

COLLATERAL DAMAGE OF THE OPIOID CRISIS

Grandparents Raising Grandchildren—What They Need and How to Help

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In 2018, grandfamilies became a prominent part of the national conversation surrounding the opioid crisis and in July, the President signed the bipartisan Supporting Grandparents Raising Grandchildren Act into law. Now that those on Capitol Hill are taking notice, it is essential that we understand the needs of these families to inform policies that aim to provide services and support. To add to the small but growing body of knowledge¹ on this topic, Altarum collected data about grandfamilies both in Michigan and nationally. This report focuses on grandparents raising grandchildren, identifying first the perceived needs and barriers to obtaining services, and then exploring the possible influence of the burden of the opioid crisis in this population. Finally, we offer recommendations for supporting and improving outcomes for these grandfamilies who are in this extremely difficult situation.



BACKGROUND

By all metrics, our country is now facing the largest drug epidemic of all time. 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. Nationally there was a 10% increase in the number of children entering the foster care system between 2012 and 2016; for six states (Alaska, Georgia, Minnesota, Indiana, Montana, and New Hampshire) the increase was closer to 50%.² Drilling down to a local level, this data also showed that nationally from 2011 to 2016, counties with higher drug-related deaths and hospitalizations also had higher rates of new foster care cases. This makes clear the link between national increases in substance abuse and the influx of children into the welfare system. Many of these children end up in the care of relatives. Though grandparents have historically stepped in to provide varying levels of support to their adult children and/or grandchildren as needed, they are now being called upon to assume primary parental responsibility for their grandchildren in unprecedented numbers. Currently around 7.8 million children reside in grandparent-led households. While evidence-based treatment for substance use disorder (SUD) is capturing national attention, less focus is being given to the many families grappling with the collateral damage of their loved ones' struggle with addiction

*Kinship care—placing children no longer able to remain with a parent with other family—is the least disruptive for their physical, emotional, and mental well-being. **Unfortunately, resources available to support the more than 2.7 million grandparents raising their grandchildren are severely lacking.***

¹ Raising the Children of the Opioid Epidemic: Solutions and Supports for Grandfamilies. State of Grandfamilies 2016. Generations United.

² Ghertmer, R., Baldwin, M., Crouse, G., Radcliff, L., Waters, A. The Relationship between Substance Use Indicators and Child Welfare Caseloads. ASPE Research Brief, 2018. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.



Research shows that when children are no longer able to remain with a parent in their home, placing them with other family—called kinship care—is the least disruptive option for their physical, emotional, and mental well-being.³ Resources available to support these caregivers, however, are severely lacking. Grandparents providing custodial levels of caregiving to their grandchildren often face hurdles with housing, school enrollment, health, and legal issues. The resources they have are often stretched thin, with 21% of grandparent-headed households living below the poverty line.⁴ Meanwhile, government financial assistance or programming can be difficult to secure, with eligibility depending on a variety of factors, including a grandparent’s age, their income and/or savings, and whether or not they become a licensed foster care parent. Though working through the foster care system is a route that some grandparents do take, there are also emotional and logistical barriers to entry that prevent many from utilizing this option. This leaves grandparents hamstrung—wanting desperately to provide safe and nurturing homes for their grandchildren, but with few services and supports.

METHODS

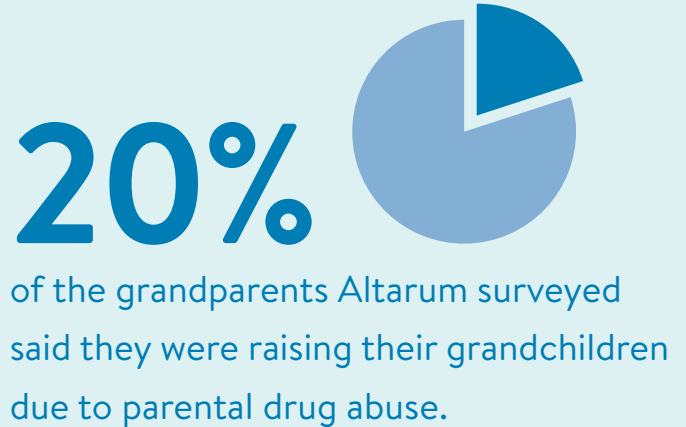
Altarum conducted primary data collection during the summer of 2018. The first phase of this study sought to shed light on the lived experience of grandparents who are called upon to raise their grandchildren because of the prevalence of parental substance misuse and concomitant mental health issues or incarceration. To do so, we conducted in-depth interviews, both in-person and via phone, with 20 grandmothers living across the state of Michigan. During the second phase, we wanted to explore emerging themes from the interviews with a broader sample and on a national scale. To accomplish this we conducted an online survey with 1,015 grandparents nationwide.

AIM OF THIS RESEARCH BRIEF

In this brief, we provide the findings from our study that were both exceptionally thought provoking and lend themselves to action. In the upcoming weeks, Altarum will expound on

³ Rubin, D. M., Downes, K. J., O’Reilly, A. L., Mekonnen, R., Luan, X., & Localio, R. (2008). Impact of kinship care on behavioral well-being for children in out-of-home care. *Archives of Pediatrics & Adolescent Medicine*, 162(6), 550-6.

⁴ Murphey, D. & Moore, K.A. Grandparents Living with Children: State-Level Data from the American Community Survey. *Child Trends Research Brief*. Publication #2102-30.



these findings by providing individual discussion pieces that provide more detail from our research and highlight stories from grandparents that illustrate the hardship the opioid crisis has brought upon their lives. We hope these stories capture the attention of a wide variety of stakeholders, providing those capable with the motivation to create new programs and transform existing policies and systems to benefit grandfamilies.

RESULTS AND KEY FINDINGS

Grandparents told their stories generously, often through tears, citing grief, guilt, and heartbreak, and acknowledging a desperate desire for their struggle to be given a voice. About 20% of the grandparents in our study cited parental drug abuse as the reason they were currently acting as parents to their grandchildren; other reasons included incarceration, death, homelessness, and mental health issues. Overall, survey responses provided a broader perspective on grandfamilies and their origins, and demonstrated the needs—and intricacies in the circumstances—of this emerging segment of the population.

Grandfamilies deal with complex mental and behavioral health needs of children who have experienced severe psychological and physical trauma.

In our interviews, grandparents described psychological, sexual, physical, and emotional abuse that their grandchildren endured while in parental custody. In cases where abject abuse was not present, there was often neglect—including the



most basic needs of children, such as adequate food, housing, clothing, and supervision, going unmet. About a quarter of the grandparents in our survey reported their grandchildren had experienced some form of abuse or neglect. Sixteen percent of grandparents also described persistent mental and behavioral health conditions their grandchildren had been diagnosed with, including Post Traumatic Stress Disorder (PTSD), Attention Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder, anxiety, and depression. This is consistent with a robust body of work showing that children involved with the child welfare system are likely to have experienced cumulative traumatic events negatively associated with health and well-being.⁵

Few people would have the requisite skills to help these children cope. Grandparents are tasked with learning a breadth and depth of psychological and counseling techniques under extreme levels of duress.

Grandparents must cope with their own grief and emotional distress while parenting grandchildren with complex emotional needs.

Given that more than half of the grandparents that responded to our survey were under 60 years old, grandparents raising their grandchildren belong to a new conception of the “sandwich generation,” caring for their aging parents, adult children, and grandchildren simultaneously. They are often torn between caring for the needs of their parents, their adult children who

Twenty-five percent of the grandparents Altarum surveyed said their grandchildren had experienced abuse or neglect. Sixteen percent reported their grandchildren had been diagnosed with persistent mental and behavioral health conditions.

cannot care for themselves, while also acting as parent to their own children’s children. They describe the grief and guilt in dealing with their own child’s substance abuse or mental health struggles, while at the same time providing a secure and stable environment for their grandchildren. Grandparents who participated in our interviews described acute emotional turmoil. And just as they are not trained as child psychologists, they are not trained as addiction counselors either. Further, the cognitive and emotional demands of dealing with the mental and behavioral health needs of multiple generations increases the complexity of this issue.

Raising a second family places grandparents in a financially perilous situation and contributes to the number of children and elderly living in poverty.

Grandparents often take over responsibility for their grandchildren with little notice or time to prepare. They may have already sold the homes in which they raised their own children, downsizing to accommodate modest fixed incomes. They are now once again subject to all the same stressors that apply to working families—including high health care, childcare, and housing costs—but with the added financial strain of being semi- or fully-retired. Thirty-four percent of survey respondents noted being forced out of, or delaying, retirement. Eleven percent indicated that in the last three months they often or always had trouble paying for food. The same number had difficulty covering rent or mortgage payments. From our in-depth grandparent interviews, we learned that many are savvy about searching for community resources such as foster closets and foodbanks. Grandparents with low incomes and no savings also utilize nutritional assistance programs such as those offered through Women, Infants, and Children (WIC) (12% of survey respondents) and the Supplemental Nutrition Assistance Program (SNAP) (28% of survey respondents). However, many others fall into a gap of not qualifying for government subsidies, but also not being able to make ends meet. This is compounded by the fact

⁵ Turney, K. & Wildeman, C. (2017). Adverse childhood experiences among children placed in and adopted from foster care: Evidence from a nationally representative survey. *Child Abuse & Neglect*, 64, 117-129.



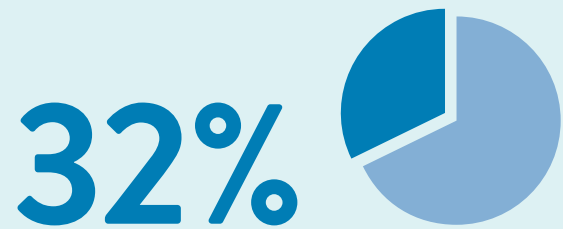
that many grandparents do not have legal custody, which is often required for families to be eligible for food-assistance programs.

The road to custody is complicated. Grandparents are ill-prepared to deal with the legal system.

Gaining and maintaining custody of grandchildren is not straightforward—23% of grandparents in our survey did not currently have legal guardianship and 18% were extremely worried about losing custody. There is often a period of time leading up to grandparents assuming full responsibility when children go back and forth between caregivers, many times staying with grandparents for increasingly longer periods. When grandparents fear for the safety and well-being of their grandchildren, they step in to call child protective services, as did 24% of grandparents in our survey. This is a tremendously difficult decision as it forces them to report the dysfunction of their own children.

Michigan, like many other states, does not recognize the legal rights of grandparents or de facto parents generally. Therefore, even grandparents who have had their grandchildren since infancy do not have the parental rights necessary for functions such as school enrollment or health care decisions unless they are conferred to them by the court. In some straightforward cases—either when parents give up their rights voluntarily or their behavior is so glaringly unfit that a judge chooses to terminate these rights—grandparents are awarded custody relatively easily. But, in other seemingly straightforward cases that may involve both direct abuse of the child and suspected substance abuse by the parent, long and protracted custody battles ensue. Twenty-four percent of grandparents in our survey reported they would have to continue fighting through the court system to maintain custodial caregiving rights for their grandchildren.

Twenty-three percent of the grandparents Altarum surveyed said they did not have legal guardianship of their grandchildren. Without custody, they risk ineligibility for safety net programs such as SNAP and WIC, despite financial need.



32%

of the grandparents Altarum surveyed said they were delaying retirement or going back to work to make ends meet.



28%

relied on SNAP benefits to put food on the table.

The foster care system, as it currently exists, may not be the best option to meet grandparents' needs.

An argument can be made that grandparents could increase their eligibility for subsidies by actively engaging with the foster care system. Twenty-six percent of grandparents in our survey currently maintained custody of their grandchildren through the foster care system, reflecting this is a viable route that some families take. However, for other grandparents, being a foster parent is either not an option, or entry into the foster care system is unappealing—leaving grandparents essentially abandoned by the safety net system. In our interviews, we sought to understand the factors that prevent grandparents from accessing the foster care system. We found that reluctance to deal with the system often stems from a deep fear that it will invite investigation and increase the chances that their grandchildren will be taken away. Around 30% of survey respondents, indicated that the foster care system made them feel excessively scrutinized during home visits and check-ins with foster care case workers, and they discontinued their involvement for this reason despite the resulting subsequent loss of services.



1 out of **4**

of the grandparents Altarum surveyed felt estranged from their peer group.



1 out of **3**

no longer participated in hobbies they formerly enjoyed.

Peer Support Helps

17% belonged to support groups for grandparents raising grandchildren, and an additional **21%** thought they could benefit from joining one.

Grandparents subvert their own needs to provide support for their grandchildren.

Grandparents we interviewed demonstrated their extreme love and devotion towards their grandchildren, and it is clear that they find joy and pride in their families. However, like parents of any age, they often stated that they had to put their own needs behind those of their grandchildren. They described feelings of grief as they processed moving forward with a life that looked very different than the one that they had planned. Caring for young children does not leave grandparents with much availability or extra resources to pursue personally fulfilling activities. About 33% of grandparents reported no longer being able to participate in hobbies they once enjoyed and 25% said parenting their grandchildren put a strain on their relationship with same-aged friends. Grandmothers in our interviews also described the difficulties of maintaining or pursuing romantic relationships. Grandparents who take on the responsibility of raising their grandchildren are plunged back into a stage of life rife with difficulties that they thought they had moved on from long ago.

Grandparent peer groups are an important source of knowledge and strength.

Several grandparents came to us by way of support groups facilitated by local Area Agencies on Aging. These groups offered a shared perspective that grandparents raising their grandchildren were not able to find anywhere else. Participants described not quite identifying with traditional foster families wherein children and foster parents come

together as strangers. Other grandparents who are able to spoil their grandchildren with sleepovers, special outings, and holiday surprises are no longer their peer group either, as they have shifted to the more mundane and often taxing primary caregiving—bedtime routines, parent-teacher conferences, and discipline. Though parents of similarly aged children have overlap in the day-to-day toil, they are also chronologically a different cohort and don't have the additional burdens of a dysfunctional adult child. In our survey 17% of respondents currently belonged to a support group for grandparents raising grandchildren, and 21% of those that didn't thought they would benefit from joining one.

It is clear grandparents in our study looked to others in their same situation for knowledge, help, and empathy that they couldn't get elsewhere. Though this type of support has many advantages, it is also susceptible to the spread of misinformation. A former guardian ad litem in the Detroit Metro area, currently working as an attorney specializing in custody cases, said her number one recommendation for grandparents is to get more education about navigating the court system. False information or a misunderstanding of the details of specific situations can be taken as fact by those who have few sources of information or help

RECOMMENDATIONS

At this point, the fallout from our nation's opioid epidemic is impacting multiple generations; children of individuals struggling with substance use disorder are at risk of being unable to make up the ground lost as a consequence of the



trauma of their fundamental years. A way to mitigate this damage is through supporting the grandparents who are in extremely difficult situations, attempting to provide safety and stability for their young grandchildren who, in their short lives, have already accumulated a lifetime's worth of hardship. Here, we provide several recommendations aimed at resolving essential issues in kinship care broadly and remediating deficits in children and families of those with substance use disorder.

Sort Out the Provision of Subsidies

Though policy changes are warranted, an important immediate action should be connecting grandparents with existing resources and subsidies. This is complicated because availability and eligibility varies drastically by location, custody status, income, and sometimes even grandparents' age. Environmental scans of federal, state, county, and community resources need to be executed to populate resource clearinghouses. These clearinghouses should provide accurate eligibility criteria and serve as an up-to-date and reliable source of information about supports that are available. Once these resource banks are established, frequent grandparent contacts—including caseworkers, preschool teachers, guidance counselors, and those in the foster care and court systems—need to become adept at helping identify, apply for, and utilize subsidies and programs that are in place. Further, those who deal with older populations, such as geriatric social workers, may need to expand their understanding of certain programs like WIC and Head Start, or at least be well-versed enough to connect grandparents with those who can help them attain these services.

Enhance the Foster Care System

The foster care system is a mechanism through which intervention, counseling, and subsidies are available to kinship caregivers. Though some grandparents do take the steps necessary to become licensed caregivers and work within the guidelines of the system to use its resources, others are unsure of their eligibility, do not want the intrusion into their lives the system invites, are fearful that it will leave them vulnerable, or do not feel like it is a socially acceptable option. This calls for an examination of the system in its current form to evaluate its suitability for kinship caregivers and look for ways that services can be adapted to fit this growing segment of the population. For instance, by creating tracts within the system better suited to navigating familial relationships, or by providing additional training to case workers on the nuances of navigating familial relationships.



Grandparents are caring for children two generations removed while facing the declining health and energy of older age. Health care providers are key to providing support.

Develop and Implement Continuing Education and Mental Health Interventions

Continuing Education (CE) curricula aimed at trauma informed care that includes recognizing signs and symptoms of abuse, neglect, and other forms of trauma in children and adolescents needs to be developed and implemented with pediatric and primary health providers. This also calls for continued expansion of the integration of behavioral health into primary care. Grandparents in our survey reported having positive and open relationships with their grandchildren's pediatricians and generally felt they were treated with respect (69% of respondents) when accessing services through the health care system. Thus, pediatric and family doctors remain a fundamental point of contact through which at-risk children can be identified and referred to appropriate mental and behavioral health resources. Likewise, providers must become attuned to the potential for emotional and psychological struggle in grandparent caregivers. Points of contact in the health care system for grandparents, such as their own primary care doctors, need to expand their knowledge to accommodate individuals who may be dealing with child health issues while at the same time dealing with the needs of their elderly parents and their own declining health and energy.

Developing mental and behavioral health tools and interventions for this target population, or implementing



tools that already exist, should be placed within the broader context of mental health access barriers in this country. First, there is a wide gap that exists between Americans who suffer from mental and behavioral health disorders and those that actually receive appropriate and sufficient treatment.⁶ There are general issues of removing barriers to care such as cost, provider shortages, and a lack of health care infrastructure in non-urban areas that must be concurrently addressed.^{7, 8, 9} In addition to structural barriers, there is also still a pervasive stigma to receiving psychological or psychiatric care felt by many individuals.¹⁰ Americans are still relatively new to mental health literacy as the typicality of receiving treatment and resources for emotional and mental issues outside the family, close friends, or church community grows. In order to see success in this area, those providing services to grandfamilies must meet grandparents where they are in their knowledge and comfort with child development, psychiatry, and psychology.

Clarify Legal Rights

Legal rights of grandparents—or any adults who have been responsible for custodial caregiving—differ by state. A first order of business is educating grandparents within each state on what their legal rights are and the course of action necessary to gain and maintain legal custody of their grandchildren. Legal aid and elder law needs to continue to be expanded to include this group. Continuing education for family lawyers for whom custody cases more often entail divorcing parents, rather than grandparents battling their children, child-in-law, or in-law grandparents, is also needed. Just as the utility of health system navigators has become clear in recent years, the creation of court navigators may be necessary to prepare and guide grandfamilies for dealing with the family court system in their state.

Develop and Implement Peer Support Trainings and Peer Led Programs

Lacking conventional system support and facing unique

6 Mental Health America (MHA). The State of Mental Health in American 2018.

7 Rowan, K., McAlpine, D.D., & Blewett, L.A. (2013). Access and cost barriers to mental health care, by insurance status, 1999-2010. *Health Affairs*, 32:10, 1723-1730.

8 U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Workforce, National Center for Health Workforce Analysis (2016). National projections of supply and demand for selected behavioral health practitioners: 2013-2025.

9 Kelleher, K.J., & Gardner, W. (2017). Out of sight, out of mind – Behavioral and developmental care for rural children. (2017). *The New England Journal of Medicine Perspective*.

10 Corrigan, P. W., Druss, B. G., & Perlick, P. W. (2014). The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care. *Psychological Science in the Public Interest*, 15(2), 37-70.

challenges, grandparents raising their grandkids often turn to those in similar situations as sources of advice and support. Peers can be an important conduit to transmitting accurate and timely information to grandparents. Behavioral health programs should develop and implement peer support training programs, interventions that leverage existing peer connections, and peer support groups. Organizing peer led groups and arming members to disseminate and distribute information may be one of the most efficient and direct ways to help grandparents as federal and state resources (hopefully) grow to meet demand.

CONCLUSION

Our lives touch the lives of so many around us. When someone gets caught in the grips of addiction, it has devastating consequences for their family and loved ones. As the opioid epidemic continues its scourge on America, many grandparents are sweeping in to care for children who have been abused, neglected, and abandoned by their parents. Struggles come at these grandparents from every angle. They comfort babies who have gone through drug withdrawal in their first hours of life. They soothe little children whose nightmares feature memories of crying for hours alone in dark apartments. They teach adolescents that they don't have to take food from their garbage because in their house there will always be enough. And, they do all this while experiencing crushing heartbreak for their own children, and under the threat that they may lose their grandchildren at any moment. Grandfamilies have captured our attention, and now that they have, it is our duty to support and assist them as they care for this afflicted generation.

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