

What supports can benefit kinship caregivers in **families affected by** substance use disorder?

This brief was developed in partnership with <u>Children and Family Futures</u>. For additional information about substance use disorder and child welfare, see <u>Casey Family Programs resources</u> on the topic.

While the number of children entering foster care annually has <u>decreased</u> in recent years, children affected by parental substance use disorders <u>continue to enter</u> <u>foster care at an increased pace</u> — and the children are coming in at a younger age, with greater needs, and staying longer.¹ The number of children living with kinship caregivers — family members and chosen or fictive kin — has increased over the past two decades.² States with <u>higher opioid prescription rates</u> have higher proportions of grandparents raising grandchildren. Children affected by parental substance use disorders are more likely to be placed with kin when compared to children not affected by parental substance use disorders.³

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Most research on substance use disorders and child welfare focuses on children involved in the <u>formal child welfare system</u>, but because the vast majority of kinship caregivers are informal (that is, outside of the child welfare system), this excludes a large number of families. For every child in foster care living with a

relative, <u>19 children are being raised by grandparents</u> or other relatives outside of the foster care system. Kinship caregivers provide much-needed care and stability to children, allowing them to live with people they know rather than being placed with strangers. Kinship caregivers provide a great benefit not only to the children in their care, but also to society as a whole (saving taxpayers an estimated \$4 billion per year, an estimate from 2018 that is likely significantly higher now). Yet they often do so at great personal and economic cost, as the child welfare system usually provides insufficient support to help them

This brief describes the needs of kinship caregivers whose families are affected by substance use disorders and the needs of the children in their care, and includes recommendations and strategies for how the child welfare system can best support them.⁵

Needs of kinship caregivers

raise the children.⁴

Family circumstances among kinship caregivers vary. Taking responsibility for a grandchild due to parental substance misuse can be gradual or sudden, planned or unplanned, voluntary or obligatory, and formal (involving child welfare authorities) or informal (not involving child welfare authorities).⁶ There is a gap between the needs of kinship caregivers and available, accessible, and relevant services. Stressors that kinship caregivers experience specific to substance use disorders may include social isolation from friends, problematic family dynamics, and living in dangerous communities. "Grandparents are afraid," said kinship caregiver Rosemary Nugent, of New Hampshire "They want the help, but they are afraid to ask. I guess they are afraid of admitting failure. But they haven't failed. They stepped up to the plate."

Navigating systems and resources

Kinship caregivers often don't know about the resources that are available to them. They need help understanding and accessing legal services, mental health services, and health care for the children in their care, and assistance developing a legal relationship with the children so they can access medical records, authorize medical treatments, and enroll children in school. Kinship caregivers report dissatisfaction with available services and frustration because of the lack of collaboration across agencies and programs.⁷

Given the overwhelming number of tasks to do when taking in a child, kinship caregivers need guidance on what resources to seek when a child first enters their home (such as acquiring bedding and car seats), versus what steps to take later (such as applying for respite care). "How do you eat an elephant? It's one bite at a time," said kinship caregiver Cheryl Lissak, of New Hampshire. "But let's identify which is the first bite. I had this huge list of resources, and I didn't know who to call."

Economic supports

The <u>estimated cost of raising a child</u> born in 2015 is more than \$310,000. For kinship caregivers who did not plan on raising the children in their care, these costs can be daunting or altogether unaffordable. About half of kinship caregivers <u>live in poverty</u>, and many grandparents are forced to leave the workforce to care for their grandchildren.⁸ Kinship caregivers need financial supports (including increased eligibility for Temporary Assistance for Needy Families benefits), legal supports, childcare, and health insurance for the children in their care. Sometimes grandparents and other older kinship caregivers already have downsized their house or their car and must figure out how to accommodate children in their revamped lifestyle.

When my grandson started kindergarten, there were 11 kids at our bus stop — nine of them being raised by their grandparents. Eight of those children were in families with substance use disorders.

> - ROSEMARY NUGENT, KINSHIP CAREGIVER AND KINSHIP NAVIGATOR, NEW HAMPSHIRE

Kinship caregivers who earn too much to qualify for state or federal benefits but too little to absorb the additional expenses of raising a child are particularly squeezed. Kinship caregivers who are not licensed foster care providers or are caring for the children outside the child welfare system receive very little, if any financial support even though they are providing safe, familiar homes for children and diverting them from entering foster care. "Dollars need to be spent on families that are going through this and getting zero support," said kinship caregiver Keith Lowhorne, Alabama. "Grandparents get little to nothing in most states unless they go through the formal process, which very few do." Since expenses are ongoing - children move from cribs to beds, they outgrow clothing, etc. support should be ongoing, too.

Mental health care

Although many kinship caregivers report that raising the children in their care gives them an increased sense of purpose, grandparents raising grandchildren have poorer mental health outcomes overall compared to their peers who are not raising grandchildren.⁹ Losses of freedom, a carefree retirement, and relationships with friends can feel overwhelming. Kinship caregivers who are caring for children who have emotional disorders or hyperactivity (which are more common among children with exposure to substance use disorders) report lower levels of life satisfaction and higher levels of anxiety, depression, and stress.¹⁰ Often, kinship caregivers delay or downplay their own self-care needs to focus on the needs of their grandchildren.¹¹

Kinship caregivers can benefit from individual and family therapy, including grief counseling. They may be

grieving the loss of their relationship with the person who has a substance use disorder, the expected relative relationship they had with the child in their care, and their dreams of retirement.

Navigating family relationships

When kinship caregivers take in children, the family dynamic is substantially shifted and previously clear roles become ambiguous.^{12,13} When grandparents take on the role of parent, for example, they forfeit the special role of grandparent.¹⁴ Their other children and grandchildren may feel left out. "Grandparents can be resentful about having to do this all over again when they were preparing to enjoy their retirement," said Becky Berk, impact director and interim programs director at New Hampshire Children's Trust. "And their children are often resentful of the grandparents or other relatives for stepping in and meddling or for interfering in a place that they sometimes don't feel is warranted."

Relationships with family members who have substance use disorders can be a source of stress. Kinship caregivers worry about the potential of overdose, suicide, incarceration, and negative health consequences. They may feel disappointment and resentment when family members are not able to fulfill their responsibilities as parents. Relationships may become hostile.¹⁵ Navigating these relationships can be challenging. "My grandma was really good at supporting my relationship with my mom and dad," said Aleks Talsky Kort, alumnus of foster care and board member for the National Advisory Council for Children's Legal Representation, Wisconsin, "but some of her siblings judged her for that."

I cannot afford to take the children on a vacation. These are the childhood memories of normalcy I'm not providing. People may say it's not important, but it is. It's family bonding, the change of scenery, experiencing the world beyond the end of your nose. They're never going to get that because I just can't do it.

- CHERYL LISSAK, KINSHIP CAREGIVER, NEW HAMPSHIRE

Social supports

Many kinship caregivers cite peer support as very beneficial. It is important to know peers who are going through similar experiences, including experiences specific to substance use disorders. Kinship caregivers who have lower levels of social support from friends and family have higher levels of anxiety, depression, and stress.¹⁶

Needs of children

Most of the response to the opioid epidemic has focused on individuals experiencing a substance use disorder, with significantly less attention paid to the <u>needs of children and other family members</u>, despite demonstrated short- and long-term effects of exposure to substance use disorder-related trauma. Young children are particularly vulnerable because they rely on adults for their basic needs. School-age children often experience emotional difficulties and challenges at school due to a lack of appropriate screening, diagnosis, and treatment for the trauma they are experiencing.

Early childhood and educational supports

It can be challenging to prioritize school in the midst of the trauma students are facing, but it is important to ensure school stability (including regular attendance) and prioritize early care and education, including the identification of developmental delays (such as from prenatal alcohol or other substance exposure), early interventions and supports, and opportunities for social interaction. Kinship caregivers should be provided with information about student rights, including individualized educational plans and 504 plans. They also should be supported in developing and implementing those plans. Often, the effects of prenatal substance exposure on children are not identified until children reach preschool or primary school age, as is typically the case with Fetal Alcohol Spectrum Disorders (FASDs). Late and missed diagnoses of FASDs are detrimental to child and caregiver well-being because appropriate interventions are not put in place to mitigate effects.

Some states, such as <u>California</u>, include an FASD diagnosis as an automatic qualifier for special education services. Other states, such as <u>Ohio</u>, include a

INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA), PARTS B AND C

This federal law provides early intervention and special education services for children with developmental delays, including those with prenatal substance exposure. Part B of IDEA provides special education services to youth ages 3 to 21. Part C requires child welfare systems to provide early intervention assessments to all children under age 3 who are substantiated victims of child maltreatment. IDEA provides valuable opportunities for kinship caregivers to work with child welfare professionals to ensure early identification of the effects of prenatal substance exposure, and that interventions are in place to mitigate the developmental, behavioral, and other effects of prenatal substance exposure on children in their care.

diagnosis of FASD or neonatal abstinence syndrome as an automatic qualifier for early intervention services. For more information, see the Early Childhood Technical Assistance Center's <u>Summary of State</u> and Jurisdictional Eligibility Definitions for Infants and <u>Toddlers with Disabilities</u>.

Mental and behavioral health supports

Children whose parents have substance use disorder may experience trauma due to unstable living environments, separation from their parent, or death of a parent due to overdose. Children with younger siblings may have to step into the parenting role when their own parents are unable to fulfill parental duties. Compared to their peers, children whose parents have substance use disorder have higher rates of anxiety, depression, and behavioral challenges, and lower social competence and self-esteem. Without appropriate support, they are also at higher risk of developing substance use disorders themselves. When a child moves in with a kinship caregiver, the child should be screened by a pediatrician for developmental delays or behavioral problems so that they can receive treatments as needed.

Unfortunately, a lack of therapists, particularly therapists that accept government-issued insurance, has led to long waiting lists, and children are not receiving the timely, high-quality counseling and other supports that they need. Whether they are in therapy, children need to know they are not to blame for their parents' substance use. People who work with children whose behavior has been affected by their parents' substance use need to know that the children's behavior is not a character flaw but rather a manifestation of having lived in an untenable situation.

Normalcy and consistency

Providing normalcy and consistency can help children work through and resolve underlying trauma and support emotional development. This includes maintaining connections to culture and community (such as houses of worship, sports, clubs, and play groups) and supporting relationships with friends and family members. "No matter whether the children have been taken out of the home or placed with other relatives, it's important for them to know the relatives that they have," said caregiver Robert Brown, Louisiana. "They may not be with their mother or father or may not even be with their grandparents, but those other relatives can reach out and visit them."

Children in kinship care outside of the child welfare system generally don't qualify for funding for enrichment activities, such as summer camps, and their families often can't afford to take them on vacations. This undermines a sense of normalcy. Programs like <u>Camp Mariposa</u>, offered at numerous locations nationwide, help address this gap, providing substance use prevention and mentoring for children who have family members with substance use disorder.

Strategies

Child protection agencies play an important role advancing practices and policies that prioritize <u>placing</u> <u>children with kin</u> and supporting kinship families after a placement has been made. For families affected by substance use disorder, additional services may be needed. While urgent needs related to substance use disorder treatment often receive the most attention,

MOVING UPSTREAM

When safe and appropriate (that is, when it has been determined that child maltreatment is not taking place), a <u>Plan of Safe Care</u> permits infants with prenatal substance exposure to stay with their parents. Plans of safe care require a thorough assessment of the home for safety concerns. Both parents and infants receive services, such as substance use assessment, medical care, mental health care, assistance obtaining safe housing, training in how to take care of an infant, and vocational training.

Keeping children with their parents during substance use disorder treatment is ideal, allowing for stronger parent-child relationships and increasing parents' motivation to overcome their disorder. Residential care facilities that allow babies and young children to stay with parents undergoing treatment may obviate the need for kinship care. The federal Family First Preservation Services Act allows states to use <u>Title IV-E funds to pay for residential treatment</u> for families in the child welfare system and for prevention services payments for evidence-based substance use disorder services.

longer-term, proactive strategies also need to be developed, including upstream prevention strategies.¹⁷

Include people with lived experience in developing solutions

The development of programs and policies to better support kinship caregivers should <u>incorporate</u> the perspectives, ideas, and recommendations of people with lived experience. The National Center on Substance Abuse and Child Welfare's <u>resource for</u> engaging parents and youth with lived experience provides guidance for developing effective and respectful partnerships, and the Grandfamilies & Kinship Support Network has a <u>tipsheet</u> with recommendations for engaging kinship families, including those led by grandparents.

Educate child welfare workers

Kinship caregivers have different needs than licensed foster families and should be treated differently. Workers in the child welfare system should be trained in how to work with kinship families, including a general overview of kinship care (including the needs of kinship families affected by substance use disorder), available resources (such as services for infants and children with prenatal substance exposure), and how to help kinship caregivers navigate relationships with family members (including setting healthy boundaries).

Disrupt stigma

Stigma (from professionals, friends, family, and those struggling with substance use disorder) can result in embarrassment, guilt, and shame, which deters people from accessing help. It also increases disparities for already underserved groups, such as people of color, people who are living in poverty, and people who identify as LGBTQ+. Language matters. For example, instead of calling someone an "addict" or "drug abuser," use a "person with a substance use disorder," and instead of talking about "clean" or "dirty" drug screens, screening test outcomes should be referred to as "positive" or "negative." For more information, see the National Center on Substance Abuse and Child Welfare's *Disrupting Stigma: How* Understanding, Empathy, and Connection Can Improve Outcomes for Families Affected by Substance Use and Mental Disorders.

NEW HAMPSHIRE'S FAMILY RESOURCE CENTERS

All family resource centers (FRCs) that are part of the Family Support New Hampshire coalition employ kinship navigators, who provide caregivers with information and resources to help identify and access services. More than 80 percent of the coalition's kinship caregiver cases involve substance use disorder. Kinship navigators receive a thorough orientation and ongoing professional development, including a module specific to substance use. The kinship navigator program is funded through a braided series of funding sources, including significant funding from the Centers for Disease Control and Prevention's Overdose Data to Action program. "The kinship navigator has been a godsend," said Cheryl Lissak, a kinship caregiver in New Hampshire. "She brought so many resources, I was mesmerized. I had no clue that financial support was available or that other agencies provided clothing allotments or respite care. Without my kinship navigator, I don't know where I'd be right now."

Coordinate with other agencies

Supporting families dealing with substance use disorder is a task far too large for one agency. Child protection agencies should coordinate with other agencies, including those working in housing, substance use treatment, education, and mental health, to provide

The experience of being a grandparent raising a grandchild due to substance use disorder is gut-wrenching. And it starts with stigma. Nobody shows up to your house with a lasagna because you're in a crisis like this. You're left out in the cold. And stigma is what keeps people who are struggling from getting help. Stigma marginalizes families. And stigma kills. The question I have is what are we going to do about it? Solutions can only come from understanding the problem.

> - CHARLOTTE STEPHENSON, GRAND VOICES MEMBER, GENERATIONS UNITED, WISCONSIN

support to families. For more information, see Children and Family Futures' <u>Comprehensive Framework to</u> <u>Improve Outcomes for Families Affected by Substance</u> <u>Use Disorders and Child Welfare Involvement</u>.

Establish kinship navigator programs

Kinship navigator programs provide outreach to kinship families, information and referral services (including information on legal assistance and eligibility and enrollment for public benefits), collaboration with state and local agencies, and advocacy about the needs of kinship families. Many kinship navigator programs also provide support groups, which give kinship caregivers an opportunity to develop relationships with peers in

Additional resources

similar situations. Kinship navigator programs are beneficial for caregivers and the children in their care and have high rates of satisfaction. Provide training

Provide training

Kinship families need training on understanding the effects of prenatal substance exposure, the effects of parental substance use disorders on child development, and how to help children who have lost a parent due to overdose. In addition, they could benefit from trainings on parenting strategies and educational systems, given that practices may have changed since kinship caregivers were rearing children.

Resource	Description
Administration for Community Living: <u>2022 National Strategy</u> <u>to Support Family Caregivers</u> (2022)	Includes actions that federal agencies can take to improve support for grand- parents raising grandchildren, with the goals of increasing awareness and outreach, advancing partnerships and engagement, strengthening services, and ensuring financial and workplace security.
Administration for Community Living: <u>Supporting Grandpar-</u> <u>ents Raising Grandchildren</u> (SGRG) Act: Initial report to <u>Congress</u> (2021)	The Supporting Grandparents Raising Grandchildren (SGRC) Act, signed into law in 2018, created an advisory council to identify and promote resources, best practices, and recommendations to better support kinship caregivers and the children in their care. This report includes 22 recommendations in five priority areas to better support formal and informal kinship caregivers.
Generations United: <u>Grand</u> <u>Resource: Help for Grandfam-</u> <u>ilies Impacted by Opioids and</u> <u>Other Substance Use</u> (2019)	Information for kinship caregivers in informal or formal care arrangements, as well as a list of resources.
Generations United: <u>Caring for</u> <u>a Child Affected by Fetal Alco-</u> <u>hol Spectrum Disorder</u> (2023)	This resource provides information for kin caregivers raising children exposed to alcohol before birth. It includes tips for how caregivers can care for themselves and best support the children in their care.
National Center on Substance Abuse and Child Welfare: <u>Disrupting Stigma: How</u> <u>Understanding, Empathy, and</u> <u>Connection Can Improve Out- comes for Families Affected</u> <u>by Substance Use and Mental</u> <u>Disorders</u> (n.d.)	This report describes how stigma keeps people from accessing needed services and can lead to discrimination. Stigma exists on three levels — structural (laws, policies, "war on drugs"), public (stereotypes, media portrayals), and self-stigma (shame) — all requiring different strategies.

stance Use and Mental Health Disorders: Supporting Kinship	Resource	Description
<u></u> /	Abuse and Child Welfare: <u>Sub-</u> stance Use and Mental Health	substance use and mental health disorders, implications for children's needs,

To learn more, visit Questions from the field at Casey.org.

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- 2 While the vast majority of kinship caregivers are grandparents, kinship caregivers can also be aunts, uncles, cousins, other relatives, or family friends ("fictive kin").
- 3 Center for Children and Family Futures. (2022). Analyses of the 2020 Adoption and Foster Care Analysis and Reporting System (AFCARS) from the National Data Archive on Child Abuse and Neglect (NDACAN), File Number 255.
- 4 Davis, M. T., Warfield, M. E., Boguslaw, J., Roundtree-Swain, D., & Kellogg, G. (2020). Parenting a 6-year old is not what I planned in retirement: Trauma and stress among grandparents due to the opioid crisis. Journal of Gerontological Social Work, 63(4), 295–315.
- 5 Content of this brief was both envisioned and informed by ongoing consultation with members of the Knowledge Management Lived Experience Advisory Board. This team includes youth, parents, kinship caregivers, and foster parents with lived expertise in the child welfare system who serve as strategic partners with Family Voices United, a collaboration between FosterClub, Generations United, the Children's Trust Fund Alliance, and Casey Family Programs. Members who contributed to this brief include: Robert Brown, Aleks Kort, Keith Lowhorne, and Lisa Myles. In addition, Ana Beltran, Director of Grandfamilies and Kinship Support Network, Generations United, and Shalah Bottoms, Technical Assistance Specialist, Generations United, participated in an April 27, 2023, consultation. Additional material came from a September 14, 2022, webinar ("Substance use and mental health disorders: Supporting kinship families") led by the National Center on Substance Abuse and Child Welfare. This brief is also based on interviews with Becky Berk, Impact Director and Interim Programs Director, New Hampshire Children's Trust, on July 10, 2023; Rosemary Nugent, Kinship Caregiver and Kinship Navigator, The Grapevine Family & Community Resource Center, on August 2, 2023; Cheryl Lissak, Kinship Caregiver, New Hampshire, on August 11, 2023; and Charlotte Stephenson, GRAND Voices member, Generations United, on October 27, 2023.
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- 7 Dolbin-MacNab & O'Connell, L. (2021).
- 8 Aron, L., Benatar, S., & Peters, R. (2020) Supporting children and families affected by the opioid epidemic. Urban Institute, page 12.
- 9 Kelley, S. J., Whitley, D. M., Escarra, S. R., Zheng, R., Horne, E. M., & Warren, G. L. (2020). <u>The Mental Health Well-Being of Grandparents Raising Grandchildren: A</u> <u>Systematic Review and Meta-Analysis</u>. *Marriage & Family Review*, 57(4), 329–345.
- 10 Doley, R., Bell, R., Watt, B., & Simpson, H. (2015). <u>Grandparents raising grandchildren: Investigating factors associated with distress among custodial grandparents</u>. Journal of Family Studies, 21(2), 101–119.
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- 14 Lent, J. P., & Otto, A. (2018). Grandparents, grandchildren, and caregiving: The impacts of America's substance use crisis. Generations: Journal of the American Society on Aging, 42(3), 15–22.
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- P 800.228.3559
- P 206.282.7300
- F 206.282.3555

casey.org KMResources@casey.org

