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Supporting Children Impacted by Parental Addiction: A Toolkit for Kinship Caregivers

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Abstract

Kinship caregiving has become increasingly common in the United States, specifically due to parental substance use disorder. These kinship caregivers (KC) have unique needs that are largely unmet. Often, there is no comprehensive resource for KCs specific to their community. KC's greatest needs are financial, legal, and mental health assistance, as well as educational information about care of children for the kinship caregivers. The objective of this project was to develop a KC resource toolkit to meet priority needs within the community. The project design utilized an EBP framework and followed a community-based participatory research approach.

Project leads worked with a local non-profit organization (NPO) in a mid-sized midwestern city to inform the project in September 2021 to June 2022. Consultation with social work, addiction medicine, and law enforcement professionals as well as kinship caregivers with lived experience who were also partners within the NPO were completed throughout the process of creating the resource toolkit. Using evidence-based information, the toolkit was created with continuous input from professionals as well as persons with lived experience, over a period of six months. Project leads, working in collaboration with the NPO and professionals within the community, attempted to recruit kinship caregivers from within community settings.

The Caregiver Toolkit Survey (CTS) was developed to measure usefulness of the KC toolkit as perceived by KC. The CTS was administered at baseline and distributed to KC for completion 2 – 4 weeks after baseline. A second survey was developed and administered to professional stakeholders to obtain professional perspectives of the usefulness of the toolkit. Data was collected between March 15, 2022, and May 15, 2022.   The main findings indicate that professionals all agreed or strongly agreed that toolkit will help caregivers understand the needs of children impacted by parental SUD. The results of the surveys will assist in modifying

the toolkit for future use within the community. This project offers a starting point for others who wish to create an evidence-based toolkit for KC.

What is known about this topic:

- Kinship caregivers not involved in the formal foster care system receive less support compared to kinship-foster caregivers.

- Children placed in kinship care have better outcomes than those in foster care.

- There is significant stigma associated with SUD that may impede research and practice related to this topic.

What this paper adds to the topic.

- Information for social science and health professionals who intend to create a community-specific resource toolkit for kinship caregivers.

- An evidence-based toolkit outline, based on an interdisciplinary collaboration between professionals and persons with lived experience.

- Defines challenges associated with reaching kinship caregivers who may be wary of participating in research.

Keywords: *kinship caregivers, caregiver needs, substance use disorder, children, community resource toolkit, navigator program*

Introduction

More than 2.5 million children in the United States are currently being raised by their grandparents or other relatives (i.e., kinship caregivers), both formally through the child welfare system and informally through private family arrangements (Casey Family Programs, 2018). Kinship placements promote family and cultural continuity and better outcomes for children in comparison to non-relative foster placements (Washington et al., 2018). However, they also can present unique dynamics and stressors, and kinship caregivers benefit from a specific array of social supports and economic resources (Rodriguez-JenKins et al., 2020).

Kinship caregiving is becoming increasingly common when parents experience substance use disorder (SUD). SUD is characterized by recurrent use of alcohol or drugs (or both) resulting in problems such as being unable to control use of the substance; failing to meet obligations at work, home, or school; having poor health, and spending an increased amount of time getting, using, or recovering from the effects of using the substance (National Institute of Drug Abuse, 2020). From 2000 to 2017, the number of foster care entry cases attributed to parental SUD increased by 147% (Meinhofer & Anglero-Diaz, 2019). The lack of resources for kinship caregivers (KC) negatively affects the family and can compound difficulties related to SUD.

SUD is traditionally treated by focusing predominantly on the individual with SUD (Maina et al., 2021). However, there is adequate research demonstrating that treatment of this complex and pervasive disease requires a comprehensive plan that includes families, friends, and community (Crowley & Miller, 2020). Despite the evidence establishing the need for support for families experiencing addiction, there has been a lack of resources, counseling, and support for families and children (Maina et al., 2021; Tye et al., 2021).

Children who live with an adult with SUD are more likely to experience adverse childhood experiences (ACEs) compared to a child who does not live with an adult with SUD

(Bryant et al., 2020; Tye et al., 2021). ACEs are defined as negative experiences that are

potentially traumatic occurring before the age of 18. ACEs can take the form of abuse (physical,

verbal/emotional, or sexual abuse), neglect (physical and emotional), or significant household

disruption (parental incarceration, witnessing domestic violence, parental substance use, parental

mental illness, or parental separation/divorce) (Centers for Disease Control and Prevention

[CDC], 2022). ACEs have been shown to be inextricably linked to adult chronic illnesses and

increased mortality in the United States (Felliti, 2002). By providing KC with resources and

materials designed to promote resiliency and healing, the NPO offers hope to those suffering

from SUD and prior ACEs.

There is extensive literature detailing the importance of kinship care when social services

have determined that a child cannot remain with their birth parents. In a detailed systematic

review of child placement outcomes, Winokur et al. (2015) noted that children in kinship care

experience better outcomes than children who are placed in the foster care system. Specifically,

children in kinship care showed improved outcomes in (a) behavior problems; (b) psychological

problems; (c) well-being, and (d) placement stability (Winokur et al., 2015).

Kinship navigator programs are evidence-based programs that have been shown effective

at assisting KC in locating resources. These programs offer enhanced services to kinship

caregivers by establishing a specific coordinator, referred to as a navigator, who assists kinship

caregivers by providing specific information, education, and referrals to other state or federal

services as well as establishing peer networks for kinship caregivers (Casey Family Programs,

2018).

Although KC resources are available in almost every state, many of these specific

programs are only available to certain areas or cities in the United States (U.S.) (Casey Family

Programs, 2018). Twenty-one states in the U.S. offer KC navigator programs in all counties of the state, while eight states offer these programs in specific counties or cities. Twenty states currently offer KC resources, but they are not navigator programs, and one state does not offer any specific KC resources (see Figure 1). Although many states have navigator programs, they are often privately-funded and are not well-known or advertised. Providing a toolkit specifically designed for KC provides detailed information about resources while allowing for privacy and anonymity.

Figure 1

Kinship navigator services availability in the United States
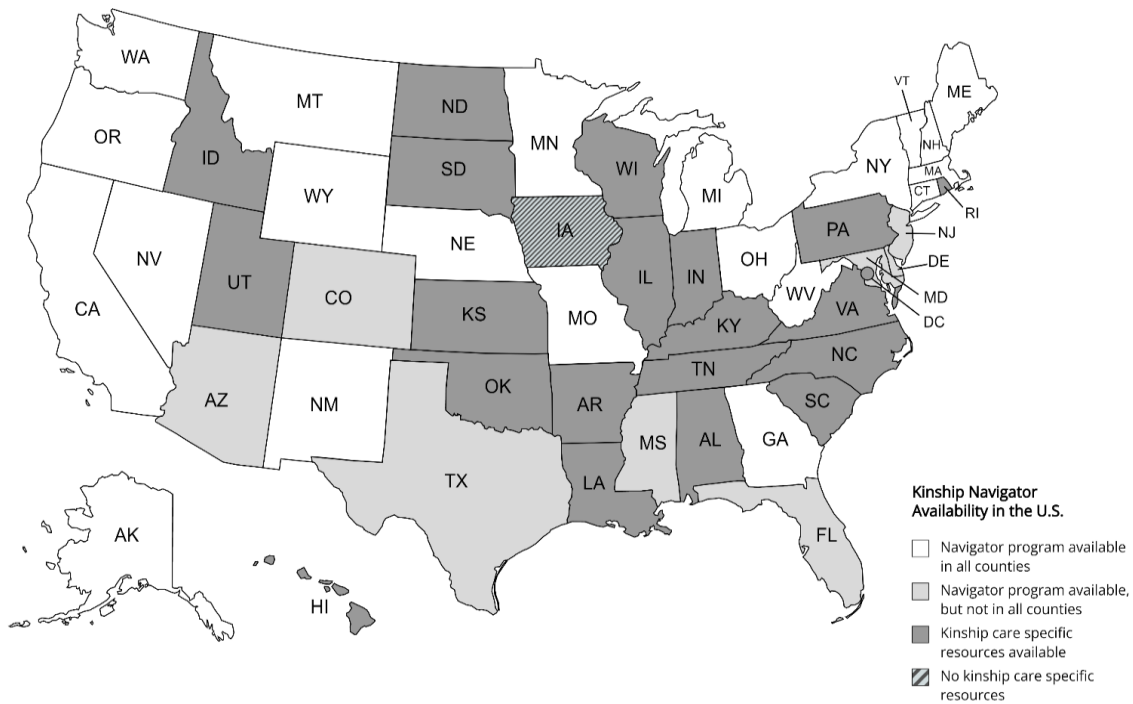
Note: Data compiled and valid as of June 28, 2022.

The project goal was to create an evidence-based toolkit, tailored to the needs of KC, that contained local resources and educational materials about SUD, ACEs, and communication skills, and offered resources in an easy-to-read format in collaboration with community stakeholders. The benefits of providing a reference toolkit of available community resources to KC include:

- Increasing awareness of programs designed to support those affected by SUD;

- Increasing knowledge about effective educational materials to use for KC and children affected by SUD;

- Increasing awareness of support services in the community;

- Decreasing stigma surrounding SUD.

Materials and Methods

An evidence-based practice project plan was to create, distribute, and evaluate a KC resource toolkit and assess caregivers' and professionals' perception of usefulness of information contained in the toolkit (See Appendix A for Topics and materials included in Caregiver Toolkit).

Toolkit Development

Project leads obtained detailed information from one-on-one interviews with individuals (professional and/or those with lived experience), attending family support group meetings and e-mail contact with community stakeholders representing social services, law enforcement, school counselors and mental health professionals to best understand the needs of children and KC in the community. Scholarly journal articles detailing interventions that demonstrated utility specifically for KC were reviewed and synthesized by project leads.

Development of the toolkit was a collaboration between project leads and the collaborating non-profit organization members, consisting of two nurse practitioner students, an advanced practice pediatric nurse practitioner, and other professionals within the field of health and social sciences. The major facilitator of this project was the NPO, an all-volunteer, academic-community partnership dedicated to helping families who are affected by parental SUD.

Professional participants from local community agencies were asked to review content throughout the toolkit development phase. Professional participants included physicians, advanced practice nurses, nurses, social workers, recovery specialists, and SUD counselors who actively work with clients who are being treated for SUD or are KC. Many of these participants were recruited prior to the beginning of the project through collaboration with the NPO.

Compiling the toolkit was a weekly process using suggestions and feedback from various professionals (e.g., a Licensed Marriage and Family Therapist with a specialty in SUD). The toolkit was created over a period of six months, while toolkit items were approved by the NPO along the way.

After an extensive literature synthesis, and obtaining recommendations from local professionals, community members, and caregivers, a list of priority KC needs were identified. From that list five main sections were created as follows:

- understanding SUD;

- how SUD affects families;

- the impact of SUD on children and how to support them;

- how SUD affects caregivers;

- local resources (including obtaining food, childcare, healthcare, mental health

   resources, legal resources, and accessing financial benefits)

To best fit a diverse population of KC, the toolkit utilized language at or below a nineth-

grade reading level and was available to caregivers in paper copy or as a portable document

format (PDF). The project was approved by a University Institutional Review Board prior to

implementation.

Evidence-based practice model

Throughout the development of this project, an evidence-based practice (EBP) model was

used to foster adoption of evidence, enable users to speak a common language, standardize

Figure 2

Johns Hopkins Nursing Evidence-based Practice: Model
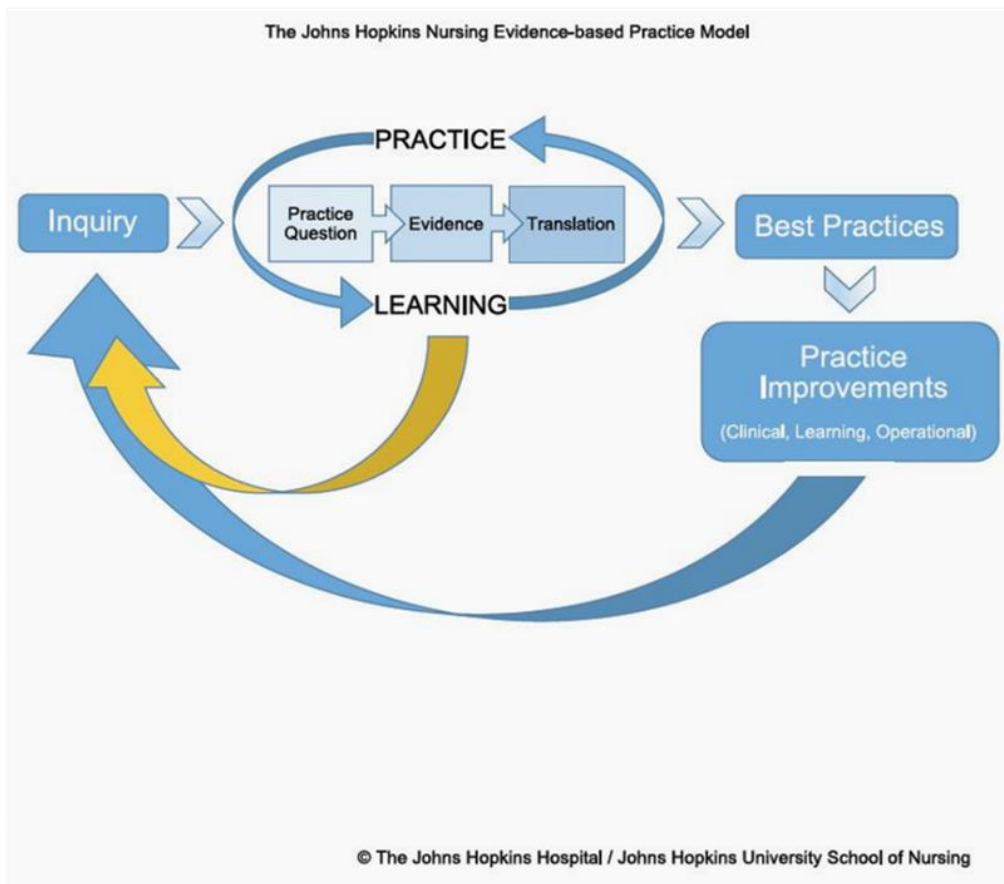
processes, and set a foundation for future work. The Johns Hopkins Nursing Evidence-Based

Practice (JHNEBP) model was used for this project as it describes a continuous cycle of

improvement, and the toolkit will be altered by the NPO as needed in years to come (see Figure

2).

The JHNEBP model has three interrelated components: inquiry, practice, and learning.

Inquiry is the foundation to question, examine, and collect information about a problem, issue, or

concern (Dearholt & Dang, 2017). Practice occurs in three phases: practice question, evidence,

and translation (PET). "Based on the problem statement, a *practice question* is developed and

refined. A search for *evidence* is conducted to provide support." (Dearholt & Dang, 2017, p. 45),

"If evidence is found to support change, evidence is *translated* so practice change can be

planned, implemented, and evaluated" (Dearholt & Dang, 2017, p. 46). During translation,

changes to practice are assessed for feasibility and appropriateness (Dearholt & Dang, 2017).

Surveys

A 10-question Likert-scale survey, the Caregiver Toolkit Survey (CTS), was developed

and used to assess baseline knowledge of community resources available to KC and

understanding of SUD, communication tools, and ACEs, and re-assess knowledge 2-4 weeks

after implementation. (See Appendix B for CTS). Project leads and stakeholders requested that

the caregiver complete the survey prior to reviewing the toolkit, and then repeat the survey 2-4

weeks after receiving and reviewing the toolkit.

A second survey was created and sent out to key organizational stakeholders and

professionals involved in reviewing and distributing the KC toolkits within the community. This

survey consisted of 10 Likert-scale questions regarding the utility of the KC toolkit, with an

additional fill-in-the-blank question requesting any further comments on the toolkit (see

Appendix C for the professional survey).

Participants and Recruitment

Eligible KC participants were those living in an upper mid-west community in the United

States, and who (a) were 18 years of age or older, of any gender, race/ethnicity, and

socioeconomic status; (b) had the ability to read and write in English; and (c) cared for children

impacted by an adult with SUD, formally (involved with social services) or informally (having

an agreement with the parent). There was no requirement for length of time caring for the

children or whether care was full or part-time care. KCs unable to read or write in English were

excluded. The setting for participant recruitment included multiple community organizations

(e.g., detoxification facilities and SUD counseling centers).

Participants were recruited via community events or locations (such as churches or

outpatient clinics) and utilization of various community members such as public health workers.

The main focus of this strategy was a partner approach, where community resources

stakeholders, (i.e., the director of a detoxification facility), were informed about the project and

word of mouth was used as the basis for increasing interest among KC. Community outreach

was also conducted via family support meetings led by the NPO.

Toolkit Distribution

In order to reach caregivers, project leads collaborated with three community agencies

who agreed to participate in the project and supplied the agencies with physical toolkits, as well

as an educational handout about the project. (See Appendix D for Instructions for Distribution of

Toolkit).

After obtaining consent, participants were given the caregiver toolkit, two copies of the CTS, and a pre-paid, addressed envelope for return of the reassessment of the CTS. KCs were asked to fill out the second CTS two to four weeks following distribution and use of the toolkit and return it by mail or complete online. To improve post-survey compliance, a QR code was included on the surveys so the participant could complete the survey online via Qualtrics[©]. Additionally, a brightly colored post-it note was attached to the survey with a reminder to complete the post-survey in two to four weeks.

A second, professional survey (Appendix C) was created and sent out to key stakeholders involved in reviewing and distributing the KC toolkit within the target population. The survey was sent and returned via e-mail and/or a Qualtrics© QR code. Professionals were asked to rate the toolkit using a Likert scale in regard to (a) the ease of navigating through the toolkit to find specific resource topics; (b) the potential to improve caregiver understanding of the needs of children impacted by parental SUD; (c) the toolkit offered specific ideas to improve family communication; (d) the toolkit was presented in a way that helps reduce the stigma of SUD; and (e) the toolkit offered practical information to help clients understanding of substance use disorder. The professional survey also asked which section of the toolkit would be most helpful to KC, and if there was additional information they thought should be included.

Results

Approximately ten toolkits were distributed, however no surveys were returned to project leads. Approximately fifteen surveys were e-mailed to professionals, with a total of six surveys returned with feedback on the utility of the toolkit. The results of the survey are described in Table 1. Overall, most of the professionals perceive that the toolkit is useful for their clients, that it offers specific ideas to improve communication, and is presented in a way that helps reduce the

stigma associated with SUD. One hundred percent of professionals agreed with the statement,

"The toolkit offers practical information to improve clients' understanding of substance use

disorder." Thirty-three percent of the professionals did not find it easy to navigate the toolkit to

locate specific resources and suggested adding more specific section dividers, so that resources

could be more easily accessible, as well adding more information in the beginning, as opposed to

the end of the toolkit, about how to access a computer if the caregiver does not have one. When

asked which section was most helpful, three participants chose "The impact of SUD on

children," while one participant each chose "Understanding SUD," "The impact of SUD on

families, and "County resources." Recommendations for review will be followed up with project

leads and the NPO to improve the toolkit and continue to offer it to families in need.

It is important to note that some professionals were also persons with lived experience in

kinship caregiving and SUD. One of the participants noted that it was challenging to read some

of the materials as it brought back memories of difficult times, and had to "take a break" from

reviewing the toolkit in their professional role.

Table 1

Results of Survey of Professionals (N = 6)

	Response Options				
Questions	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
The toolkit is easy to navigate to find specific information on topics such as legal or medical assistance.	3 50%	1 16.7%	0	2 33.3%	0

Table 1 (continued).

The toolkit will help caregivers understand the needs of children impacted by parental SUD.	3 50%	3 50%	0	0	0
The toolkit offers clients specific ideas to improve family communication.	3 50%	2 33.3%	1 16.7%	0	0
The toolkit is presented in a way that helps reduce the stigma of SUD.	4 66.7%	2 33.3%	0	0	0
The toolkit offers practical information to improve clients' understanding of substance use disorder.	3 50%	3 50%	0	0	0

Discussion

This project focused on addressing the problems associated with the lack of information available to KC, in order to improve care for children affected by SUD. Input from stakeholders, professionals, volunteers, community agencies, caregivers, and families affected by SUD was essential to develop a toolkit of high priority needs and resources for KC, the children they care for, and the families affected by SUD.

 The toolkit has the potential to be beneficial to community agencies who encounter families affected by SUD. The toolkit is a quick reference families can take home and review as needed and privately, choosing which services best their situation.

Previous research on KC shows obtaining feedback from KC is notoriously difficult (Sutphin, 2015). Project leads and stakeholders used multiple methods to remind the participants of the importance of obtaining their opinion after reviewing the toolkit and encourage them to

return the survey. In addition, project leads included a brightly-colored reminder "post-it" note on the self-addressed stamped envelope, in hopes of increasing response rates.

One idea for further recruitment would be offering gift cards for participation. Studies indicate that the offer of financial compensation is an effective incentive for participation. (Stunkel & Grady, 2011). Financial incentives most likely play a more important role in recruitment for studies conducted in socioeconomically disadvantaged populations (such as populations in developing countries or impoverished regions of developed countries) than they do in studies conducted in more prosperous populations (Resnik, 2015). Funding to offer incentives in the future could be obtained from university grants or community donations.

Based on the results of this project, further involving KC participants in survey assessments for future projects prior to distribution may be a successful strategy in encouraging KC input and feedback. Establishing a group of informant participants may increase rapport and open communication between participants and professionals, while increasing the probability of receiving feedback about the toolkit's usefulness. Further evaluation of the toolkit by KC may be enhanced by finding multiple reliable connections to KC prior to distribution. Advertisement of the toolkit would assist with informing the public of such a resource, while creating an online toolkit link which KC can access privately would support anonymity.

Conclusion

Currently scholarly evidence shows that KCs are less likely to use formal resources and services than foster parents (Coleman & Wu, 2015), despite the fact that children have improved outcomes when placed in kinship care (Schmidt & Treinen, 2017). A collaboration of community stakeholders came together to provide evidence-based resources and materials to create a free, easy-to-use toolkit that offered community resources as well as educational

materials to assist these caregivers. Professional stakeholders provided useful feedback about

benefits of toolkit. Suggestions can be used to modify the toolkit for further use within the

community. Ongoing research is needed regarding specific resources KC find beneficial when

caring for children affected by SUD. Use of this toolkit will allow community stakeholders to

focus on reaching the target population. Creating a toolkit with evidence-based materials, in

collaboration with multidisciplinary professionals was the main goal of this project, as there was

no comprehensive resource for KC specific to this community. Although a number of resources

are available for caregivers, few are kinship caregiver focused, and provide KC little information

other than a phone number for contacting the resource. This project provided a resource to KC

to increase knowledge of resources available in the community as well as increase understanding

of SUD, communication skills, and ACEs, in an upper Midwest region of the United States.

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    d%20experiences%2C%20or%20ACEs,experiencing%20violence%2C%20abuse%2C%

    20or%20neglect

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Appendix A

Topics and materials used in Caregiver Toolkit

Toolkit Topics	Website links available in PDF toolkit (local websites removed for anonymity)	Physical toolkit materials
Assistance locating basic needs – childcare, food, clothing & housing[12345678]	https://helpmeconnect.web.health.state.mn.us/HelpMeConnect https://www.211.org	City and county specific food shelves, description of food available and hours. Housing contacts, Salvation Army information and county United Way contact information. Printed resources with specific contact for crisis nursery and hours available.
Financial resources and assistance[12345678]	https://helpmeconnect.web.health.state.mn.us/HelpMeConnect https://www.grandfamilies.org/Resources/Financial-Assistance	Printed resources, along with contacts and phone numbers for local agencies, used with permission.

Resources for caregivers of children[1234678]	https://www.addictionpolicy.org/post/how-addiction-affects-the-family	Printed materials from various websites, with permission.
	https://sesamestreetincommunities.org/topics/parental-addiction/	Printed materials created by community non-profit organization members.
	https://www.helpguide.org/articles/parenting-family/grandparents-raising-grandchildren.htm	Printed materials to help explain common questions about parental reunification.
	https://www.aarp.org/relationships/friends-family/info-08-2011/grandfamilies-guide-family-challenges.html	
	https://www.cdc.gov/childrenindisasters/helping-children-cope.html	
Healthcare resources[1234678]	https://helpmeconnect.web.health.state.mn.us/HelpMeConnect	Printed state and county-specific social services contacts for sliding scale and/or free healthcare. Printed contact information for local healthcare clinics.
	https://www.grandfamilies.org/Topics/Healthcare/Healthcare-Resources	
	https://www.medicaid.gov/state-overviews/stateprofile.html?state=minnesota	
Mental health resources[123467]	https://helpmeconnect.web.health.state.mn.us/HelpMeConnect	Printed resources from websites (used with permission), along with contacts and phone numbers for local low-cost/sliding-scale free clinics.
	https://namisemn.org/resources/links.html	

Resources for finding peer support groups & self-care[123467]	https://www.lssmn.org/services/families/kinship https://www.smartrecovery.org https://al-anon.org https://www.familiesanonymous.org/	Printed materials of specific contacts and phone numbers for assistance with peer support groups. Printed self-care materials obtained from Mayo clinic and other healthcare organizations, free for reproduction.
Assistance working with governmental agencies[12357]	https://www.childwelfare.gov/pubs/f-kinshi/	Materials with information about how the process works when involving social services, common legal terms, and definitions, created by project leads and printed materials used with permission.
Legal assistance[23567]	https://www.helpguide.org/articles/parenting-family/grandparents-raising-grandchildren.htm https://mn.gov/dhs/people-we-serve/children-and-families/services/adoption/programs-services/northstar-kinship-assistance.jsp	Information for state and regional low-cost or free legal contacts and phone numbers. Printed information from websites, used with permission.

Note. Scholarly journal article references detailing effectiveness of KC-specific interventions are as follows:

[1] Lin, C-H (2014)

[2] Littlewood et al. (2021)

[3] Pandey et al. (2019)

[4] Rodriguez-JenKins et al. (2021)

[5] Rushovich et al. (2017)

[6] Schmidt & Treinen (2016)

[7] Sutphin (2015)

Appendix B

Caregiver Toolkit Survey

You may answer the survey below either on paper or online. To
complete the survey online by using a smartphone, scan this QR code:

Please remember to include this 3 digit number in your online
survey_____

Please rate the following questions according to how strongly you agree, disagree, or neither.	Strongly Disagree	Disagree	Neither/ Neutral	Agree	Strongly Agree
1. I know where to find housing and food if my family needed it.	1	2	3	4	5
2. I understand what adverse childhood experiences are.	1	2	3	4	5
3. It difficult to communicate with my family member who has substance use disorder.	1	2	3	4	5
4. I know where to find financial help if I have trouble making ends meet.	1	2	3	4	5
5. If my family experiences a crisis, I know where to find support.	1	2	3	4	5
6. My community has the support resources I need as a caregiver.	1	2	3	4	5
7. I know about the services and resources available in my community.	1	2	3	4	5
8. I know where to find items for children (clothing, food, car seats, etc) in my care.	1	2	3	4	5
9. I practice self-care as a caregiver.	1	2	3	4	5
10. I am uncomfortable talking about substance use disorder with the children in my care.	1	2	3	4	5

11. How much of the toolkit did you use? (Circle your answer) None   Some   Most   All

12. What was the most helpful support or service you used from the toolkit?

13. What section(s) of the toolkit were most helpful? (Circle your answer, one only please –
Circle all that apply)

Understanding SUD	Olmsted County Resources
Impact of SUD on Children	Mental Health Resources
Impact of SUD on Families	Healthcare Resources
Impact of SUD on Caregivers	Legal Information

14. What additional information would you suggest including in the toolkit in the future?
(Feel free to use the back of this paper as well)

Appendix C

You may answer the survey below either on paper or online. To complete the survey online by using a smartphone, scan this QR code:

Your professional title:
Number of toolkits distributed to date:

Please rate the following questions according to how strongly you agree, disagree, or neither.	Strongly Disagree	Disagree	Neither/ Neutral	Agree	Strongly Agree
11. The toolkit is easy to navigate to find specific information on topics such as legal or medical assistance.	1	2	3	4	5
12. The toolkit will help caregivers understand the needs of children impacted by parental SUD.	1	2	3	4	5
13. The toolkit offers clients specific ideas to improve family communication.	1	2	3	4	5
14. The toolkit is presented in a way that helps reduce the stigma of SUD.	1	2	3	4	5
15. The toolkit offers practical information to improve clients' understanding of substance use disorder.	1	2	3	4	5

6. What section(s) of the toolkit do you think will be most helpful to your clients? (Circle one answer only please)

Understanding SUD Olmsted County Resources
Impact of SUD on Children Mental Health Resources
Impact of SUD on Families Healthcare Resources
Impact of SUD on Caregivers Legal Information

7. What additional information would you suggest including in the Caregiver Toolkit in the future? (Feel free to use the back of this paper as well)

Appendix D

Instructions for Kinship Caregiver Toolkit Distribution

1.   Explain to the caregiver the reason for the survey, request that the participant complete

the initial Caregiver Toolkit Survey (CTS) upon delivery:

"You are being asked to participate in this survey because you are providing care for a

family member's children. We are interested in learning more about how to best serve

kinship families. Your responses will be part of a university project to help improve

kinship family services, your responses will be anonymous. Thank you for

participating."

2.   Request participant complete the CTS included in the toolkit between 2 and 4 weeks after

they have received the toolkit. Return by date will be written on the CTS.

3.   Request participant mail the CTS back in the pre-addressed stamped envelope included in

the toolkit OR scan the QR code on the survey and complete the survey online via

Qualtrics (remind them to enter the 3-digit number at the top of the survey).

4.   You may ask more questions about the study at any time.