Supporting Children and Kinship Caregivers in the Context of Substance Use Disorder: Perspectives of Key Professionals

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Abstract

One in eight children in the United States grows up in a household with parental substance use disorder (SUD). The purpose of this study was to explore the needs of children and kinship caregivers affected by SUD, as perceived by 23 professionals who interact with these families. A community-based participatory research approach with exploratory and descriptive qualitative methods was utilized. Results indicated that (a) children need relationships and connections, stability, emotional and health care support, and protection from risks associated with SUD; (b) caregivers need community resource and navigation supports, skills development, and understanding of the caregiver's role; and (c) there is a lack of existing comprehensive resources and services to support families affected by SUD. This study adds to existing literature by identifying key professionals' perceptions and examining various types of kin relationships. Future research and practice implications are discussed.

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Introduction

Substance use disorder (SUD) is a chronic, progressive, and potentially fatal disease (American Psychiatric Association, 2013). Alcohol and drug related deaths in the United States have more than tripled in the last 20 years and currently one in four deaths is caused by alcohol, tobacco, and drug use (National Institute on Drug Abuse, 2020). For every person who dies of substance use, many more endure the devastating effects of this disease. About 50% of individuals with SUD also have co-occurring mental health problems such as anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), bipolar, post-traumatic stress disorder (PTSD), and personality disorders (Ross & Peselow, 2012; Santucci, 2012).

SUD Affects the Family

SUD disrupts fundamental aspects of family functioning including parent-child attachment, roles, routines, communication patterns, social life, and finances. Families affected by SUD often exhibit secrecy, shame, loss, conflict, violence, chaos, role reversal, and fear (Lander, Howsare, & Byrne, 2013). Family belief systems influence how families understand and experience SUD. For instance, cultural and religious beliefs influence the acceptability of the use of alcohol and drugs, and these beliefs influence norms that may be either protective or risk factors (Abbott & Chase, 2008). Sociocultural determinants also inflence how families experience SUD. Specifically, families of color are more likely to experience negative consequences from SUD including biased responses from the criminal justice system; reduced access to services; and greater morbidity, mortality, and violence as compared to Caucasian families (Matsuzaka & Knapp, 2019).

SUD and Children

Data from the National Survey on Drug Use and Health collected from 2009 to 2014 found that approximately one in eight children (13%) aged three to 17 lived with at least one parent affected by SUD in the preceding year (Lipari & Van Horn, 2017). Alcohol use disorder was most common,

occurring in nearly 10% of households with children and affecting about 7.5 million children. About 2.1 million children (approximately 3%) lived in households affected by illicit drug use.

Children raised in families affected by SUD have a higher risk of negative outcomes and are at increased risk for developmental, behavioral, academic, and emotional problems (Lander, et al., 2013; Smith & Wilson, 2016). They also are three to four times more likely to develop SUD themselves than children in families without SUD (Smith and Wilson, 2016). Children of parents with SUD are three times more likely to be physically, emotionally, or sexually abused and four times more likely to be emotionally or physically neglected than peers in families without SUD (Smith & Wilson, 2016).

More children in the child welfare system (51%) have had at least four adverse childhood experiences (ACEs), such as parental SUD, domestic violence, neglect or abuse, or incarceration of a parent, compared to the general population (13%) (Generations United, 2017). The stress children experience when parents struggle with substance use may overwhelm their ability to cope, permanently affecting brain development and creating the potential for life-long physical, mental, emotional, social, and behavioral problems (Shonkoff, 2016).

Children of parents with SUD have elevated rates of depression, anxiety, low self-esteem, oppositional behavior, conduct disorders, and aggression when compared to peers in families without SUD (Solis, Shadur, Burns, & Hussong, 2012). Adolescent children of parents with SUD also experience elevated rates of substance abuse (Neger & Prinz, 2015). According to Solis et al. (2012), children of parents with SUD have a unique risk for increased usage of alcohol and drugs, with earlier onset and more rapid acceleration when compared to peers in families without SUD. By young adulthood, the risk of an alcohol or drug use disorder is 53% in children whose parents have SUD, nearly double that of their peers from families without SUD (Solis, et al., 2012).

In view of the negative influences of parental SUD on children, it is important to understand that protective factors may mitigate the negative effects. Wlodarczyk, et al. (2017) suggest that a substantial number of children exposed to difficult life circumstances, such as parental SUD, show positive development and good adjustment. Protective factors against the negative influences of parental SUD include older age; high levels of self-esteem, self-regulation, and cognitive abilities; and having a flexible and optimistic outlook. Being in a positive parent-child relationship, having secure attachment, and experiencing a consistent parenting style are also protective factors. Additional factors include high family cohesion, adaptability, the presence of someone to trust, social support, and extracurricular activities.

SUD and Kinship Caregivers

Children in families affected by SUD are often cared for by kinship caregivers (hereafter referred to as “caregivers”). Kinship care is defined as “the full-time care, nurturing, and protection of a child by relatives, members of their tribe or clan, godparents, stepparents, or other adults who have a family relationship to a child” (Child Welfare Information Gateway, 2020), and is mostly provided by grandparents (Vandivere, Yrausquin, Allen, Malm, & McKlindon, 2012).

Based on data from the 2010 United States Census, Ellis and Simmons (2014) found that about 2.7 million grandparent caregivers had primary responsibility for meeting the basic needs of one or more grandchildren under the age of 18. Among grandparent caregivers, 39% had cared for their grandchildren for five or more years. Approximately 4.5 million children under age 18 lived in their grandparents’ homes, with over 2 million under age 6, and 45% of these households received no public assistance.

The number of children in kinship care and foster care is increasing overall, mostly due to parental SUD (Meinhofer & Angleró-Díaz, 2019; Vandivere, Yrausquin, Allen, Malm, & McKlindon, 2012). For every child in formal foster care being raised by kin, there are 20 children being raised by relatives informally outside the foster care system (Generations United, 2017). Caregivers and children in informal kinship care relationships often lack access to available support and resources (Generations United, 2016).

Caregivers raising children are at greater risk of depression, social isolation, hypertension, insomnia, diabetes, and decreased physical and emotional well-being (Ge & Adesman, 2017; Hadfield, 2014; Woods, 2020). They also are faced with challenges of financial stress, lack of legal relationship with the child, inadequate housing and resources, and social isolation (Letiecq, Bailey, & Porterfield, 2008; Sharda, Sutherby, Cavanaugh, Hughes, & Woodward, 2019). In addition, many grandparent caregivers have relationship conflicts with the grandchild’s parent with SUD over the nature and extent of appropriate parental involvement with the grandchild (Taylor, Marquis, Coall, & Wilkinson, 2017).

Despite the challenges of parental SUD for caregivers, protective factors may minimize the challenges. Woods (2020) found that spirituality and social supports were key coping mechanisms for caregivers of grandchildren. Dunfee, Brown, and Schoenberg (2020) suggest that religion and spirituality provide a sense of purpose, perspective, and coping among grandparent caregivers. In addition, they found that church communities provide stability and increased social cohesion for

grandparent caregivers. Sharda, Sutherby, Cavanaugh, Hughes, and Woodward (2019) found that caregivers' parenting stress and informal social supports were related to their own well-being. These studies suggest that spirituality, religion, and social supports may act as resilience factors for caregivers.

The influences of parental SUD on children and their caregivers are signficant. Yet, previous research identifying the needs of children and caregivers by professionals who provide services to families affected by SUD is lacking. In addition, studies that examine a variety of kin relationships beyond grandparents are lacking. Thus, the purpose of this study was to explore the needs of children and kinship caregivers in families affected by SUD, as perceived by professionals who interact with these families within one Midwestern community.

Method

Design

A community-based participatory research approach (Israel, et al., 2005) with exploratory and descriptive methods guided identification of the significance of the problem within the community, the study design, and data analysis. This approach allowed a broad range of community stakeholders to participate, explore the extent of the problem, and identify an approach to recruiting a relevant group of key professionals. The research team was composed of community and academic professionals, including individuals with the lived experience of SUD. The protocol was approved by the Institutional Review Board of the affiliated university, and participation of interviewees constituted implied consent.

Sample and Recruitment

Twenty-three professionals who interact in various capacities with families affected by SUD were interviewed, including 13 women and 10 men. Sixteen (70%) had professional experience working directly with children and family members affected by family SUD. The sample encompassed one or more individuals in the following primary professions: addictions counselor, attorney/judicial system worker, educator, family counselor, health care interpreter, law enforcement, mental health counselor, physician, probation officer, public health nurse, and social worker.

All were aged 18 and over, and from one Midwestern state in the United States. Interviewees were identified from within the community based on their professional expertise. Names and contact information were drawn from publicly available governmental, private organization, and business directories. A member of the research team made initial contact by phone, in person, or by email. They explained the study and invited potential interviewees to participate according to a defined recruitment script.

Data Collection

Data were collected from March 2019 to September 2020. Two interviewers conducted the interview and used a semi-structured interview guide to explore the needs of children and caregivers affected by SUD (Table 1). Follow-up questions were asked to clarify answers. Each interview was recorded, and the interviewers wrote field notes following interviews to note overall impressions, challenges encountered, and/or opportunities discovered. The recording was then transcribed by a professional transcriptionist who de-identified the transcript for confidentiality and anonymity.

Data Analysis and Credibility

Investigators followed content analysis methods (Graneheim & Lundman, 2004) for analyzing data text. A subgroup of investigators thoroughly read each transcript and highlighted meaningful statements or phrases of text within the data analysis software program ATLAS.ti 8. The subgroup then met as a team to review meaningful statements and codes that described the meaningful statements in words close to the text. Codes were then aggregated into larger themes with subthemes (Graneheim & Lundman, 2004) within the ATLAS.ti database. Exemplar statements of themes and subthemes were retrievable from within the database for the purpose of assuring validity.

Measures to assure credibility of the data were addressed through the criteria set forth by Lincoln and Guba (1985). Transferability to other settings was enhanced by providing a description of the research process employed (Hays & Singh, 2012). Dependability was addressed by having achieved agreement on study findings by all investigators. Confirmability was addressed through the evidence of focusing on the data and reporting them as directly as possible. De-identified exemplars of data text are used to demonstrate theoretical authenticity. Data collection ceased when data saturation was reached, thus demonstrating adequate sample size. Researchers approached the study with a sense

of flexibility and implemented novel ways of organizing, presenting, and analyzing data consistent with the method.

Results

Children's Needs

The professionals interviewed in this study perceived that children's various developmental needs must be met. The children need relationships and connections with parents and other adults, stability and consistency, and emotional and health care support. Finally, children must be protected from risks that occur in the context of SUD. Within the exemplars that follow, the use of an ellipsis (. . .) signifies statements or portions of the statement that are not necessary or relevent to the theme.

Developmental needs. Children's needs vary according to their developmental level, although according to one professional parental SUD "has a huge impact on the child" at any age. Infants, toddlers, and preschoolers are most vulnerable for not having their basic needs met because they are very reliant on their parents. "When substance abuse is in the mix, sometimes [the substance] gets prioritized . . . over those basic needs for the kids," such as food, shelter, clothing, and safety. One professional shared, "We've had kids walking down the street in a diaper in the dead of winter because Mom or Dad is passed out and the child . . . [gets] out of the house."

With school-age children, "we start seeing more of the depression, the anxiety, maybe ADHD, oppositional defiant behavior, disruptive behavior." Children may be "missing a lot of school, showing up without the materials that they need. . . . Showing up without a winter jacket. . . . Not having forms signed [or] money in the lunch account." School-age children also may be taking care of their younger siblings. One professional shared about a boy,

> Twelve years old, and he had been acting out a lot in school. . . . It turned out that his mother had moved and left him . . . and his two [younger] siblings. . . . [They] had been living in a car for a week.

In older children "we see a lot of anger toward the parent who's been using." Although "older kids . . . [are] a little better able to advocate for themselves," they may not be willing to disclose personal information. "That measure of love and loyalty [for their parents] is really hard on kids. They

wouldn't want to be snitches." Their status as minors also acts as a barrier to self advocacy. "A lot of times we can't talk to the kids without the parental consent." Adolescents are "making more decisions and doing their own thing, but really having someone who can act and function as a parent [is still important]."

Relationships and connections. The majority of professionals reported thinking that most parents want to be good parents, although parenting quality can depend on the state of the parent's substance use. One expressed,

> I think there is a [misunderstanding] out there, that parents who are struggling with chemical use are bad parents. . . . My experience has been that they are really great parents actually, but they are just struggling with an addiction.

Several professionals described the need for keeping the child safe and cared for while maintaining the parent-child relationship. One professional with a personal history of SUD stated,

> I think that you have to assess the harm, right? . . . I took care of my children. I drank, I used drugs, but I don't think that my children would have been better during that time in a foster home.

Another advocated that "kids need to be able to continue their relationship with their parent, whether [the parents] are in or out of their recovery." "Removal of kids from their families . . . should be the very, very, very last case scenario." "When you remove children, you're creating further trauma . . . so if there is a way to wrap safety around that child within the context of the parent's use, we're always going to try that first."

Children also benefit from the support of extended family members, community supports, and connections with other adults. Children benefit from programs such as "Boys and Girls Club, or places where they can get those adults, those caring adults, in their world."

> It really takes one person to think that a kid is the most amazing person in the entire universe for them to be successful, and so if . . . their parents are struggling with addiction, we know that there are relationships and connections that can help them to be resilient even outside of that [family] structure.

Stability and consistency. Stability and consistency were identified as priority needs for children. “The biggest thing for them is just to feel like they have some kind of stable, predictable, safe environment.” “People who are facing chemical dependency issues may be burning bridges . . . and so that little one ends up getting bounced around, and the effects of that are pretty detrimental.” Such transitions can create “a new normal for the kid.” “Most of these kids, they just don’t know what is next for them.”

Parental SUD often creates confusion for children, who need “somebody who’s able to understand what’s appropriate for them at their age and then tell them what’s going on in real terms, so that they’re not making up their own stories.” Living in a family affected by SUD may give children a distorted idea of normal family life. One professional noted that “people who come from homes where addiction is prevalent . . . think everybody’s parents drink, use drugs.” This “teaches them early patterns . . . and then that sort of sets [them] up . . . to that same lifestyle.” Another suggested that the children need “somebody to talk to, to understand what is normal and what is not normal.”

Stability in school placement was also recognized as important. Kids sometimes get “bopped around to different schools,” and

> there’s a lot of research . . . [that] multiple school placements reduce a child’s graduation rate and their academic learning. Every time they move, we say they lose about four months of learning, and so we try very hard to keep kids in their school of origin.

“I would say that school itself is structure. You go to school at the same time, you have the same classes, eat at the same time, and get done at the same time.” Another professional described how the school plays a central role in the lives of children: “The needs of the children in these families are to have a positive experience at school, and to have adults who care about them, and for them to have a sense of confidence and competency.”

Emotional and health care support. Emotional support is critical for children raised in the context of SUD, and they may not develop healthy coping strategies “because they did not get the opportunity to learn in their nuclear families.” One professional noted that it is not necessarily how much the parent is using.

> The impact on the child is much more about the unique circumstances. . . . Some kids [in families where] abuse or conflict in the home . . . is part of that substance abuse, they are more affected. So, I think that's really where we would focus in, is on their ability to cope.

Children "need to be reminded that their feelings are real . . . [and need help expressing] . . . those emotions, because kids that bottle up big-time feelings are going to explode someday." Children "deserve a model for a way to make different choices in life, and a way to handle challenges in life differently than they've maybe seen their parents do."

Children in families with parental SUD also need health supports. Pediatric health care providers can play an important role in providing these supports. As one professional suggested, "These kids need to be followed much more closely than an average child." The stress of living in a family with SUD may manifest as somatization, the tendency to experience and communicate psychological stress through physicial symptoms. As one professional shared,

> Irritable bowel is associated with anxiety and for other mood issues. . . . Chronic regional body pain without a defined cause is a very common one. These kids are oftentimes traumatized, and that can manifest itself in different ways, and a lot of the time that is as behavior problems.

Thorough health assessments are key to appropriate and timely treatment. One professional reported that children affected by SUD are often diagnosed with ADHD or oppositional defiant disorder, when "actually the majority of them have PTSD. And so I will see kids on multiple antipsychotics and anti-ADHD meds, and they are not getting better, they are getting worse . . . because with PTSD it makes it worse." Getting a thorough mental health assessment early in life "gives kids a much better chance for success down the road." Professionals recommended long-term mental health treatment. "Any child who experiences alcohol or drugs in their family . . . they probably need . . . mental health care from infancy on up." Others recommended "intense services with long-term monitoring" and services to "wrap around these kids from preschool to high school." Despite awareness of the need for emotional and health care supports, several professionals commented on the limited resources for children. One stated, "I don't really know of services that are focused on children specifically related to their parent's substance use."

Protection from risk. Professionals noted that SUD in the family may place children at increased risk for inadequate supervision, drug exposure, neglect and abuse, and exposure to criminal activity. For instance, children may be exposed to drugs during pregnancy, breastfeeding, or while living in the home. One professional noted that a child may be injured

> by getting into the parent's drugs that are being left around . . . and there are times when the parents purposefully will give drugs [to a child] . . . to get a response, either to sedate them or to, um, see how funny it looks.

Substance use increases the risk of neglect and abuse.

> Most people think of neglect as 'It's only neglect, thank God it is not head trauma.' But . . . neglect carries as great potential effects physically and developmentally and socially and behaviorally on these kids. So, even if they do not get the drug in their system, the lack of stimulation and inconsistency puts these kids very much in harm's way.

Another professional stated,

> If the parents are dealing, now I have drugs and . . . loaded weapons under the cushions, and stuff in the house. Plus, you are bringing bad people into the house, so now the risk of physical abuse and sexual abuse is increased for that child.

Several professionals stressed the importance of protecting children from these risks. According to one, "Our job is to identify the risks to the kids. They need to be in a safe environment."

Kinship Caregivers' Needs

The professionals interviewed in this study identified grandparents as most likely to be the caregiver, but also discussed caregiving by other relatives, church members, or friends who have a relationship with the family. Professionals perceived that caregivers need a variety of community resource supports, skills development to maintain the family system, support for navigating systems on behalf of children, and understanding of the caregiver's role in the context of SUD.

Community resource supports. Caregivers need financial support and case management services such as counseling, food support, housing, and childcare to maintain the family system. The most immediate need confronting kin when they assume the role of caregiver is financial support for the child, particularly when the situation is urgent. “Caregivers are working so hard to try to take care of these children that weren’t something that they had expected.” One professional stated that the biggest need of caregivers is “probably economic resources. All of a sudden instead of five mouths to feed you’ve got seven.” Another elaborated, “It’s an unexpected cost, it’s not a small one, and . . . [public assistance programs aren’t] available unless you have adopted these children or have custody of them.”

Several professionals described the need for caregivers to have access to affordable childcare, housing, and food support. “Childcare assistance would be really helpful for these family systems, but sometimes they do not qualify because they are not [legally considered] the direct custodial [parent] of the children.” The need for caregivers to have access to affordable, appropriate housing for themselves and the child was voiced by one professional,

> I think it needs to be safe, and I have some situations where there’s nine or ten people living in a two- or three-bedroom apartment. You’ve got kids sleeping on the couches and blow-up mattresses on the floor. . . . Everybody likes a measure of privacy, and I’m not sure there’s much of a measure of privacy when everybody’s on top of each other.

Last, the need for food assistance for caregivers to ensure food security for children was expressed. One professional stated, “A lot of grandparents are living on a fixed income and now they have the financial burden [of providing] food and clothing and sports and whatever else that they’re trying to give.”

Professionals frequently commented on the inadequacy of resources to support families and caregivers, and expressed the need for case management services to support the child’s growth and development. “I think a lot of times it is teachers . . . or possibly child protective services . . . [that] try to get these wrap-around services.” One commented, “I think often times in the past the family is neglected in that sense, where they don’t necessarily receive the resources or assistance.” Others noted that sometimes caregivers hesitate to access the few available resources “because we [the family] don’t want too many people to know our business.”

Skills development to facilitate the family system. Caregivers also need support for developing skills to faciliate the family system. Most immediately, caregivers need to know how to address the adverse childhood experience (ACE) of SUD because "the children, they really are special needs children that come into the [caregiver's] home." Many kin who assume the role of caregiving have had little experience with ACEs and need to know that "those really young kids . . . who had this horrible existence up to this point [can be] hardwired this way." Likewise, it may have been a long time since a caregiver has taken care of a young child and they may need to be reacquainted with basic parenting skills such as "When do they toilet train? When it is acceptable to tolerate that [behavior]?" Finally, caregivers may need training in technology skills necessary to support the child and family system. For instance, one professional shared about a caregiver who was unable to access an online report card and requested, "Can I just get a printed report card?"

Support for navigating systems. Caregivers also need support for navigating multiple systems on behalf of children, including childcare, health care, education, and legal systems. Caregivers are temporarily navigating systems while the parent with SUD is unavailable. One professional describes, "We might do an intake with the caregiver rather than the parent, depending on where [the parent with SUD is] at in the process."

Accessing and navigating health care systems must also be done emergently by caregivers. Oftentimes caregivers do not have health insurance information, knowledge about the child's health care providers, or decision-making authority for the child. One professional stated,

> Making sure that [the child has] health insurance, figuring out a way that [the caregiver] can make those medical decisions . . . for those children in the absence of a parent [is necessary]. . . . [They need] some sort of navigator.

It is particularly arduous to access mental health services for children because "children's mental health. . . . They have a wait list for case management. . . . Even if you are being proactive and you're trying to get help for your kid . . . it's not easy."

Navigating the legal system to access important child services is also difficult. One professional described, "Do they [the caregiver] have the power of attorney? Do they have temporary guardianship?" Another stated that caregivers need

> helpers who can help navigate this complicated process, and whether that is needing to go to court to get some sort of custody, or to transfer custody over, or if it is needing to figure out how to get mental health services when you are not legally their parent. How do you navigate that? How do you navigate the school?

Understanding the caregiver's role in the context of SUD. Caregivers need knowledge about the entirety of the caregiver role in the context of SUD, when children are likely to have had ACEs. Physically, caregivers become tired to the point of exhaustion from the responsibilities of caring for the child while dealing with the uncertainties of SUD. "Many times they don't even have time to live. They get physical and psychological exhaustion because they don't have time to sleep, to think, and to eat." Thus, it would be helpful

> for the grandparents to know that there's such a thing as crisis nursery. . . . Or maybe they have the funding enough to pay for their own babysitter to come and help out or something because . . . they need a little bit of free time, too."

Caregivers are also confronted with role conflict in supporting the person with SUD while being responsible for that person's child. "The grandparent may not believe that their son or daughter really would do anything wrong, so they let the parents continue to have exposure to the kids, unbeknownst to the county." Caring for the child of a loved one with SUD forces caregivers into coparenting. As one professional described,

> Caregivers struggle when there is not court involvement, or there is not child protection involvement, and it is just me trying to talk my daughter through her needing to do something, or I need to take her child, right? My daughter can either agree with me or not, and then if she does not agree with me, I have very few options to be able to just get that child in a safe place.

Discussion and Conclusion

The purpose of this study was to explore the needs of children and kinship caregivers in families affected by SUD, as perceived by professionals who interact with these families. Using a community-based participatory research design with a qualitative method allowed examination of the naturally occurring needs of these children and their caregivers. The results indicated that professionals

are aware of the needs of children and caregivers; however, there is a lack of comprehensive resources and services to support families affected by SUD.

The findings showed that professionals perceived children's needs as being linked to their stage in development, and their desires for relationships and connections with parents and other adults. These findings are consistent with previous research identifying that the influence of parental SUD and associated manifestations vary according to the developmental level of the child (Neger & Prinz, 2015; Solis, et al., 2012). Results also showed that children need emotional and health care support, stability and consistency, and protection from risks associated with SUD. Consistent with the findings of the present study, Wlodarczyk et al. (2017) suggest that protective factors against the negative influences of parental SUD include older age, high levels of self-esteem and self-regulation, being in a positive parent-child relationship, having secure attachment, experiencing a consistent parenting style, and engagement in extracurricular activities.

Professionals in this study reported that caregivers need a variety of community resource supports to maintain the evolving family system, especially at times of sudden transition. Caregivers need assistance with finances, food, housing, and childcare to support the family. Previous research also has shown that kinship caregivers are faced with challenges of financial stress, lack of legal relationship with the child, inadequate housing and resources, and social isolation (Letiecq, Bailey, & Porterfield, 2008; Sharda, Sutherby, Cavanaugh, Hughes, & Woodward, 2019). Professionals in the present study also expressed the caregivers' needs of skills development, support for navigating systems on behalf of children, and understanding the role of a caregiver. These results are consistent with Taylor et al. (2017), who found that many grandparent caregivers have relationship conflicts with the grandchild's parent with SUD over the nature and extent of appropriate parental involvement with the grandchild.

Despite the professionals' awareness of the needs of children and caregivers affected by SUD, many noted that resources and services for families are inadequate. These findings align with existing data identifying that children and caregivers in informal kinship care relationships often lack access to available support and resources (Generations United, 2016). This lack of support is concerning in view of the profound impact that parental SUD has on children, emphasizing the urgent need for communities to address these issues.

Although the study has several strengths, limitations do exist. The study was based on a convenience sample from a small Midwestern city of middle-class, professional, primarily Caucasian

citizens of the United States. Thus, findings may not be generalizable to other populations and settings. Perceptions of professionals regarding needs of children and caregivers in informal kinship arrangements are minimally represented. Most importantly, the perceptions of the needs of children and caregivers are second-person discernments from professionals.

Despite these limitations, this study adds to the existing literature by examining a broad range of key professionals' perceptions of the needs of children and caregivers affected by familial SUD. In addition, the needs of various types of kinship caregivers were identified; this aspect has received limited research attention and is largely unknown. The findings indicated that professionals who interact with families managing in the context of SUD are aware that children and caregivers have needs that are not being met with existing resources and services.

Future research is needed to understand the specific needs and experiences of familial SUD as reported by children and caregivers themselves. Involving children and caregivers in future samples is essential to identifying needs and to developing interventions and resources to meet unmet needs. With this type of information, communities could create comprehensive services to promote whole family health and recovery for those affected by SUD.

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Table 1

Interview Questions

Questions about background

1. What is your role in working with families and children affected by substance abuse?
2. What is your educational background?
3. Describe your work experience in dealing with families affected by substance abuse?
4. What services does your agency/organization provide for persons affected by substance abuse?

Questions about children's needs

5. As you think of families affected by substance abuse, what do you see as the needs of the children in these families?
6. As you think about the children in these families, how do you see the children's needs change depending on their ages? For example, what do you see as the main needs of preschoolers? School agers? Teen agers?
7. In your experience, what types of resources do you think children in families affected by substance abuse need and why?
8. Which of these are currently available in your community?

Questions about caregiver's needs

9. In your experience, who are the adult caregivers of children in families affected by substance abuse?
10. In your experience, what do you see as the challenges for adult caregivers of children in families affected by substance abuse?
11. In your experience, what types of resources do you think caregivers of children in families affected by substance abuse need and why?
12. Which of these are currently available in your community?
13. Is there anything else you think would be helpful for us to know? Anything you would like to add? Are there other individuals or agencies whom you think would be helpful for us to interview?

Supplemental questions

14. Do you have any ideas on how we might identify and contact caregiving adults and/or adult children raised in families affected by substance abuse so we can request their participation?
15. As our larger project moves forward would you be interested in continuing to participate? In what area might you be interested?