during the COVID-19 pandemic. According to



Generation United, barriers that can impede access to food assistance programs for kinship families and grandfamilies, can include:

- Income eligibility for programs
- Exhausted food supplies
- Hours of operation for food assistance services
- Age restrictions for access to programs and services
- Transportation to locations providing food assistance services
- Location of those services (Generations United, 2018b)

Several respondents to the RFI noted what they perceive as an unfair treatment for a segment of society whose unpaid caregiving services collectively saves the country approximately \$4 billion annually, besides a host of other proven benefits to the children, their families, communities/tribes and society. As several respondents pointed out, licensed foster care families in similar situations are supported, nationally recognized, and receive enough financial assistance to feed themselves and the children in their care. On the other hand, kinship families and grandfamilies outside the system—the majority of kinship families and grandfamilies—do not have access to these benefits.

For further analysis and a list of recommendations for reducing food insecurity among kinship families and grandfamilies, refer to <u>Hunger and Nutrition in America: What's at Stake for Children</u>, Families and Older Adults.

Respite Care

One hundred and fifty-six respondents to ACL's RFI (5.62%) mentioned respite as an unaddressed need. Because of the round-the-clock nature of caring for children, especially young children and children with disabilities or exposure to trauma, kinship families and grandfamilies need a variety of formal and informal respite options.

"We need time to ourselves. Once a week even once a month for time for ourselves. Our friends tend to stay away because they raised their kids and are enjoying their time. We don't get that. There needs to be child care available and paid for so we can get time to ourselves."

-Response to the RFI

Undertaking primary responsibility for raising a grandchild is a life-changing commitment, especially when the caregiver is in their older years. It can be especially challenging for older adults who have not been around children for many years or have physical disabilities. In taking on this role, which is almost always an unexpected life event, caregivers experience physical, emotional, social, legal, and financial challenges that they did not face when raising their own children.



Respite provides a temporary break from caregiving responsibilities so caregivers can attend to their own medical needs, accomplish critical household tasks, develop social relationships, and engage in self-care. For example, many caregivers—40% of whom are older than age 60—forego medical treatments (especially dental care), filling prescriptions, and engaging in self-care to raise a grandchild. Respite can also rebalance the loss of leisure activities and social relationships that many kin and grandparent caregivers experience. That can prevent social isolation and, in turn, reduce stress and prevent burnout.

Many kinship families and grandfamilies cannot afford respite services. Whether they come in the form of babysitting, daycare, camps, or enrichment classes; safe and reliable respite care that is also convenient and accessible is often cost-prohibitive for many of these families. This underscores how intertwined most issues are for kinship families and grandfamilies. For example, even if the activities are affordable, transportation can be a barrier. For families who have children with disabilities and challenging behaviors, it can be even more difficult to find a trusted respite provider who is able to offer the level of support the child needs.

"If I had some financial help, it would allow me to take much needed breaks or at least take the worry and stress down a notch for sure!"

-Response to the RFI

Programs that Provide Respite Care

The National Family Caregiver Support Program and the Lifespan Respite Care Program both fund respite opportunities for kinship families and grandfamilies. In addition, in some states, there are a number of private and state-funded initiatives available through Area Agencies on Aging (AAAs). Despite the presence of these formal services, many kin and grandparent caregivers never take a break. One participant in the previously discussed grandparents focus group spoke for many when she observed, "you can't just leave your kids with anyone these days."

These barriers to a meaningful break have only been amplified by the COVID-19 pandemic, which has placed in-person education on hold across the country and led to multiple reports of children losing access to special education services and counseling support, and as a consequence, experiencing a loss of critical skills and abilities.

To learn more about the value of respite care, refer to the <u>ARCH Respite Research</u> <u>Consortium webpage</u> on the ARCH website. ARCH also offers a tip sheet for finding respite care titled <u>9 Steps to Respite Care for Grandfamilies</u>.



Physical and Mental Health and Health Care

"Medicaid was difficult to get info on or for my grandchild through social services since she was covered under her biological mothers name and for privacy purposes, I couldn't make changes very easily, even with a court order."

-Response to the RFI

The financial uncertainty and stresses that kinship families and grandfamilies face can leave them vulnerable to poor health outcomes and can also have serious consequences on the health of the children in their care. Children in kinship families and grandfamilies are more likely than children in the population as a whole, to have physical, behavioral, and emotional problems, often because of the events that led to the formation of the new family (Generations United, 2020a). While mental and physical health are distinct areas, it is worth noting that an almost equal number of responses to the RFI mentioned each realm (105 and 101, respectively). In total, close to 8% of all RFI responses mentioned the challenges of managing stress, finding time and money for self-care, and accessing and managing health care.

According to a policy statement by the American Academy of Pediatrics, "the growing number of children in kinship care arrangements requires pediatricians to be better informed about the unique needs of these children and their families." For example, kinship families and grandfamilies are less likely to have appropriate health coverage than families led by birth parents. In 2012, 21% of children living in kinship care arrangements, where there was no biological parent living in the home, were uninsured. This was compared to 9% of children who were living with their parents. Today, only 42% of children in kinship families and grandfamilies receive health coverage under Medicaid (Rubin, Springer, Zlotnik, Kang-Yi, & Council on Foster Care, Adoption, and Kinship Care, 2017). Uncertain guardianship agreements, difficulties faced by kin and grandparent caregivers in navigating access to health insurance, and the tremendous cost of purchasing insurance are just a few of the reasons for the lack of health coverage for children in kinship families and grandfamilies.

Barriers to Care

Because the vast majority of kinship families and grandfamilies are outside of the child welfare system and so many lack a legal relationship to the child, many caregivers face barriers when it comes to the medical care of the child. In many cases, the decision-making rights are retained by the parents. While emergency care can be provided to children without a parent's consent, vaccinations, well-child appointments, and dental care can pose challenges for caregivers (Rubin, Springer, Zlotnik, Kang-Yi, & Council on Foster Care, Adoption, and Kinship Care, 2017).



While older caregivers in kinship families and grandfamilies receive health insurance under Medicare, many of those who are younger than 65 lack coverage and do not qualify for Medicaid. Kin and grandparent caregivers are more likely to have an existing disability. About a quarter of all grandparents responsible for grandchildren live with a disability according to the ACS (ACS, Table S1001, 2019). As a result, these caregivers have significant physical health needs of their own, which can be compounded by the increased stress of full-time caregiving.

In the face of limited finances, many kin and grandparent caregivers forego medications or visits to the doctor because of the expenses related to their grandchildren. In addition, lack of child care or respite makes health appointments and hospitalizations difficult, if not impossible for many kin and grandparent caregivers.

The health challenges of raising grandchildren are even higher for ethnically and culturally diverse populations and those in rural settings. For example, a study of rural African American kin and grandparent caregivers found higher rates of multiple conditions including chronic pain that interfered with sleep and daily functioning, mobility issues exacerbated by child care, and the pressure of managing their own medical conditions as well as their grandchildren's. Emotional strain was common as grandparent caregivers struggled to protect their grandchildren in communities where rates of substance use disorders, HIV, and incarceration were high. Caregivers worried about their mortality and the related consequences for their grandchildren. Chronic stress, which is linked to a number of poor health outcomes, was self-reported by most rural grandparent caregivers.

The COVID-19 pandemic has heightened the health vulnerability of kin and grandparent caregivers, many of whom are age 60 and older and at greater risk if exposed to the virus. Black, African American, and Native kinship families and grandfamilies have been affected by the pandemic at disproportionate rates, leaving children in kinship families and grandfamilies vulnerable to increased trauma and loss (Generations United, 2020f).

For additional information on the health and medical needs of kinship families and grandfamilies, refer to the <u>Needs of Kinship Care Families and Pediatric Practice policy statement</u> released by the American Academy of Pediatrics in 2017.

Emergencies and Unplanned Events

"The system is too [un]wieldy for people to manage it, especially if they are given wrong information. I gave up. I have spent thousands of dollars rescuing my granddaughter from her mother's choices."

-Response to the RFI



Kinship families and grandfamilies often take on responsibility for a child or multiple children in response to a crisis. That means that from the moment they receive the child, they are in "catch up" mode, trying to learn new ways of parenting, while navigating the child welfare system and the byzantine systems of social supports.

No Time to Prepare

Any emergency has the potential to disrupt the balance within a family. Whether it is a public health emergency, a weather event, a flooded basement, or parental death or incarceration, becoming the primary caregiver of a child is an unexpected situation for which there is little time to prepare. When such situations occur, the physical and financial limitations of many kin and grandparent caregivers may disproportionately limit their ability to manage and respond to the needs of the children who are suddenly in their care. For some situations, resources may be readily available, whereas other crises may require specialized intervention(s).

This vulnerability amid unplanned events was particularly evident during the COVID-19 pandemic. Kinship families and grandfamilies have also been disproportionately affected by the pandemic and many have faced the loss of critical services, such as special education and respite care, while at the same time experiencing increases in their responsibilities and expenses. During the April 2020 meeting, Advisory Council members discussed the impact of the COVID-19 pandemic on kin and grandparent caregivers. It was clear, even only a few months into the public health emergency, that the spreading virus created challenges for kinship families and grandfamilies that were unique. While kinship families and grandfamilies faced many of the same challenges as other families across the nation, they were at greater risk because many of the caregivers are older or have underlying health conditions that make them more vulnerable to infection. Many kinship families and grandfamilies found the public health guidelines difficult to implement. Social distancing was a challenge for families living in smaller dwellings. Caregivers responsible for young children could not shield themselves to reduce risk of viral transmission. The closing of schools meant that families experienced disruptions in much-needed special education and counseling interventions. Several Advisory Council members noted that because kinship families and grandfamilies often live on a limited income, just buying extra cleaning supplies and personal protective equipment (i.e., gloves and masks) recommended by public health authorities was impossible.

In addition, kinship families and grandfamilies are less prepared than the general population to deal with the financial shock of sudden unemployment, increased health expenses, or the loss of child care and nutritional assistance that schools typically provide. Balancing caregiving with employment became particularly challenging during the pandemic for all caregivers, and it particularly impacted kin and grandparent caregivers who are still in the workforce.



In recognition of the risks kinship families and grandfamilies experience in the face of any type of unplanned events — including weather emergencies — the Advisory Council determined that its first work product would be a COVID-19/emergency preparedness resource. Over the ensuing months, Advisory Council members devoted a considerable amount of effort to gathering content and collaborated on drafting text to finalize and publish the COVID-19/Emergency Preparedness Resource Guide for Kinship Families and Grandfamilies. This one-of-a-kind resource, posted to the ACL website, features a collection of three dozen vetted sources of information and assistance from federal, state, and local entities that could be of value to any kinship or grandparent caregiver during a crisis.



V. Supporting Kinship Caregivers in Indian Country: Lessons from the ACL Title VI Programs

"It's a 24/7 job, you know it's hard. Sleep with them, get them up in the morning, get them ready, like a mom... is supposed to be doing. But like I said, it's got to be done and I'm doing it, the best way I know how. Sometimes I lose it. I just get irritated and all that, you know, but that's age I guess."

- Grandparent response to Title VI Evaluation

As discussed in Section I of this report, kin and grandfamily caregiving has significant advantages over other child care arrangements, particularly foster care with non-relatives. For Native children, kin and grandparent caregivers offer the additional

benefit of keeping them immersed in their heritage and allowing them to "maintain connections to their family members, traditions, and cultural identity" (Day, Cross, & Farrell, 2011).

Extended family kinship structures are deeply rooted in almost all Native cultures, ensuring Native children have several potential caregivers and many natural supports (Generations United, 2020c). While American Indian (AI) and Alaska Native (AN) children make up just 1% of all children in the U.S., they comprise over 8% of all children in kinship families and grandfamilies (Generations United, 2020c). When AI/AN/Native Hawaiian (NH) grandparents and other

For historical context on how a legacy of trauma, discrimination, and unresolved grief continues to impact Native American kinship families and grandfamilies, refer to American Indian and Alaska Native Grandfamilies:

Helping Children Thrive Through Connection to Family and Cultural Identity.

elders take primary responsibility for their grandchildren, they experience challenges similar to those faced by other populations. For example, there is a strong need for legal assistance and financial support, as well as programs and interventions that address mental and physical health, education, nutrition, and housing. In one study American Indian grandparents surveyed received the following services: Medicaid, financial assistance, nutritional programs, health services, and services for food, heat, and weatherization. Caregivers also identified services that would be beneficial but were not available in their communities including dental care for the child, and respite care for the grandparent (Cross, Day, & Byers, 2010).

Typically, these needs are greater in Native populations because the poverty rate on reservations is three times the national rate, and there are fewer services available. The remote nature of many Native communities, combined with aging populations and high levels of disability, create a disproportionally high need for caregiving support in general. Al/AN/NH families provide approximately 90% of long-term care to older adults and people with disabilities in their communities—10% more than the general



U.S. population (Institute of Medicine (US) Committee on the Future Health Care Workforce for Older Americans, 2008).

While Native communities have a strong and proud tradition of caring for family, limited access to supportive services means that caregivers often experience more intense caregiving and are at greater risk for caregiver fatigue and burnout. In addition, in the planning and delivery of supportive services to these families, there are important considerations that are unique to Native communities that must be recognized and addressed to ensure that services and supports are effective, while also clearly respecting the sovereignty, culture, and self-determination of each community.

In 1978, Congress passed the Indian Child Welfare Act of 1978 (ICWA). ICWA protects American Indian and Alaska Native (AI/AN) children and families from diversionary child welfare practices that separate them from their extended families, communities, and culture. Today, in some Native communities, such as Pine Ridge in South Dakota, 58.7% of grandparents living on the reservation are raising their grandchildren. In the 2006-2008 American Community Survey, AI/AN/NH grandparents represented approximately 48,000 of the total number of grandparents raising their grandchildren. Actual figures are likely higher because many AI/AN/NH grandparents are not involved with the child welfare system and are reluctant to report their status.

"What I need is information on how to help me... with [my grandchildren]. I know we got counselors up at the hospital... maybe once a month they come in or whatever, but sometimes I need it daily. If they had a pamphlet or information on how I can be a better grandparent, because I'm not young like I used to be, and I do need my rest."

- Grandparent response to Title VI Evaluation

Many of these grandparent caregivers are living with multiple chronic health conditions and disabilities and are themselves care recipients of other caregivers. Often multiple caregivers will coordinate their efforts to support one individual. It is not uncommon for grandchildren to also serve as caregivers for the grandparents who are raising them. While Native populations share a commitment to putting family first and taking a holistic view of family to encompass neighbors, distant cousins, and close friends, the communities themselves are extremely diverse. A service delivery system developed for the needs of one community may not be replicable in another community.

One of the major reasons for this is geography. While federally recognized tribes are sovereign nations, the tribal reservations are nonetheless affected by the laws and regulations of the state within which they are located. This presents special challenges for tribal entities that are spread over multiple states, where some members live in rural areas and others live in metropolitan environments. For example, the Navajo





Nation has a total population of approximately 331,813 tribally enrolled members. More than half of these people live on the reservation which includes three states: Arizona, New Mexico, and Utah. While the nation itself has a rich linguistic and cultural history of family interconnectedness, each state interprets federal requirements such as ICWA differently, which affects how resources can distributed within local and tribal communities that straddle state borders.

These wide variations in level and type of need and circumstances among Native populations must be accounted for when planning the delivery of services and supports, especially when resources are scarce. The cost in terms of actual resources and logistics to deliver a respite program to a tribe in the continental U.S. is lower than the cost to bring a similar supportive service to a remote population. For example, delivering services to the Aleut people in Alaska's Aleutian Islands is made complicated by the fact that the community is only reachable by seaplane in winter. The local population is so small that any extra hands must be brought in from the mainland. To complicate things further, the local population speaks three different dialects. In addition, supportive services must also consider the traditional roles of grandparents and elders in Native populations. Traditionally, elders are highly revered. While they provide day-to-day care of children, this is part of the process of cultural and spiritual education; their role is "tantamount to nearly that of the supernatural deities" (Iron Cloud-Two Dogs). However, when grandparents and elders take on primary responsibility for a child, including discipline, many experience a difficult process of "role transformation" as they balance their new roles as parents with their traditional roles.

Finally, because Native populations tend to view family holistically and needs tend to be multifaceted, it is not easy to differentiate between services for family caregivers, services for kin and grandparent caregivers, and services for grandchildren. This integrated sense of family can make it difficult for service providers to differentiate, measure, and track roles and services for family caregivers, services for kin and grandparent caregivers, and services for grandchildren. If a volunteer is providing chore services at the home of an elder who is the recipient of a family caregiver's support while also serving as the primary caregiver to a minor child, it can be difficult for service providers to determine, for the purposes of data collection and evaluation, if those chore services are delivered to benefit the elder, the caregiver, or the child. In reality, the entire family likely benefits from such assistance. The data collection required by non-native service providers parses services in ways that are not intuitive for the population, and therefore cultural awareness needs to go beyond service provision to the data collection itself.

In addition, while all Native American cultures value and prioritize connection and harmony among the individual, family, tribe, community, and land, there nonetheless exist strong cultural differences between and among individual communities (Tilly & Hudgins, 2017).



Title VI of the Older Americans Act

"Sometimes I get so mad but then I can't because those are my kids, they're my grandkids. I can't... That's the kind of information I would kind of like to receive, even through the mail. How to deal with stress. How to deal with kids of certain age. Just like, parenting."

- Grandparent response to Title VI Evaluation

The Older Americans Act (OAA) of 1965 established grants for community planning, social services, research, and development for older persons. In 1978 the Act was amended to establish Title VI programs to provide nutrition and supportive services for Al/AN/NH. A further expansion added caregiver support services to Title VI, including support for grandparents and other elders raising children. ACL administers the Title VI programs with recognition of the strengths and resiliency of Al/AN/NH elders and with respect for Native communities' sovereignty, culture, and self-determination. A core value of the Native American Caregiver Support Services, as expressed by tribal leaders, is that the program should not replace the tradition of families caring for their elders. Rather, it provides support that strengthens the family's caregiver role.

In FY2020, Congress authorized \$2.23 billion for ACL under the OAA. Despite significant need, only 0.5% of that figure (just \$10.3 million) was allocated to support Native American family caregivers under Title VI. Currently, ACL oversees 233 individual grants to over 400 tribal organizations across the nation for Title VI caregiver services; typical services offered by these grants include:

- Information and outreach on topics related to providing care, such as insurance coverage, dementia, diabetes, and substance abuse. In 2018, the program provided approximately 199,495 contacts to provide information on services and programs to 42,198 unduplicated AI/AN/NH elders and their families (Administration for Community Living, 2018).
- Access Assistance. Examples include home visits to assess the needs of both caregivers and recipients of care, help with accessing insurance, Medicare, or medical services and referrals to local health clinics or other medical providers.
- Counseling, support groups, and training. In 2018, the program provided 125,480 units of assistance to 18,346 unduplicated Al/AN/NH elders (Administration for Community Living, 2018).
- Respite care, most typically in the form of payments to a respite care worker (often a family member) for a certain number of hours per week or per month. In 2018, the program provided 245,586 units of respite services to 3,280 unduplicated Al/AN/NH caregivers caring for elders or grandparents caring for their grandchildren (Administration for Community Living, 2018).



 Supplemental services such as supplies and equipment available through lending closets, for example, support them in their caregiving roles.

A nuanced understanding of cultural beliefs and values toward caregiving in Native communities can assist providers of supportive services to integrate those values into services and demonstrate cultural humility and respect. This, in turn, can help Al/AN/NH caregivers feel their values and beliefs are respected, improving trust, and increasing uptake of beneficial supports. Since 2016, an evaluation team has been conducting a three-year study of ACL's Title VI programs to better understand how tribal organizations operate their Title VI programs and to measure and document the impact of the programs.

Year 3 of the evaluation focused specifically on caregiver support services, including support for grandparent and kinship caregivers. The evaluation used a mix of information that grantees had already collected, as well as new sources of information to describe the implementation and outcomes across services. During site visits held in March, April, and May of 2019, the evaluation team conducted focus groups and interviews to understand caregivers' experiences with the program, including met and unmet needs related to spirituality, social connectedness and isolation, physical, mental, and emotional health and wellness, and independence and quality of life. The evaluation and focus group findings revealed that:

- Caregiving, including raising grandchildren, is a rewarding, yet challenging, experience for members of Al/AN/NH communities. For example, one grandparent described being concerned about whether her grandson, who struggles with behavioral health issues, could pose an unintentional danger to her husband, whose mobility and sense of balance was declining. She suggested that caring for both family members in the same household was stressful.
- Many caregivers do not self-identify as caregivers and as a result may not consider themselves eligible for services.
- When services are received through Title VI, they provide important support to improve the caregiver's overall quality of life.
- Many caregivers view their Title VI program services holistically and often do not distinguish between services specifically intended to support caregivers in comparison to services intended to support elders. For example, Title VI-supported nutrition and supportive services offered to elders often supported caregivers in their caregiving role(s).
- Many caregivers, including those already receiving some services, were not aware of the breadth of services available or had only recently become familiar with the program.





The evaluation also uncovered specific challenges faced by Al/AN/NH grandparents raising grandchildren. These included the difficulty of "starting all over," taking on the role and responsibility of being a primary caregiver for a child or adolescent, at a time when many grandparents are in need of greater support themselves, related to declining health or mobility. Issues include the time required to care for and raise a child, the related expense when financial resources may be at a low point, and the fact that managing the many tasks needed to raise a child requires energy and agility. Such tasks include providing meals, supporting routines, helping children with homework, attending to grandchildren's health care needs, and arranging for transportation to activities. Some grandparents noted that raising a child in today's environment is very different from their own experiences of growing up, as well as compared to the experience of raising their own children. For some grandparents, additional factors greatly intensified these challenges. These included:

- Caring for children who are less independent, including very young children.
- Caring for multiple children at once.
- Caring for children who struggle either with developmental disabilities or behavioral health issues, in some cases due to exposure to ACEs.

Al/AN/NH families have a strong tradition of cultural emphasis on in-home care, respect for elders, and community, yet various forms of historical trauma are significant factors in the lives of both the grandparents and grandchildren, and this history shapes how decisions are made to access services. Funding and delivering supports that recognize and respect the dynamic nature of the caregiver/care recipient relationships in Native communities is critical for the effective delivery of services to assist them. The final report of the evaluation is anticipated to be released in 2021 and will be available on the Services for Native Americans (OAA Title VI) webpage. ACL is using the preliminary findings to refine program delivery, most recently in developing tools that tribal organizations can use to improve data collection and stakeholder communication.

To review an overview of the Year 3 evaluation, refer to <u>Evaluation of the ACT Title VI Programs Year 3 Interim Report</u>. For more information on supporting the needs of caregivers in Native communities, refer to <u>LTSS Research</u>: <u>Annotated Literature Review Caregiver Support in Indian Country</u>. A series of <u>case studies describing AI/AN/NH caregiver support programs at six locations</u> is available on the CMS website.



VI. Services and Supports Currently Available to Assist Kinship Families and Grandfamilies

In 2017, as part of the RAISE Family Caregiving Act, Congress charged ACL with developing an inventory of all federal programs supporting family caregivers. The SGRG Act of 2018 contained a similar requirement to gather information about programs and resources to support grandparents raising children.

The report shall include— (i) best practices, resources, and other useful information for grandparents and other older relatives raising children identified under paragraph (1)(A) including, if applicable, any information related to the needs of children who have been impacted by the opioid epidemic; (ii) an identification of any gaps in items under clause (i); and (iii) where applicable, identification of any additional Federal legislative authority necessary to implement the activities described in clause (i) and (ii).

To reduce duplication of effort and enhance fidelity between developed materials, the RAISE Family Caregiving Advisory Council and the Supporting Grandparents Raising Grandchildren Advisory Council both participated in this effort. Each federal Advisory Council representative was responsible for surveying their home institution to gather specific knowledge important to caregivers and their families and communities and the staff and organizations who care for those caregivers. Members also provided referrals to agencies not represented on either council to ensure a broad collection of information. The inventory will support efforts across the federal government while at the same time avoiding duplication of effort and the creation of gaps in service when developing the National Family Caregiving Strategy.

As of July 2021, the inventory included information from the following agencies:

- AmeriCorps
- Consumer Financial Protection Bureau
- U.S. Department of Education
- U.S. Department of Health and Human Services (10 operating divisions)
- U.S. Department of Labor
- U.S. Department of Veterans Affairs

The resulting inventory of programs is intended to support all family caregivers, including kin and grandparent caregivers. The inventory includes information such as legislative authority of programs, identified gaps and opportunities, and information the public can use to access the programs. The Inventory of Federal Caregiver Support Programs & Initiatives is available on the ACL website and will be updated periodically.



Best Practices and Evidence-Informed Supports to Assist Kin and Grandparent Caregivers

"Our library system sponsors a monthly Grandparent Club, which is a support group and sponsors the Grandparent Project which is a series of speakers dealing with issues pertinent to our situation."

-Response to the RFI

In an effort to identify and document the breadth of emerging best practices to support kin and grandparent caregivers, the Advisory Council launched a series of ad hoc work groups in October 2020. These work groups reviewed and vetted best practices, resources, and other useful information about kinship families and grandfamilies submitted through the RFI

The RFI specifically sought information, resources, programs, and/or best practices to help kin and grandparent caregivers meet the diverse needs of the children in their care, along with similar resources to help them maintain their own physical and mental health and emotional and financial well-being. Respondents provided 337 recommended resources. These included 201 state or national programs, 78 publications, 39 research articles, 13 books, and six videos. Members of the Advisory Council formed a workgroup to review these materials and develop resource lists to share with other kin and grandparent caregivers. The workgroup, led by Charlotte Stephenson, reviewed each of the submitted materials in detail to determine to what extent each resource could be of value to a wide variety of kinship family and grandfamily stakeholders, including policymakers.

The result of that effort, <u>Supporting Grandparents Raising Grandchildren: Resources for Consumers and Professionals</u>, includes a list of resources and best practices for kinship families and grandfamilies and the professionals who support them.

Federal Programs and Resources to Support and Assist Kin and Grandparent Caregivers

Kinship Navigators Help Kin and Grandparent Caregivers Forge a Path to Success

Multiple RFI respondents, including the <u>Academy of Nutrition and Dietetics</u>, cited kinship navigator programs as a recognized and proven best practice for supporting kinship families and grandfamilies. Federal law defines kinship navigator programs as programs that assist kinship caregivers in learning about, finding, and using programs and services to meet the needs of the children they are raising and their own needs, and promote effective partnerships among public and private agencies to ensure kinship caregiver families are served.





In its RFI response, the Academy described a successful example of a kinship navigator effort underway with SHARE New Mexico, a resource directory on New Mexico community health resources, social services, initiatives, and counties.

"Although there are many government agencies at all levels whose missions are to provide support, the reality is that the needed support is not there. I have checked online resources and have contacted various agencies but ultimately find myself isolated without support."

-Response to the RFI

To develop and sustain programs to support kinship families and grandfamilies, an understanding of the current landscape of existing support is necessary. A number of federal agencies provide support and assistance directly or indirectly to kinship families and grandfamilies. Yet, finding information about these programs is challenging. At present, there is no single repository of information on available federal supports and services to kinship families and grandfamilies.

Congress' call for a National Family Caregiving Strategy—which is to be informed by the inventory of existing federal caregiver support programs—is an important step in the realization of a vision where caregivers across the nation can receive the assistance they need in a coordinated and efficient manner.

The information presented below provides highlights of key federal programs that serve kinship families and grandfamilies directly or indirectly. The programs were identified by members of the Advisory Council, respondents to the RFI, and through the inventory development process. They are included in this report to illustrate the diversity of programs and the potential for gaps or duplication of effort when planning for the delivery of supports and services for kinship families and grandfamilies.

Administration for Children & Families (ACF)

ACF, a division of HHS, promotes the economic and social well-being of families, children, individuals, and communities with funding, strategic partnerships, guidance, training, and technical assistance.

- TANF can provide kinship families and grandfamilies with financial support to help meet the needs of the children they are raising. States receive block grants to design and operate programs that accomplish one of the purposes of the TANF program. Therefore, these programs vary dramatically from state to state.
- Kinship Navigator Programs are services that assist kin and grandparent caregivers
 in learning about and accessing programs and resources to meet the needs of
 the children they are raising, to provide help for the family as a whole to safeguard



stability, and to promote partnerships among public and private agencies. Kinship navigator programs aim to improve caregivers' knowledge of services and assist them in being able to identify and access the services they need. Some are not intended to directly provide the services needed by kinship families, whereas others do provide direct services and assistance (Child Welfare Information Gateway, 2019). See sidebar above for an example of a successful kinship navigator program. According to Generations United, positive outcomes for families receiving services from kinship navigator programs include:

- Safety: Relative caregivers receiving navigator services achieved identified safety goals for their families.
- Permanency: Children in the care of relative caregivers receiving navigation services had higher rates of permanency through legal guardianship and reunification with parents.
- Well-being: Results showed that kinship navigator programs were successful at ameliorating the needs of grandfamilies (Generations United, 2020d).
- Child Welfare Information Gateway offers information for families and professionals on a range of child-welfare related topics, including family-centered practice, child abuse and neglect, abuse and neglect prevention, child protection, family preservation and support, foster care, achieving and maintaining permanency, adoption, management of child welfare agencies and related topics such as child and family assessment, laws and policies, statistics, and related family issues (e.g., domestic violence and substance use).
- Administration for Native Americans (ANA) promotes self-sufficiency for Native Americans by providing discretionary grant funding for community-based projects, and training and technical assistance to eligible tribes and Native organizations. To maximize resources on behalf of Native communities, ANA partners with related programs within ACF and HHS, as well as with other federal agencies and nonprofit organizations.
- Office of Head Start manages grant funding and oversees local agencies providing Head Start services. Head Start and Early Head Start (HS/EHS) promote school readiness and provide comprehensive services for children birth to age five and their families. Head Start and Early Head Start programs serve families with low incomes, families experiencing homelessness, and children in foster care by providing education, health, and family support services, and by engaging parents and families in education and leadership roles in programs. In addition, HS/EHS play a key role in the delivery of early childhood disability services, including screening and connecting families to early intervention and special education services.



 Office of Child Care manages <u>ChildCare.gov</u>, a website that provides links to state or territory child care resources that kin and grandparent caregivers can use to search for child care and consumer education information.

Administration for Community Living (ACL)

ACL was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities. By funding services and supports provided by networks of community-based organizations, and with investments in research, education, and innovation, ACL helps make this principle a reality for millions of Americans. In addition to supporting the implementation of the Act, ACL offers the following initiatives that directly and indirectly support kin and grandparent caregivers:

- The <u>National Family Caregiver Support Program</u> funds a variety of supports that help family and caregivers care for older adults in their homes for as long as possible and includes supports for grandparents and other older caregivers raising children.
- The <u>Lifespan Respite Care Program</u> works to improve the delivery and quality of respite services for caregivers of older adults and people with disabilities through coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs.
- RAISE Family Caregiving Advisory Council is charged with providing recommendations to the Secretary of Health and Human Services on effective models of family caregiving and support to family caregivers, as well as improving coordination across federal government programs.
- The National Technical Assistance Center on grandfamilies and kinship families (NTAC), created in September 2021, is the first national technical assistance center devoted to kinship families and grandfamilies. Through a broad range of technical assistance and information dissemination, the NTAC measurably increases the capacity and effectiveness of states, territories, tribal organizations, and nonprofit and other community-based organizations to serve and support members of kinship families and grandfamilies.
- University Centers for Excellence in Developmental Disabilities (UCEDDs) offer a variety of resources for families and caregivers including guides, videos, webinars, and trainings.
- OAA Title VI (Services for Native Americans) provides a range of programs that support American Indians, Alaska Natives and Native Hawaiians in the areas of nutrition, supportive services for older adults, and caregiver services. The nutrition and supportive services grants include congregate and home-delivered



meals, information and referral, transportation, personal care, chores, health promotion and disease prevention, and other supportive services. The caregiver services grants include assisting families in caring for older relatives with chronic illness or disability and grandparents caring for grandchildren.

- Aging and Disability Resource Centers Program/No Wrong Door System is a
 collaborative effort with ACL, CMS, and the Veterans Health Administration to
 support state efforts in streamlining access to long-term services and support
 options for older adults and people with disabilities.
- <u>Eldercare Locator</u> is a nationwide service that connects older adults and their caregivers with trustworthy local support resources, including meals, home care or transportation, or caregiver training, education, or a well-deserved break from caregiving responsibilities.
- <u>State Health Insurance Assistance Program</u> provides Medicare beneficiaries with information, counseling, and enrollment assistance.

AmeriCorps

AmeriCorps operates <u>AmeriCorps Seniors</u> which offers two distinct volunteer programs that pertain to kinship families and grandfamilies. These programs are funded through grants to qualified agencies and organizations for the purpose of engaging adults age 55 and over in meaningful volunteer service:

- Foster Grandparent program is an intergenerational program where volunteers have the sole mission to help strengthen the education and emotional development of children at risk of falling behind in school, many of whom are being raised by grandparents.
- RSVP program also supports older caregivers through several focus areas that include education, economic opportunity, healthy futures, and veterans and military families. For example, RSVP volunteers help renovate homes, tutor students with disabilities, and help teach money management to those grandparents who might be challenged with developing family budgets and securing credit. They also help educate grandparents on issues around financial exploitation and avoiding fraud and scams. Additionally, in the education realm, RSVP volunteers also teach English to grandparents for whom English might be a second language.

Census Bureau

<u>The Census Bureau</u> is the nation's leading provider of reliable and quality data about its people and economy. While the Census Bureau did not participate in the initial development of the inventory, the agency plays a role in supporting kinship families and grandfamilies that is worth noting. According to the Census website, by collecting



data about the ages of children, household income, disability, and poverty status, the agency is able to help communities "enroll eligible families in programs designed to assist them." Communities use census data about how many people within the community are over a certain age and whether older Americans are caring for grandchildren, to fund programs and services targeted to reach older adults through the OAA.

The "grandparents as caregiver's question" originated with the 2000 Census and was transferred to the American Community Survey in 2005. The question asks whether adults in the household live with their grandchildren under 18 and if they are responsible for their basic care. The resulting statistics about grandparent caregivers help federal agencies understand the special provisions needed for federal programs designed to assist families.

Centers for Medicare and Medicaid Services (CMS)

CMS is the agency within HHS that provides access to health coverage to more than 100 million people through Medicare, Medicaid, Children's Health Insurance Program (CHIP), the Basic Health Program (BHP), and the Health Insurance Marketplace[®].

- Medicare is the federal health insurance program for people who are 65 or older; certain younger people with disabilities; and people with end-stage renal disease.
- Medicaid provides health coverage for eligible low-income individuals and families, children, pregnant women, older adults, and people with disabilities. Medicaid is administered by states, according to federal requirements. The program is funded jointly by states and the federal government.
- CHIP provides health coverage to eligible children in families with incomes too high to qualify for Medicaid, but who cannot afford private coverage. CHIP is administered by states, according to federal requirements. The program is funded jointly by states and the federal government.
- The <u>BHP</u> provides states the option to establish health benefits programs for low-income residents who would otherwise be eligible to purchase coverage through the Health Insurance Marketplace®, providing affordable coverage and better continuity of care for people whose income fluctuates above and below Medicaid and CHIP levels.
- The Health Insurance Marketplace® provides health plan shopping and enrollment services for individuals and families (the individual market), as well as employees of small businesses [the Small Business Health Operations Program (SHOP)] through websites, call centers, and in-person assistance. A marketplace can be operated by a state or the Federal Government.



Consumer Financial Protection Bureau (CFPB)

The CFPB is a U.S. government agency that protects consumers from unfair, deceptive, or abusive practices and arms people with the information, steps, and tools they need to make wise financial decisions.

- Managing Some Else's Money is a series of guides for the millions of Americans who manage money or property on behalf of others. The guides help financial caregivers in three ways: they walk them through their duties, they tell them about protecting their loved ones from financial exploitation and scams, and they tell them where to go for help.
- Protecting your finances during the coronavirus pandemic has resources to help consumers protect and manage their finances during this difficult time.
- Free financial education activities for parents to use with kids to help them build the skills to manage money into adulthood.

Individuals interested in receiving updates from the Office for Older Americans can subscribe at https://www.consumerfinance.gov/consumer-tools/educator-tools/ resources-for-older-adults/.

Indian Health Service (IHS)

The IHS, an agency within HHS, is responsible for providing federal health services to American Indian and Alaska Native (Al/AN) people through the following programs:

- The Youth Regional Treatment Center (YRTC) program provides education and culture-based prevention initiatives, evidence-based and practice-based models of treatment, family strengthening, and recreational activities to assist youth in overcoming their challenges and recovering their lives to become healthy, strong, and resilient leaders in their communities.
- The <u>Substance Use and Suicide Prevention</u> (SASP) program exists to reduce the prevalence of substance use and decrease the overall use of addicting and illicit substances among AI/AN populations. The program helps ensure access to comprehensive, culturally appropriate services and promote quality programming to address substance use for AI/AN community members. The IHS encourages and supports cross-system collaboration, the inclusion of family, youth, and community resources, and culturally appropriate approaches.
- IHS offers web-based training on <u>Trauma-Informed Care</u> (TIC). IHS TIC training has been modified and adapted to address the unique experiences, including historical trauma, of American Indians and Alaska Natives. Historical trauma is the cumulative psychological and emotional wounding across generations.



National Institutes of Health (NIH)

NIH's 27 Institutes and Centers produce easy-to-understand educational materials about health and science for family caregivers. Many of these resources also apply to kinship families and grandfamilies. The following are a few examples of caregiving websites across NIH that are relevant to kinship families and grandfamilies.

- The National Institute on Aging (NIA): NIA's Health Information webpages cover a broad range of health topics and include numerous tips and resources on <u>caregiver</u> <u>health</u> and for <u>family caregivers</u>.
- The National Institute of Nursing Research (NINR): Health Information pages include videos, tear-off pads, resource cards, fact sheets, a provider toolkit, and brochures for health care providers and for families with seriously ill children, as part of their Palliative Care: Conversations Matter campaign, aimed at increasing the use of palliative care for children and teens living with serious illnesses.
- The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD): Health Information webpages offer brochures, booklets, reports, and other materials on topics within its research portfolio for different audiences, and the <u>Grandparent Videos</u> section features <u>Safe Infant Sleep for</u> <u>Grandparents and Other Trusted Caregivers</u>.
- MedlinePlus: A free online health information resource for patients and their families and friends, includes information for caregivers.

Social Security Administration (SSA)

According to the <u>SSA website</u>, "Social Security is one of the most successful antipoverty programs in our nation's history." While the agency did not participate in the inventory, the agency operates a number of programs that may assist kin and grandparent caregivers who qualify.

- Survivors' benefits are paid to widows, widowers, and dependents of eligible workers. This benefit is particularly important for families with children. Some of the deceased's family members may be able to receive Social Security benefits if the deceased person worked long enough in jobs insured under Social Security.
- Social Security's Representative Payment Program provides benefit payment management for beneficiaries who are incapable of managing their Social Security or Supplemental Security Income (SSI) payments. A payee's main duties are to use the benefits to pay for the current and future needs of the beneficiary, and properly save any benefits not needed to meet current needs.



 Social Security Benefits for Children are available to qualifying children whose parents are disabled, retired, or deceased. Under certain circumstances, a stepchild, grandchild, step-grandchild, or adopted child can also receive benefits.

Substance Abuse and Mental Health Services Administration (SAMHSA)

SAMHSA is the agency within HHS that leads public health efforts to advance behavioral health. Its mission is to "reduce the impact of substance abuse and mental illness on America's communities." SAMHSA offers two specific programs that can assist kin and grandparent caregivers:

- The Statewide Family Network Program Grants, administered by the Statewide Family Network (SFN) program, provide support to families who are raising children with serious emotional disturbance (SED).
- The National Family Support Technical Assistance Center (NFSTAC) provides information to persons and communities across the country who are caring for family members with serious mental illness and/or substance use challenges. NFSTAC is led by the National Federation of Families, a family-run organization, in partnership with the Partnership to End Addiction, C4 Innovations, SAFE Project, and Boston University. The approach of NFSTAC is anchored by the underlying principle that families play a vital role in supporting their children and are the experts regarding their family support needs.
- For providers and organizations that serve American Indian and Alaska Native communities, SAMHSA also offers a guide that enhances cultural competence. The <u>American Indian and Alaska Native Culture Card</u> covers regional differences, cultural customs, spirituality, communication styles, the role of veterans and older adults, and health disparities.

U.S. Department of Agriculture (USDA)

The USDA provides leadership on food, agriculture, natural resources, rural development, nutrition, and related issues based on public policy, the best available science, and effective management.

The Supplemental Nutrition Assistance Program (SNAP), also known as "food stamps," is a supplementary program to help an individual or family in buying nutritious food. Since SNAP benefits are managed by each individual state program, applicants should consult the <u>SNAP State Directory of Resources</u> for contact information for local SNAP offices.



- The <u>National School Lunch Program (NSLP)</u> is a federally assisted meal program operating in public and nonprofit private schools and residential child care institutions. In 2016, the program served 30.4 million children (United States Department of Agriculture, 2017). USDA also operates a school breakfast program and a summer food service program for qualifying children.
- The <u>Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)</u> offers healthy food, nutrition counseling, and referrals to health, welfare, and social services to low-income women and young children. WIC also offers an online <u>WIC Pre-screening Tool</u> to assist families with determining their eligibility status.
- The <u>Emergency Food Assistance Program</u> provides a variety of nutritious, high-quality USDA foods, and makes those foods available to families in need of short-term hunger relief through emergency food providers like food banks.

For more information by state on related programs, browse the <u>Food and Nutrition</u> category on Benefits.gov.

U.S. Department of Education (ED)

ED offers assistance with obtaining information on educational rights through the following programs:

- Individuals with Disabilities Education Act (IDEA) website brings together IDEA information and resources from the Department and grantees that caregivers, parents, educators, service providers, or students can use to find information and explore resources on infants, toddlers, children, and youth with disabilities.
- Resources for Families and Caregivers Helping Your Child Become a Reader is a curated webpage of federal offices and federally funded clearinghouses that provide information on literacy and learning.
- Parent and Family Digital Learning Guide helps caregivers understand how digital tools can provide tailored learning opportunities, engage students with course materials, encourage creative expression, and enrich the educational experience.
- The Office of Elementary and Secondary Education (OESE) empowers "states, districts, and other organizations to meet the diverse needs of every student by providing leadership, technical assistance, and financial support."
- The Center for Parent Information and Resources provides information and resources to support families of children with disabilities, and a listing of the parent centers throughout the country that receive federal funding to support families at the state and community levels.



U.S. Department of Housing and Urban Development (HUD)

HUD is responsible for national policy and programs that address housing needs and enforce fair housing laws. HUD did not participate in the development of the inventory, but its role in offering multiple programs that provide affordable/subsidized housing for low-income families, including kinship families and grandfamilies is important to note. In 2019, HUD provided rental assistance to 5.2 million households, of which 68% included children, older adults, and people with disabilities (Center on Budget and Policy Priorities, 2021).

- The <u>Housing Choice Voucher Program (HCVP)</u> or "Section 8" is a recognized HUD program. The most notable component of this program is its "portability" feature which gives recipients the choice of living in any community of their choice across the U.S. and the territories.
- The Resources for Tribal Housing webpage on HUD.gov provides an overview of the Indian Housing Office of Native American Programs (ONAP). In compliance with the Native American Housing Assistance and Self Determination Act of 1996 (NAHASDA) (Public Law 104-330), HUD is required to treat Native American tribes as sovereign nations entitled to receive direct funding from HUD. As a result, each tribe designates an organization/entity, which can be a department within the tribe, a tribal housing authority with its own Board of Commissioners, or a non-profit to administer a housing program on its behalf, these are referred to as Tribally Designated Housing Entities (TDHEs).
- Across the country, HUD is partnering with local housing agencies to address the housing struggles of kin and grandparent caregivers by creating affordable subsidized housing for kinship families and grandfamilies. Plaza West — a 223-unit affordable rental community in downtown Washington, D.C., with 50 units in the 12-story complex dedicated to grandparents raising grandchildren — and the 36unit grandfamily housing at Pemberton Park, developed by the Housing Authority of Kansas City, Missouri, are two key examples.

For a detailed list of HUD mortgage, grant, assistance, and regulatory programs offered in 2020, refer to Programs of HUD 2020.

U.S. Department of the Treasury

The Treasury office manages currency, government accounts, and public debt. The Department of the Treasury also enforces finance and tax laws. While it does not offer any direct programs for caregivers and did not participate in the development of the inventory, it is worth noting that the federal tax code does offer tax credits that may be available to kinship families and grandfamilies who qualify.



- The Internal Revenue Service, within the Treasury, offers a fact sheet, Raising Grandchildren May Impact Your Federal Taxes, which describes tax benefits available to qualifying kin and grandparent caregivers. These include filing status considerations, possible exemptions, available tax credits, qualifying expenses, and information on which tax forms are applicable and how to access them.
- Economic Impact Payments: <u>The Get My Payment tool</u> helps families learn when their payment is scheduled to be sent and how it was sent.
- The Treasury Department also offers the <u>Tax Counseling for the Elderly (TCE)</u> <u>Program</u>, which may help some kinship families and grandfamilies who qualify in completing their tax forms.



VII. Recommendations: What Kinship Families and Grandfamilies Need to Thrive

The Advisory Council developed the following recommendations over a year, after multiple discussions to uncover the root causes of the challenges described in the RFI and in the research data. The Advisory Council's 22 recommendations will inform the development of the National Family Caregiving Strategy, which is being developed in collaboration with the RAISE Family Caregiving Advisory Council. When fully developed, the strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers. It will promote greater adoption of person- and family-centered care in all health care and long-term service and support settings, increase use of evidence-informed tools, information, education, training supports, referral, and care coordination to increase support for caregivers and expand access to respite options. Finally, it will increase financial security and reduce workplace discrimination faced by caregivers, including kin and grandparent caregivers.

The recommendations are organized into five priority areas to allow for maximum integration of federal, state, local, and tribal initiatives to support kinship families and grandfamilies. The development of the recommendations is the first phase in an effort to support kinship families and grandfamilies. Specific actions that must be taken to address each goal will be outlined in the National Family Caregiving Strategy. Beneath each recommendation is a rationale statement developed by members of the Advisory Council that explains in plain language why that particular recommendation is critical to the future well-being of kinship families and grandfamilies.

Priority Area 1: Awareness of/Outreach to Kin and Grandparent Caregivers

Recommendation 1.1: Increase public awareness and recognition of the unique strengths and needs of kin and grandparent caregivers and the importance of supporting them while they support the children in their care.

Rationale: Kinship families and grandfamilies face unique circumstances and challenges. While often faced with stigma and misconception, these families exhibit considerable strength and resilience. Many of the entities and systems (e.g., schools, doctors, law enforcement, etc.), that regularly connect with and support these families, lack the understanding and awareness of the challenges they face and how to address them. One of the most effective ways of fighting stigma and debunking misconceptions is through proactive public awareness and education. When stakeholders and the public understand the importance of supporting kinship families and grandfamilies, they are more likely to be a part of the solution.



Recommendation 1.2: Improve outreach to kinship families and grandfamilies to help them to identify their critical role as primary caregivers so they seek access to appropriate services and supports.

Rationale: Those who step in to provide care and support for children, often do so without realizing they are becoming a "family caregiver" and, as a result, are often not served by child welfare services. Kin and grandparent caregivers often encounter numerous unanticipated hurdles that quickly can become overwhelming. Many are fearful or mistrustful of the formal system of supports, and very seldom reach out to ask for help. To counter this, both traditional and non-traditional sources of support (e.g., schools, churches, libraries, doctors, dentists) must be proactively engaged in outreach with information on a wide range of topics.

Recommendation 1.3: Increase kinship families and grandfamilies' awareness of, and access to, the full range of available information, services, and supports to help them meet their needs and the needs of the children in their care.

Rationale: Publicly funded supports are of little use if the people for whom those programs are designed never know they exist or how to access them. When kin and grandparent caregivers step in to care for a child, they often do so with little knowledge of the types of programs that are available to support them. One of the major barriers to accessing supports and services is the lack of consistency in the programs, even those within the same state. Bridging the awareness and information gaps in creative and coordinated ways is essential to ensuring that kinship families and grandfamilies can easily locate and access supportive services.

Priority Area 2: Kin and Grandparent Caregiver Engagement

Recommendation 2.1: Ensure kin and grandparent caregivers are recognized as an integral part of the child's care team, engaged in programs that are family centered, and cognizant of the conflicting goals in care.

Rationale: Raising a child can take a village. Today, that village might be called a "care team" and can include extended family, the school system, counselors, faith communities, civic organizations and, even, in some instances, the child welfare system. Regardless of the makeup of the child's care team, it is critical that each member recognize the important role of kin and grandparent caregivers as the bridge between the child and that team. They are the "glue" that connect children to their past and present, which is important to their future well-being. For these reasons, every member of the child's care team must ensure that the kin and grandparent caregivers are recognized and included as equal members of the team by putting them at the forefront of the care planning process.





Recommendation 2.2: Increase the use of comprehensive assessments to determine caregiver and family strengths and needs when identifying appropriate services for kinship families and grandfamilies who are seeking help.

Rationale: Kinship families and grandfamilies can often have complex, fluctuating, and nuanced needs for information, services, and supports. Many of the kin and grandparent caregivers are faced with a complex reality in which "they don't know what they don't know." A comprehensive needs assessment can be a critical tool for understanding and effectively implementing a plan of care that benefits the whole family. Evidence-based and evidence-informed assessment tools can be indispensable for understanding the strengths and needs of each family so that services provided achieve maximum benefit.

Recommendation 2.3: Increase the inclusion of kin and grandparent caregivers and young people's voices in the planning of services by all relevant entities such as child welfare, aging, income support, and community-based organizations and service providers.

Rationale: When community agencies undertake planning and program design, a familiar mantra from the likely consumers of those programs is "nothing about us without us." Developing and delivering the right mix of services in the right ways at the right times, with an eye toward cultural competence and sensitivity requires the input and advice of the individuals served. Including guidance, input, and feedback, from the families they serve, strengthens services and supports for kinship families and grandfamilies. Authentic engagement of family voices promotes trust, encourages buy-in, improves access, and fosters higher levels of involvement with services, while reducing the risk of unintended consequences.

Recommendation 2.4: Increase the inclusion of the topic of kinship families and grandfamilies in the education curricula and programs for health care, social workers, child welfare, legal, judicial, education, aging, disability, and related professions.

Rationale: Typically, when a child participates in educational, health care, and other supportive programs, the child is defined by their parent(s) and the parent(s) are expected to represent that child to the various systems. In the case of kinship families and grandfamilies, there is often a lack of, or few, established policies to guide providers so they can adjust accordingly to accommodate children and their families. Increased awareness of the unique strengths and challenges of kinship families and grandfamilies will assist relevant entities with the establishment of equitable supportive policies that are rooted in a depth of understanding and lead to the implementation of procedures to appropriately support children and their families, resulting in the best possible outcomes.



Priority Area 3: Services and Supports for Kinship Families and Grandfamilies

Recommendation 3.1: Increase kinship families and grandfamilies' access to information, services, and supports.

Rationale: Kinship families and grandfamilies often step up to care for children with little warning and may not know what supports or services are available or where to turn for help. Most traditional helping systems were not designed with them in mind and may use exclusive terms like parent or foster parent in their outreach, programs, and resource materials. As a result, kinship families and grandfamilies are often left unaware or unable to access available supports such as child welfare services, health care, legal services, respite, counseling, training, housing, financial assistance, and food and nutrition assistance.

Development and expansion of outreach, referral, and support programs specifically designed for relatives, such as kinship navigator programs, can improve access to services and supports for kinship families and grandfamilies. Access to supports around the country can be improved further through a National Technical Assistance Center on Grandfamilies that will provide training and technical assistance on exemplary kinship family and grandfamily practices, policies, and programs to systems that serve the target families.

Recommendation 3.2: Increase the availability of high quality, setting-appropriate, and kinship family and grandfamily-centered **respite** and child care services.

Rationale: For many family and kin caregivers, having a break from one's caregiving duties is essential for good self-care and to prevent stress and burnout. Often called "respite," this break from caregiving can prove critical for maintaining the health of the family caregiver and the integrity of the family unit. Respite for kin and grandparent caregivers may come in different forms including, but not limited to, after school programs, summer or day camp programs, faith-based programs, etc. Regardless of the form it takes, or the frequency with which it occurs, respite programs and services must be of high quality, culturally appropriate, and family-centered to be effective.

Recommendation 3.3: Increase the availability and types of culturally competent, trauma-informed **counseling**, **training**, **and education** for kinship families and grandfamilies, including best practices, model approaches, and evidence-based interventions.

Rationale: There is an abundance of credible literature and studies showing that children raised by kin and grandparent caregivers often have a history of





trauma. Trauma is defined as any event that is more overwhelming than that which is ordinarily expected, and can leave the child feeling out of control, terrified, worthless, unloved, insecure, and at-risk. Kin and grandparent caregivers often have little to no understanding of the specific traumas a child has experienced and as a result, are unprepared to parent a child with such a challenging history. Providing supports, including counseling, training, and education in traumainformed and culturally competent ways is key to preventing further trauma or retraumatizing the child.

Recommendation 3.4: Increase the availability of supports and services that specifically meet the needs of the caregiver.

Rationale: Increasing the availability of supports and services that address the basic needs of kinship families and grandfamilies — nutrition; education; housing; emotional, mental, and physical health; and trauma-related issues - will provide a foundation for the well-being of the entire family. Over time, this will have a positive effect on other aspects of the lives of caregivers and children. For example, being able to maintain hobbies and social engagement, or devote time to attend to needs of other family members, can have a protective effect by increasing an individual's capacity to cope with the other stressor they encounter, such as finances.

Recommendation 3.5: Expand the use of technology as a means of supporting kinship families and grandfamilies.

Rationale: The continued emergence of new technologies and the required use of them to keep pace with the ever-changing landscape of how services are acquired and delivered has widened the gap of opportunity for digitally disadvantaged families. In addition, many kin and grandparent caregivers are older adults and more likely to face challenges with understanding or accessing technology. If kinship families and grandfamilies are technologically disadvantaged, the children in their care may not have access to the technology required to be successful at school or they may have limited opportunities for social development. Disadvantaged kin and grandparent caregivers may not participate in supportive programs that require online access, and where data collection may be required for registration. Therefore, their needs remain unknown and unaddressed. Kin and grandparent caregivers need cost-effective technology, training to use it, and information relative to monitoring the appropriate use of technology for the children in their care.

Recommendation 3.6: Expand the use of volunteers, mentors, and peer-to-peer supports as a means for supporting kinship families and grandfamilies, including as a possible path to employment or career development.



Rationale: For many kin and grandparent caregivers, stepping into the role of "parent" again after many years brings about a host of challenges. In many cases, these individuals must navigate systems (e.g., schools, health care, legal assistance, and child welfare programs) that are either new to them or have changed since they were parents.

Kinship families and grandfamilies can benefit from connections to those with lived experience in today's world who can provide them with an opportunity to gain knowledge and connection to others like them. Having robust volunteer, mentoring, and peer-to-peer programs for these caregivers will help ensure they have someone who can assure them that they are not alone; help them understand what resources might be available and how to access them; and perhaps, even accompany them to school meetings, legal visits, custody hearings, and county services.

Recommendation 3.7: Improve availability and access to free or affordable quality legal and financial information, guidance, and services for kinship families and grandfamilies.

Rationale: Many times, when grandparents and other kinship caregivers come forward to prevent the child from entering the formal child welfare system, they need to have a legal relationship established. Kin and grandparent caregivers caring for children outside the foster care system need access to legal support to ensure they have the necessary authority to access supports for the children and make certain decisions on their behalf. These caregivers often have poor/inadequate access to quality, affordable legal assistance. Many spend thousands, even hundreds of thousands, on legal fees, leaving them in debt, often with insufficient funds to meet the family's basic needs, and, even more often, reduced savings to meet unexpected financial shocks. Many opportunities exist to expand and improve the availability of legal and financial services, supports, and guidance to properly address these critical priorities.

Recommendation 3.8: Improve child welfare system approaches to better prioritize and support the placement of children with relatives when they cannot remain with their parents.

Rationale: Some child welfare agencies do not have strong systems in place to conduct outreach to identify and prioritize relatives for children who must be removed from their parents' homes. As a result, children are unnecessarily placed with unfamiliar foster parents where they are more likely to lose connections to their siblings, extended family, cultural identity, and community connections. Improving child welfare system approaches to engaging and supporting kinship



families and grandfamilies will result in better outcomes for both caregivers and children. Child welfare systems must improve their outreach, engagement, and supports to relatives by: leading their agencies with a "kin-first" philosophy; developing written policies and protocols that reflect equity for children with kin and recognize their unique circumstances; identifying and proactively engaging kin for children at every step; creating a sense of urgency for making the first placement a kin placement; prioritizing kin licensing; supporting permanent families for children; and creating a strong community network to support kinship families and grandfamilies.

Priority Area 4: Financial and Workplace Security for Kin and Grandparent Caregivers

Recommendation 4.1: Promote policies that prevent kin and grandparent caregivers from being financially disadvantaged by their caregiving responsibilities.

Rationale: Most kin and grandparent caregivers come to their roles unexpectedly and were not planning to step in to raise a child in their later years. Many may also be living on a fixed income and do not have access to the information or knowledge of the programs that could help them to obtain financial support. As a result, they often spend their retirement savings to meet the children's daily basic needs and legal fees associated with getting legal custody of the children. When this happens, both the caregivers and children experience adverse impacts. Policies that provide financial support for kinship families and grandfamilies should not require them to spend any life savings they may been able to acquire before accessing supports.

Recommendation 4.2: Advance the development and broad adoption of workplace policies, flexibilities, and practices that recognize kinship family and grandfamily responsibilities as a fundamental part of each worker's life and support public-private partnerships that enable scalable solutions.

Rationale: Many kin and grandparent caregivers remain in the workforce while at the same time juggling the daily demands of raising children. These caregivers should be given the opportunity to benefit from the same workplace policies and protections as are in place for parents. Meaningful, flexible policies and practices in the workplace can afford kin and grandparent caregivers the information, tools, and resources they need to balance their responsibilities, thus allowing them to remain in the workforce and maintain their financial stability.

Recommendation 4.3: Increase the availability and use of tailored resources that kinship families and grandfamilies can use to make informed financial decisions and plan for future financial needs.



Rationale: Kin and grandparent caregivers often express concerns about their own personal financial situations and the future financial security of themselves and the children in their care. Many have persistent concerns about how to meet the costs of health care, health supplies/equipment, school supplies, housing, and other needs of the children. Caregivers have their own financial needs, and that may include supporting other family members. Kin and grandparent caregivers need a range of information and resources to support sound financial decisions and future planning for themselves and the children in their care.

Recommendation 4.4: Ensure that kinship families and grandfamilies have the resources they need to engage in advance planning so that they may provide for children in the event of illness or incapacity.

Rationale: Caregivers are often so busy meeting the children's basic needs that they do not have the time, nor do they give thought to making the necessary legal arrangements for themselves or the children in their care. Without adequate and sound legal protections, the children may end up in the foster care system. This issue is further complicated and made more urgent when the children have disabilities. Ensuring the availability of, access to, and support for developing legal and financial arrangements are critical tools for protecting the future of the caregiver and children alike.

Priority Area 5: Research, Data, and Evidence-Supported Practices

Recommendation 5.1: Establish a national approach for obtaining, analyzing, and disseminating relevant data on kinship families and grandfamilies.

Rationale: There is currently a lack of uniformity and comprehensiveness with respect to available data representing kinship families and grandfamilies. This is largely because such data is only collected on those families that come into contact with child welfare or other similar agencies. There is little data collected on the kinship families and grandfamilies that are unknown to the foster care system. Without sufficient and reliable data on these families, developing and administering programs of support that are of the proper scope will remain elusive at best. For this reason, establishing a national mechanism for obtaining, analyzing, and disseminating data is needed.

Recommendation 5.2: Increase, support, and sustain research and development, including adequate investments for evaluation of programs that support kinship families and grandfamilies.





Rationale: Few of the systems serving kinship families and grandfamilies were designed with these families in mind. Developing programs specifically tailored to the needs of kinship families and grandfamilies is a relatively new practice. Many programs that are serving them have been pieced together from varied funding sources without adequate resources to properly evaluate their efficacy. As a result, there is a dearth of research on effective programs. Many of the available federal and local funding streams for kinship family and grandfamily supports required programs to be evidence-based. Investments in research and evaluation for kinship family and grandfamily services will provide a pool of evidence-based programs and learning to inform model practices. This will better ensure that benefits, services, and supports are effectively meeting their needs, and that they will have access to ongoing funds to sustain them.

Recommendation 5.3: Increase the promotion, translation, and dissemination of promising practices, model approaches, evidence-informed and evidence-based practices to support kinship families and grandfamilies.

Rationale: Effective supports and interventions for kinship families and grandfamilies is often dependent on translating the research into real-world settings. Effective interventions require that such efforts must be multi-component and address both the pragmatic and the emotional elements of caregiving. Working with diverse communities to develop services and models that best meet their needs, while expanding and replicating promising practices that are personand family-centered are critical components. Building on evidence-informed services for caregivers is fundamental to helping organizations scale up practices and supports that are proven to be impactful and cost-effective.



VIII. Conclusion

Grandparents and other elders connect us to the past and prepare us for the future. When parents cannot care for children, the wisdom, experience, and selfless loving care of grandparents, close relatives, and family friends forms a safety net for children who would otherwise find themselves living with people they do not know.

The nation owes an immeasurable debt of gratitude and support to the millions of kin and grandparent caregivers across the nation who have primary responsibility for their grandchildren on a day-to-day basis. The U.S. Census Bureau estimates that there are 2.7 million children in the care of grandparents (U.S. Census Bureau, 2019). The true number—when taking into account the aunts, uncles, godparents, family friends, and all the people who are responsible for children without realizing they are in fact "caregivers"—is likely many times higher.

The number of children who cannot remain with their parents is increasing and expected to continue to do so in the future. Kinship families and grandfamilies are the solution to a growing national problem. Instead of placing children in the foster care system, grandparents can and do step in to nurture, financially support, and provide primary care for the child. This approach works because kin and grandparent caregivers have a different set of strengths than a foster parent would provide. More importantly, it works because they know and love the children in their care.

While the child welfare system is increasingly relying on kinship families and grandfamilies to raise the children, grandparents and other relatives are less likely than non-related foster parents to receive supports and services (Generations United, 2017). Placing children with people who know and love them enables children to stay in their communities and allows families to continue to grow and learn together. It keeps families together and ensures children grow up in homes where they feel loved. However, taking on full responsibility of a child, or multiple children, frequently comes at great personal cost to the caregivers. Even though some financial supports are available, the majority of kinship families and grandfamilies are not able to access them (Annie E. Casey Foundation, 2012). Placing children in the loving arms of friends and family should not cause the person who takes in those children to have to choose between the child and health, well-being, putting meals on the table, or obtaining basic necessities.

Kinship families and grandfamilies also face significant barriers when it comes to navigating confusing and sometimes conflicting legislation and accessing legal assistance and education (including special education). While they grapple with these challenges, they must also navigate the grief, trauma, and loss they experience, often related to the reasons they came to be part of a kinship family and grandfamily, while at the same time ensuring that the children in their care have adequate nutrition and



housing. This is a significant burden for people who would otherwise be looking ahead to what are often referred to as the "Golden Years."

On top of this, kinship families and grandfamilies contend with significant hurdles when it comes to accessing quality health care, finding child care, taking care of their mental health and need for self-care, and simply finding time for a meaningful break. Many of these families live lives so precarious a single unplanned event or emergency can be disastrous to their well-being.

This is a growing problem. Annie E. Casey Foundation has estimated that the percentage of children in the care of grandparents has held at 4% since 2010, even as the population of children has increased. The need to support kinship families and grandfamilies will not resolve unless the nation takes a holistic approach to increasing awareness, reforming policies that marginalize kinship families and grandfamilies, and increasing access to culturally appropriate services and supports — including traumainformed care.

The Advisory Council came together in late 2019 to address the multiple and often overlooked challenges faced by kinship families and grandfamilies. Their initial goal was to develop a set of recommendations to improve awareness of and services and supports for this vulnerable population. The recommendations they developed after an extended investigative process cover five priority areas that allow for maximum integration of federal, state, local, and tribal initiatives to support kinship families and grandfamilies. These include awareness and outreach, caregiver engagement, services and supports, financial and workplace security, and research, data, and evidence-based practices. Taken together, they are a critical first step in better supporting the people who selflessly step in to raise a child.

The Advisory Council's 22 recommendations will inform the development of the National Family Caregiving Strategy, which is being developed in collaboration with the RAISE Family Caregiving Advisory Council. When fully developed, the strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers. It will promote greater adoption of person- and family-centered care in all health care and long-term service and support settings, increase use of evidence-informed tools, information, education, training supports, referral, and care coordination to increase support for caregivers and expand access to respite options. Finally, it will increase financial security and reduce workplace discrimination faced by caregivers, including kin and grandparent caregivers.

The members of the Advisory Council are grandparents and professionals who have devoted their lives and careers to improving outcomes for kinship families and grandfamilies—some are both. In 2020, when a pandemic hit, many members of



the Advisory Council numbered among the populations most vulnerable to infection, long-term complications, and even death. Yet, in the face of these terrible challenges, the Advisory Council adapted and overcame, continuing their work remotely without missing a beat.

Through this important work, the Advisory Council has demonstrated the very resilience, grit, and personal integrity that makes kin and grandparent caregivers the ideal group to raise children who cannot remain with their birth parents. It is time for the nation to honor the self-sacrifices of kinship families and grandfamilies by doing all we can to identify and deliver services and supports that can help them succeed and thrive.



Endnotes

- ¹ The Advisory Council recognizes that universal language to describe the circumstances of Kinship Families and Grandfamilies does not exist at this time. For more information, refer to Kinship Caregivers and the Child Welfare System.
- The Current Population Survey/Annual Social & Economic Supplement (CPS/ASEC), has a variable (parent indicator) that the American Community Survey (ACS) does not have, which allowed us to identify children who did not have either parent living in the household (see page 55 in GAO-20-434, CHILD WELFARE AND AGING PROGRAMS: HHS Could Enhance Support for Grandparents and Other Relative Caregivers).
- ³ 2019, US Census Bureau July 1, 2019 Estimates. United States Census Bureau. July 2019.
- ⁴ 2019: ACS 5-Year Estimates Grandchildren Characteristics, Table S1001, United States Census Bureau.
- ⁵ 2019: ACS 5-Year Estimates Grandparent and Grandchildren Characteristics, Table S1002, United States Census Bureau.



Acronyms and Abbreviations

- AAA: Area Agency on Aging
- ACEs: Adverse Childhood Experiences
- ACF: Administration for Children & Families
- ACL: Administration for Community Living
- ACS: American Community Survey
- AFCARS: Adoption and Foster Care Analysis and Reporting System
- Al: American Indian
- AN: Alaska Native
- ANA: Administration for Native Americans
- ASPE: Office of the Assistant Secretary for Planning and Evaluation
- BHP: Basic Health Program
- CFPB: Consumer Financial Protection Bureau
- CHIP: Children's Health Insurance Program
- CMS: Centers for Medicare & Medicaid Services
- CPS: Child Protective Services
- ED: U.S. Department of Education
- GAO: Government Accountability Office
- HCVP: Housing Choice Voucher Program or "Section 8"
- HHS: U.S. Department of Health and Human Services
- HRSA: Health Resources and Services Administration
- HUD: U.S. Department of Housing and Urban Development
- ICWA: Indian Child Welfare Act
- IDEA: Individuals with Disabilities Education Act
- NAHASDA: Native American Housing Assistance and Self Determination Act of 1996 (Public Law 104-330),
- NFCSP: National Family Caregiver Support Program
- NFSTAC: National Family Support Technical Assistance Center
- NH: Native Hawaiian
- NIA: National Institute on Aging
- NICHD: The Eunice Kennedy Shriver National Institute of Child Health and Human Development
- NIH: National Institutes of Health
- NINR: National Institute of Nursing Research
- NSLP: National School Lunch Program



- NTAC: National Technical Assistance Center on Grandfamilies and Kinship Families
- OAA: Older Americans Act of 1965, as amended
- OESE: Office of Elementary and Secondary Education
- ONAP: Office of Native American Programs
- ONC: Office of the National Coordinator for Health Information Technology
- OPRE: Office of Planning, Research, and Evaluation
- PTSD: Post-traumatic stress disorder
- RAISE Act: Recognize, Assist, Include, Support, and Engage Family Caregivers Act
- RFI: Request for Information
- SAMHSA: Substance Abuse and Mental Health Services Administration
- SED: Serious emotional disturbance
- SFN: The Statewide Family Network
- SGRG Act: Supporting Grandparents Raising Grandchildren Act
- SUSP: Substance Use and Suicide Prevention
- TCE: Tax Counseling for the Elderly
- TDHE: Tribally Designated Housing Entities
- TIC: Trauma-Informed Care
- UCEDDS: University Centers for Excellence in Developmental Disabilities
- WIC: Special Supplemental Nutrition Program for Women, Infants, and Children
- YRTC: Youth Regional Treatment Center
- SNAP: Supplemental Nutrition Assistance Program
- SSA: Social Security Administration
- TANF: Temporary Assistance for Needy Families
- The Advisory Council: The Advisory Council to Support Grandparents Raising Grandchildren
- USDA: U.S. Department of Agriculture



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