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## Experiences of Caregivers and Healthcare Practitioners Working with Children with Histories of Family Trauma and Substance Abuse

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## LITERATURE REVIEW

Maternal opioid use is currently on the rise in the United States. The use of opioids during pregnancy causes a drug withdrawal syndrome in infants, known as neonatal abstinence syndrome (NAS). This syndrome is a collection of symptoms and issues the newborns experience as they begin to withdraw from certain drugs exposed to while in utero. During 2004-2014, the rate of infants born with NAS nationwide grew five times more with an estimate of 32,000 births. This statistic is equal to every 15 minutes an infant is born who experiences issues from this withdrawal syndrome (National Institute on Drug Abuse, 2019). In 2014, a total of 438 infants were born with NAS in Arizona and since 2008, a 235% increase (Arizona Department of Child Safety, 2017) has been documented. These infants are at risk for neonatal morbidity and mortality. Prenatal exposure to opioids may cause other complications including low birth weight, jaundice, decreased brain growth or microcephaly, abnormal structure and organization of the brain (Batshaw, Roizen, & Lotrecchiano, 2013). The physical, cognitive, language, and social-emotional development of the infant is also at risk and may cause additional challenges for the infants throughout their development.

## PROBLEM STATEMENT

According to March of Dimes (2019), little is known about long-term effects of NAS on an infant and more research is needed to determine how NAS affects a child in the first few years of their life and longer. Currently, only six states have a program that tracks these infants. No national monitoring system exists for collecting data about NAS. An improved monitoring system would assist in estimating numbers of babies born in real time and locate specific areas for targeting resources for mothers and babies to benefit from local programs (CDC, 2019).

## PURPOSE

The focus of this doctoral capstone experience is an exploration of the needs and challenges of practitioners, caregivers, and the population of children that have been exposed to substances while in utero.

## OUTCOMES/OBJECTIVES

- Completion of a qualitative research study that involved interviewing healthcare practitioners and caregivers about their experiences in working with children with histories of family trauma and substance abuse
- Participation in a substance abuse support group for pregnant mothers at Hushabye Nursery
- Participation in service programming for children with trauma histories and prenatal drug exposure at ChildHelp organization

## QUALITATIVE RESEARCH STUDY

### Participants: N = 10

<b>Role</b>	<b>5 Caregivers</b> - Foster parents, adoptive parents, biological grandmother	<b>5 Healthcare Practitioners</b> - 3 OTs, 1 RN, 1 licensed associate counselor/therapist
<b>Gender</b>	5/5 Female	5/5 Female
<b>Age</b>	35 - 70 years old	24 - 50 years old
<b>Ages of caregivers' children</b>	Children between ages of 9months- 25 years old	
<b>Number of years in practice</b>		Number of years in practice between 2 years- 27 years

### PROCEDURES

- Participants were recruited through personal contacts at the following agencies: Hushabye Nursery, Jose's Closet, ChildHelp, AZOPT, Piller Child Development
- 45 to 90 minutes interviews
- Interview sessions were arranged at location/time selected by participant
- Open-ended interview questions
- Interview was recorded using a digital recorder, informed consent to be recorded and pseudonym were provided
- Recorded data was transcribed and stored using the pseudonyms

## QUALITATIVE RESEARCH RESULTS:

### THEMES & SUBTHEMES

<b>Lack of Resources</b>	<b>Importance of Collaboration</b>	<b>Conditions of children</b>	<b>Family and Caregiver Contexts</b>
<b>Caregivers</b> <ul style="list-style-type: none"> <li>• Need for respite care</li> </ul> <b>Caregivers &amp; Practitioners</b> <ul style="list-style-type: none"> <li>• Lack of trauma-informed care</li> <li>• Lack of resources</li> <li>• Lack of education for families</li> <li>• Access to care</li> <li>• Unknown past medical history</li> </ul>	<ul style="list-style-type: none"> <li>• Collaboration between different health care practitioners and collaboration among caregivers</li> </ul>	<ul style="list-style-type: none"> <li>• Developmental delays (physical and cognitive)</li> <li>• Sensory processing issues</li> <li>• Withdrawal effects</li> <li>• Behavioral issues and triggers</li> <li>• Difficulty regulating emotions</li> <li>• Difficulties in school</li> <li>• ADD/ADHD</li> </ul>	<ul style="list-style-type: none"> <li>• Family engagement</li> <li>• Burnout</li> <li>• Grandparents raising grandchildren</li> </ul>

## DISCUSSION

The United States lacks a national monitoring system to collect data related to NAS which can also lead to a lack of resources, education, and other supports. This capstone project exemplifies the importance of obtaining the proper training when working with substance exposed infants/children. Professionals and caregivers expressed feeling overwhelmed and possible burnout. Collaboration was identified as a vital support for caregivers and practitioners. Collaboration allows for sharing of expertise and engagement in problem solving. Increased collaboration between caregivers/families helps create a community of support where resources, stories and experiences can be shared. As the literature describes, substance exposed children are at risk of complications and developmental issues. Some caregivers expressed difficulties understanding their child's development and identified school-age as a critical when issues appear. Developing a program that tracks the children and families of this population can empower the caregivers to advocate for their child's health and provide support when issues arise. Health care professionals would be able to monitor and ensure vital milestones are being met and issues are addressed and/or prevented.

## IMPLICATIONS FOR PRACTICE

Occupational Therapists can provide:

- Family centered-care approach (Snelling, 2017)
- Education
- Assessment to determine developmental delays of the infants in the NICU (Cantu, 2004)
- Developmental improvements in motor, cognitive, sensory processing, communication, and play skills (AOTA, 2020)
- Assessment for the complicated sensory needs
- Support activities for child development, positioning, environmental assessment and modification
- Recommendations and/or changes to provide a calm and relaxed environment that supports child development during the withdrawal process

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## REFERENCES

See provided reference list