# FOSTERING HOPE: A MIXED-METHODS EVALUATION OF PEDIATRIC MEDICAL HOMES FOR YOUTH IN FOSTER CARE

# By

# HANNAH C. ESPELETA

Bachelor of Arts in Psychology Miami University Oxford, OH 2014

Master of Science in Clinical Psychology Oklahoma State University Stillwater, OK 2016

> Submitted to the Faculty of the Graduate College of the Oklahoma State University in partial fulfillment of the requirements for the Degree of DOCTOR OF PHILOSOPHY July, 2020

# FOSTERING HOPE: A MIXED-METHODS EVALUATION OF PEDIATRIC MEDICAL HOMES FOR YOUTH IN FOSTER CARE

Dissertation Approved:

Larry L. Mullins, PhD
Dissertation Adviser
Ashley H. Clawson, PhD
John M. Chaney, PhD
Ginger L. Welch, PhD

Name: HANNAH C. ESPELETA

Date of Degree: JULY, 2020

Title of Study: FOSTERING HOPE: A MIXED-METHODS EVALUATION OF

PEDIATRIC MEDICAL HOMES FOR YOUTH IN FOSTER CARE

Major Field: CLINICAL PSYCHOLOGY

Abstract: Children in foster care demonstrate physical health difficulties at higher rates than the general population as well as lower rates of preventative health service utilization. This pattern places foster youth at heightened risk for long-term health complications in adolescence and adulthood (Garland, Landsverk, & Lau, 2003). The development of interventions for children in foster care is key for decreasing barriers to health services, increasing continuity of care, and ameliorating negative long-term outcomes (Kerker & Dore, 2006). The current project utilized a mixed-methods approach to evaluate the utility of Pediatric Medical Homes (PMHs) as a health intervention for youth in foster care. The current study involved interviews with 40 caregivers utilizing a PMH and assessed continuity of care from a sample of foster youth currently enrolled at the PMH (N=498). Qualitative themes demonstrated overall positive perceptions of the PMH model, with numerous advantages cited to sustain caregiver engagement at this service. Caregiver themes aligned with the seven major tenets of PMHs and highlighted additional needs specific to families with child welfare involvement. Continuity estimates suggested that youth in foster care were able to maintain good continuity with their provider, particularly for return visits and well-child check visits. The current findings address the utility of medical homes for caregivers and youth with child welfare involvement, and can inform future efforts to enhance health interventions for children affected by child maltreatment.

*Keywords*: Foster care, mixed-methods, engagement, pediatric medical home, continuity

# TABLE OF CONTENTS

Chapter	Page
I. INTRODUCTION	1
II. REVIEW OF LITERATURE	5
Foster Care Overview	5
Adjustment of Youth in Foster Care	7
Mental Health	7
Physical Health	9
Health Care Utilization	
Access to Health Care	12
Health History	
Continuity of Care	
Coordinated Care	
Community and State Barriers	15
Pediatric Medical Homes	
III. METHODOLOGY	18
Participants	18
Qualitative Participants	18
Quantitative Participants	19
Measures	20
Demographic Form	20
Qualitative Measure	20
Quantitative Measure	20
Procedures	21
Qualitative Data Collection	21
Quantitative Data Collection	
Statistical Analyses	23
Qualitative Data Analysis	23
Quantitative Data Analysis	24

Chapter	Page
IV. FINDINGS	25
Qualitative Results	25
Intent to Enroll	
Enrollment	27
Retention	30
Quantitative Results	36
V. CONCLUSION	39
Limitations	43
Future Directions	44
REFERENCES	46
APPENDICES	61

# LIST OF TABLES

Table	Page
1. Descriptive statistics of qualitative participants, foster caregivers	77
2. Descriptive statistics of qualitative participants' foster child	78
3. Descriptive statistics of quantitative participants, foster youth enrolled i	
4. Results of COC comparison analyses	80
5. Correlations of COC indices and demographic variables	81
6. Results of COC comparison analyses to extant literature	82

# LIST OF FIGURES

Figure	Page
1. The Conceptual Model of Parent Involvement	84
2. The Continuity of Care index formula	85
3. Caregiver themes related to desired characteristics in medical services	86
4. Word cloud depiction of the frequency of words used to describe the clinic.	87

#### CHAPTER I

#### INTRODUCTION

In 2016, the United States foster care system supervised approximately 430,000 children, with over 270,000 children entering care that fiscal year (Child Information Gateway, 2017). As children in foster care comprise a substantial number of children in the United States, research has increasingly focused on understanding the risks and outcomes for children placed in child welfare custody. It is well established that children in foster care experience a heightened risk for physical health difficulties when compared to same-aged peers not in child welfare custody (Halfon & Klee, 1991; Jaudes, Champagne, Harden, Masterson, & Bilaver, 2012; Jee et al., 2006). This increased risk persists through adulthood, demonstrated by disproportionally high rates of acute and chronic medical problems (Jaudes et al., 2012; Steele & Buchi, 2008; Zlotnick, Tam, & Soman, 2012), including obesity (Steele & Buchi, 2008), asthma (Jee et al., 2006), and respiratory problems (Jee et al., 2006). These adverse outcomes suggest access to and utilization of health services is of utmost social concern for youth in foster care to improve overall child well-being.

Research examining health care utilization suggests that the need for services among youth in foster care frequently goes unmet (Kerker & Dore, 2006). Although

many diverse populations experience barriers to health services, children in foster care experience unique barriers including fragmented care following placement disruptions, incomplete health history, foster parents' inability to provide treatment consent, lack of providers in their insurance network, and uncoordinated care across services (Garland et al., 2003; Jaudes et al., 2012). These noteworthy barriers, combined with foster youth's increased risk for impaired health, culminate in long-term health concerns, especially for youth aging out of care (Vinnerljung, Hjern, & Lindblad, 2006). Thus, interventions through policy and practice are essential in addressing these barriers to help reduce long-term effects of early adversity and child welfare involvement.

League of America (1988) aim to increase coordinated and continuous health care by encouraging the development and implementation of Pediatric Medical Homes (PMHs), an interdisciplinary team-based, primary care model (Jaudes et al., 2012; Jee et al., 2010). This health care delivery model represents an integrated system of care with seven major tenets: care that is accessible, continuous, comprehensive, family-centered, culturally effective, compassionate, and coordinated across disciplines (Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002). Medical homes, originally developed for children with special health care needs, have since become a "gold standard" of care for all families (Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002; Sia, Tonniges, Osterhus, & Taba, 2004). The development of medical homes has resulted in increased access to health services (Strickland, Jones, Ghandour, Kogan, & Newacheck, 2011), improved care coordination (Cooley, McAllister, Sherrieb, & Kuhlthau, 2009), enhanced caregiver satisfaction with services (Palfrey et al.,

2004), and decreased child hospitalizations in the general pediatric population (Cooley et al., 2009).

Several initiatives across the nation have supported the implementation and evaluation of PMHs (Jaudes et al., 2012; Palfrey et al., 2004), however, few of these models have been developed and tested for effectiveness for youth in foster care (Jee et al., 2010). PMHs may be particularly advantageous for these youth as they represent a group of children at staggeringly high risk for physical health difficulties due to their history of child maltreatment and inconsistent access to medical care (Jaudes et al., 2012). Preliminary results of PMHs for youth in foster care indeed suggest that these models are effective at increasing utilization rates of primary care services (Jaudes et al., 2012), improving child immunization status (Jaudes et al., 2012), decreasing emergency department visits (Jaudes et al., 2012), and identifying mental health needs for children in child welfare custody (Jee et al., 2010). Although these results document the medical benefits of PMHs for youth in foster care, additional research is needed to evaluate engagement in services within PMHs to further facilitate these positive health outcomes.

To better understand engagement in health services among children in foster care, research has targeted the role of foster parents in enhancing health care utilization (Pasztor, Hollinger, Inkelas, & Halfon, 2006; Schneiderman, Smith, & Palinkas, 2012). Qualitative research on foster caregivers has identified specific barriers to health care engagement including discontinuity of care (Pasztor et al., 2006), lack of previous relationship with a pediatrician (Pasztor et al., 2006), difficulty finding quality health care services (Schneiderman et al., 2012), and difficulties associated with having a child with complex medical needs (Schneiderman et al., 2012). A primary aim of the medical home model is to

target barriers such as these. Therefore, it is essential to evaluate whether these models are in fact reducing barriers to service engagement and meeting the needs of foster families.

In accordance with this need, the present study aims to identify foster parent engagement at an established PMH and continuity of care within this model for youth in foster care. Given the nascency of the research on these models for foster families, this study utilized an exploratory, mixed-methods approach to evaluate health care engagement at a foster care-specific PMH. More specifically, this project included qualitative interviews with foster caregivers currently enrolled at a PMH to identify caregiver perceptions of the medical home model and factors related to their initial and sustained engagement. Additional quantitative data was procured via longitudinal Electronic Medical Record (EMR) review to supplement the qualitative data and assess health care continuity of foster youth enrolled at the same PMH. As this study represents one of the first to evaluate PMHs in the context of foster care, no formal hypotheses were presented. However, given previous research on the role of PMHs in the general pediatric population, it was expected that medical homes would be associated with positive caregiver perceptions of access to health care, health care continuity, and patient-centered care. Furthermore, it was predicted that this home would be characterized by improved levels of continuity of care when compared to continuity estimates from extant literature within pediatric primary care settings. Thus, the overarching goal was to identify foster caregiver experiences and health care continuity which can then inform service engagement at PMHs and thus aid in improving foster children's physical and emotional well-being.

#### CHAPTER II

#### REVIEW OF LITERATURE

The current chapter overviews the literature that is relevant to the proposed study. First, an introduction to youth in foster care and statistics related to foster youth is provided. Next, an overview of psychosocial and physical health outcomes of youth in foster care will be presented, followed by a discussion of health care utilization and barriers to health care utilization for youth in foster care. Finally, an overview of the development of Pediatric Medical Homes (PMHs) will be presented and include subsequent studies testing the effectiveness of these models within the general pediatric population and within specialized populations, such as children in foster care.

## Foster Care Overview

The term "foster care" often refers to a program within the framework of Child Welfare that is focused on out-of-home placements for children unable to remain in the care of their biological parent(s) (Bass, Shields, & Behrman, 2004). In 2016, the United States foster care system supervised over 430,000 children across all 50 states, with greater than 270,000 entering care that fiscal year (Child Information Gateway, 2017). Children may be placed into foster care for a range of reasons, with the most prevalent

being child neglect (61%), caregiver's substance abuse (34%), caregivers inability to cope (14%), child physical abuse (12%), child behavior problems (11%), and inadequate housing (Child Information Gateway, 2017; US Department of Health and Human Services, 2017). Upon child removal from caregiver custody, children are typically placed in one the following home placements: non-relative foster family homes, relative foster homes (also known as kinship care), institutions, group homes, pre-adoptive homes, trial home visits, and supervised independent living homes (Child Information Gateway, 2017). In 2016, the majority of children in foster care were placed with either nonrelative foster families (45%) or relative foster homes (Child Information Gateway, 2017).

Following placement of a child in foster care, caseworkers then create a permanency plan based upon the child and families' current circumstance to set goals for either reunification of the child with their biological parents, or, adoption with another family (Bass et al., 2004). This permanency plan aids in providing goals and timelines for securing a permanent placement and outlining the child's involvement in foster care.

Although policy on permanency plans vary by state, the Adoption and Safe Families Act of 1997 was implemented to promote the timely placement of children following entry into care (i.e., 12-24 months following entry). Most recent data suggest that states are approaching this goal, as the median amount of time spent in care in 2016 was 13.9 months, with 45% of children being in care less than 1 year and 73% being supervised for less than 2 years (Child Information Gateway, 2017). Within this same fiscal year, 51% of children exiting care were reunified with their parents or guardians, and 23% were adopted.

Despite these seemingly high numbers of youth in foster care, several changes have been made in efforts to improve the child welfare system by decreasing time spent in care and increasing permanency and placement stability for youth (McGowan & Walsh, 2000). Trends in child welfare suggest that within the last ten years, fewer children are entering care. Of those children in care, more are now placed with biological relatives and more have been placed in permanent outcomes (Child Information Gateway, 2017). Although these statistics are promising, it is noteworthy that children involved in foster care have numerous stressors and risk factors for maladjustment associated with their child welfare involvement, including placement disruptions, involvement in other social agencies (i.e., mental health, court, public assistance, law enforcement), separation from caregivers and siblings, trauma histories, and a lack of social support or community involvement. As such, child well-being following entry to foster care is of utmost concern.

# **Adjustment of Youth in Foster Care**

Given the substantial number of children supervised by the foster care system, research and clinical efforts have been devoted to assessing physical and mental health adjustment of these youth.

Mental Health. Research spanning several decades consistently links foster care involvement with short-term and long-term mental health maladjustment (Clausen, Landsverk, Ganger, Chadwick, & Litrownik, 1998; Greeson et al., 2011; Minnis, Everett, Pelosi, Dunn, & Knapp, 2006; Pecora, Jensen, Romanelli, Jackson, & Ortiz, 2009; Sawyer, Carbone, Searle, & Robinson, 2007). Specifically, research has indicated that children entering foster care have higher prevalence rates of behavior problems (Clausen

et al., 1998), aggressive, delinquent, or antisocial behaviors (Kendall-Tackett, 2003), and diminished social skills in childhood (Stahmer et al., 2005). Furthermore, approximately 20-60% of these youth have a mental health diagnosis with related functional impairment, such as Attention Deficit/Hyperactivity Disorder (ADHD) and disruptive behavior disorders (Burns et al., 2004; Garland et al., 2001; McMillen et al., 2005). These mental health concerns are significant, as they often contribute to future psychosocial concerns including increased rates of placement disruptions (Newton, Litrownik, & Landsverk, 2000) and juvenile delinquency or criminal behavior (Smith & Thornberry, 1995).

For individuals involved in foster care, this heightened risk for mental health concerns often persists into adulthood, as demonstrated by higher rates of both internalizing and externalizing problems (Auslander et al., 2002). Additionally, adults with childhood involvement in foster care have demonstrated substantial psychosocial deficits including lower educational attainment, occupational concerns, diminished adult self-sufficiency, and lower income (Burley & Halpern, 2001; Dworsky, 2005; Gypen, Vanderfaeillie, De Maeyer, Belenger, & Van Holen, 2017; Pecora et al., 2006). In order to better understand this augmented risk for mental health and psychosocial difficulties, research has highlighted potential catalysts for maladjustment including the experience of traumatic events that led to a child's involvement in foster care as well as accompanying stressors related to removal from caregivers (Clausen et al., 1998; Kerker & Dore, 2006; Pecora et al., 2009; Stein, Evans, Mazumdar, & Rae-Grant, 1996). Long-standing research has implicated various forms of childhood adversity, such as child abuse and neglect, as factors related to impaired mental health in adulthood (Banyard, Williams, &

Siegel, 2001; Briere, 1992; Edwards, Holden, Felitti, & Anda, 2003; Greeson et al., 2011; Roberts, O'Connor, Dunn, Golding, & Team, 2004; Schore, 2001; Springer, Sheridan, Kuo, & Carnes, 2007). As such, it is possible that the circumstances leading to a child's involvement in foster care are driving forces of these mental health outcomes. Additional research has implicated placement-related factors in this augmented risk for mental health concerns (Kerker & Dore, 2006). Factors related to foster care placement that may negatively impact adjustment include time in care, number of placement disruptions, number of children in the home, and quality of care or parenting received (Kerker & Dore, 2006; Newton et al., 2000; Rubin et al., 2004). It is probable that the cumulative effect of these adversities may contribute to pronounced mental health concerns for these children.

Physical Health. In addition to heightened prevalence rates for mental health concerns for youth in foster care, these children additionally experience physical health difficulties disproportionate to same-aged peers (Hansen, Mawjee, Barton, Metcalf, & Joye, 2004; Kools & Kennedy, 2003). Specifically, youth involved in foster care have demonstrated higher rates of health problems including acute and chronic illnesses, developmental concerns, as well as difficulties accessing health services (Kools & Kennedy, 2003). Some studies have reported up to 60% of foster youth having documented physical health concerns (Chernoff, Combs-Orme, Risley-Curtiss, & Heisler, 1994; Halfon, Mendonca, & Berkowitz, 1995; Sullivan & van Zyl, 2008; Takayama, Wolfe, & Coulter, 1998; Zlotnick et al., 2012) such as growth abnormalities, developmental delays, under-vaccination, poor nutrition, vision and hearing difficulties, and higher exposure rates to substances in utero (Kools & Kennedy, 2003). Foster youth

have also reported higher prevalence of chronic medical conditions including epilepsy, sickle-cell anemia, diabetes, asthma and heart disease (Altshuler & Poertner, 2003; Halfon et al., 1995). This heightened risk for physical health concerns has been demonstrated to exist above and beyond the impacts of poverty and socioeconomic status on health (Hansen et al., 2004), and to persist through adulthood (Zlotnick et al., 2012). These deficits have been linked to subsequent lower educational attainment, economic outcomes, health outcomes, and more psychiatric diagnoses in later adulthood (Anctil, McCubbin, O'Brien, Pecora, & Anderson-Harumi, 2007).

Notably, children may enter foster care with chronic health conditions or developmental concerns related to the traumatic events that led to their placement into child welfare custody. Early experiences of abuse have been linked to adult physical health deficits such as back pain, frequent or severe headaches, pelvic or genital pain, abdominal pain, constipation, and fatigue (McCauley et al., 1997). Additional research has linked early abuse experiences to higher rates of somatization, chronic fatigue syndrome, fibromyalgia, and irritable bowel syndrome (Angst & Földényi, 1993; Springs & Friedrich, 1992). It has been suggested that childhood experiences of abuse and neglect directly affect a child's development and health. For example, physical and sexual abuse may result in acute injuries, prenatal substance abuse may result in birth defects, and child neglect may result in underdevelopment and undernourishment (Simms & Halfon, 1994). However, indirect effects of a child's home environment may also play a role. Families and homes involved with child welfare are often labeled as "high-risk" families, suggesting that they are characterized by a number of risk factors for child abuse and neglect in addition to poor child adjustment (i.e., low income, single parent household,

and caregiver mental health concerns). These homes are often characterized by numerous psychosocial stressors, and thus the effect of chronic stress on a child's immune system has also been highlighted as a possible link to the increased rates of physical health concerns in adolescence and adulthood (Shonkoff et al., 2011). Additional theories have been posited to better understand these health disparities such as foster youth engagement in health-risk behaviors (e.g., smoking) which then contribute to later disease onset (Farruggia & Sorkin, 2009; Felitti et al., 1998; Kendall-Tackett, 2002). Inconsistent access to preventative health care while in child welfare has also been implicated in the lack of identification and treatment of health problems, leading to chronic health concerns (Springer, Sheridan, Kuo, & Carnes, 2003; Springer et al., 2007).

## **Health Care Utilization**

Given the pronounced effect of early adversity on later adult health outcomes as well as indirect economic effects on healthcare systems (Brown, Fang, & Florence, 2011; Rovi, Chen, & Johnson, 2004; Takayama, Bergman, & Connell, 1994), utilization of health care for foster youth is of the utmost concern. Research on early adversity suggests that individuals with experiences of childhood trauma evidence increased utilization of health care services in adulthood, with increased primary care costs, frequency of emergency room visits, and number of prescribed medications (Arnow, 2004; Bonomi et al., 2008; Chartier, Walker, & Naimark, 2007, 2010; Kalmakis & Chandler, 2015). Although an increase in health care use is anticipated, given the effects of trauma on immune systems (Shonkoff et al., 2011), this increased utilization is not equally distributed across sectors of care. For example, although individuals with early adversity often have higher utilization of urgent care, they have also shown decreased utilization of

preventative care services, such as immunizations, routine health screenings, and general practitioner visits (Alcala, Keim-Malpass, & Mitchell, 2017; Alcala, Valdez-Dadia, & von Ehrenstein, 2017; Chartier, Walker, & Naimark, 2009). These findings may suggest a unique set of barriers for youth in accessing and utilizing preventative health or ongoing care services.

Similar to findings on youth with traumatic experiences, children in foster care have demonstrated higher utilization rates of mental health services, supportive services (i.e., nursing staff, physical and occupational therapy), specialized medical services, and hospitalizations when compared to same aged youth not in child welfare custody (Halfon, Berkowitz, & Klee, 1992; Takayama et al., 1994). Despite this increase in service utilization, chronic and acute medical conditions continue to persist for these youth (Kools & Kennedy, 2003; Simms, 1989). Thus, it is possible that children in foster care have pre-existing and complex medical needs that result in increased health care utilization, however, the services may not be adequately meeting the needs of these individuals. Research must continue to assess possible barriers to health care that impact the effectiveness and quality of these services.

#### **Access to Health Care**

To better understand continued health concerns for youth in foster care, research has highlighted access to health care as a potential contributor to these disparities (Committee on Early Childhood & Care, 2002). Although many populations experience barriers to accessing health care (Bowen, 2001; Flores & Vega, 1998; Marrone, 2007; Scheppers, Van Dongen, Dekker, Geertzen, & Dekker, 2006), children in foster care have a unique set of circumstances that may pose an attenuated risk for decreased access.

Foster care-specific barriers may originate in the enrollment of health services (i.e., incomplete health histories for providers and caregivers, foster parents' lack of abilities to consent for treatment, limited providers in their network) and culminate in not receiving adequate health services for complex medical needs (Committee on Early Childhood & Care, 2002; Garland, Landsverk, & Lau, 2003; Jaudes et al., 2012). The present review will provide a brief overview of the major barriers for foster families in accessing health services.

Mealth History. It is not uncommon for a youth in foster care to lack formal medical records with child welfare or a medical provider (Committee on Early Childhood & Care, 2002). Children in care often come from high-risk families that might not have a previously established provider or consistent set of providers. Even in the presence of an established provider, children are often removed from caregivers and placed with child welfare without the procurement of previous health care records (Committee on Early Childhood & Care, 2002; US General Accounting Office, 1995). This set of circumstances is commonplace and necessary, given the level of risk for the child at the time of entry into care. Thus, the swift removal is considered a safety measure against caregiver relocation. Furthermore, during the placement of children into child welfare custody, social workers must collect substantial information from caregivers (if available) and thus, specific details on health care management and health history are often limited.

Following child placement, health history gaps often magnify, as foster parents are then provided with limited information and documentation for the child. Quickly following placement, foster caregivers must assume the responsibility of knowing the medical needs of a child that was placed with their family, perhaps 48 hours previously.

As such, medical providers often turn to the child to serve as the information gateway for their previous medical concerns. Overarchingly, this lack of health history contributes to foster caregiver frustration, lack of identification of health needs for youth, and difficulties for pediatricians in treating children without the necessary background information (Committee on Early Childhood & Care, 2002).

Continuity of Care. Children in foster care frequently experience discontinuity of care with their medical providers, resulting in fragmented and incomplete health care (DiGiuseppe & Christakis, 2003). Despite research evidence on the positive effects of continuous care on health outcomes (Christakis et al., 2001; Christakis et al., 2002), health services for youth in foster care are often characterized by disjointed medical care resulting from placement disruptions (Committee on Early Childhood & Care, 2002; DiGiuseppe & Christakis, 2003). Between one third and two thirds of foster care placements are disrupted within the first 1-2 years (Wulczyn, Chen, & Hislop, 2007), with approximately 64% of children in foster care longer than 2 years having greater than 2 placements (US Department of Health and Human Services, 2014). As such, changes in medical providers are relatively common among foster youth. This discontinuity contributes to gaps in a health history, continued use of less than optimal preventative services, and inability to build a relationship with a trusted medical provider (Mekonnen, Noonan, & Rubin, 2009).

Coordinated Care. As mentioned previously, foster youth are at risk for complex medical histories, characterized by developmental delays, chronic health conditions, and mental health difficulties (DiGiuseppe & Christakis, 2003; Halfon et al., 1995; Kools & Kennedy, 2003). As such, these children frequently require numerous medical providers

in addition to their social agency providers (i.e., social workers, court involvement). Although coordinated care is a barrier for many populations (Chen, Brown, Archibald, Aliotta, & Fox, 2000), youth in foster care have heightened rates of cross-discipline and cross-specialty care use (Halfon et al., 1992; Takayama et al., 1994), in addition to their caseworker's involvement, thus amplifying their risk for uncoordinated care.

Community and State Barriers: Finally, additional barriers to accessing health care for youth in foster care include community and state-related barriers, such as insufficient funding for services, poor organization of services provided, prolonged waits for community-based services or lack of community-based services, and poor communication amongst health and child welfare professionals (Committee on Early Childhood & Care, 2002). Youth in foster care are restricted to the geographic distribution of foster homes in a given state, and thus their health-related services are inherently limited by the homes available for the child (Committee on Early Childhood & Care, 2002).

Given the numerous barriers presented for foster youth to accessing health care, interventions in health care delivery models must be developed to help ameliorate long-term effects of foster care on physical health. Although some efforts have been made to assist with these barriers, many still have difficulty surmounting the barriers presented with foster care families (Simms, 1989). The Committee on Early Childhood and Care (2002) urges for the following health care delivery models for youth in foster care: 1) agency based care, where children are brought into a specified agency for health care, 2) community-based care in which practitioners provide health care through private offices, and 3) specialized foster care clinics that provide a "medical home" for the child.

#### **Pediatric Medical Homes**

A Pediatric Medical Home (PMH) is a primary care model of health services, characterized by health care that is accessible, continuous, comprehensive, familycentered, coordinated, compassionate, and culturally effective (Committee, 2002; Committee on Children with Disabilities, 1999; Medical Home Initiatives for Children With Special Needs Project Advisory Committee, & American Academy of Pediatrics, 2002). These models represent collaborative, multidisciplinary care in attempts to improve access to coordinated and comprehensive health care. Although the term "medical home" has been documented as early as the 1960's, legislative initiatives to implement these health care models did not start until the latter half of the 1970's (Sia, Tonniges, Osterhus, & Taba, 2004). The first medical home model, established in Hawaii as part of a home visiting program, was created in 1984. However, the medical home model did not begin to gain traction until the 1990's, when the American Academy of Pediatrics published a statement defining the definition of a medical home. Soon thereafter, the Division of Community Pediatrics was developed which oversees the Community Access to Child Health (CATCH) program and the Medical Home Training Project, both of which are devoted to medical home development and implementation (Sia et al., 2004). PMHs were initially developed for youth with special health care needs, thus requiring screening in other health care settings to channel youth with complex medical needs to these models of care (Brewer, McPherson, Magrab, & Hutchins, 1989). However, PMHs have since been expanded to include all youth and families.

Research on the effectiveness of these models are still in their infancy. Recent research suggests that PMHs are indeed effective at improving overall health outcomes

for children and families (Rosenthal, 2008; Starfield & Shi, 2004). Rosenthal (2008) conducted a systematic review on the effects of PMHs on health care, with findings suggesting that PMHs have high levels of caregiver satisfaction with these services. In addition, Starfield and Shi (2004) conducted a review, with results demonstrating improvements in overall child health as well as lower costs of care. Furthermore, this study presented promising results that PMHs may in fact reduce health disparities across diverse socioeconomic groups. Additional research suggests that PMHs have been associated with increased use of preventative services, positive perceptions of access to health care, continuity of care, high satisfaction with services as well as decreased staff burnout and fewer hospitalizations and emergency services utilized by families (Cooley, McAllister, Sherrieb, & Kuhlthau, 2009; Palfrey et al., 2004; Reid et al., 2009; Strickland et al., 2011). Given these positive findings on PMHs and access to care, it is probable that additional high-risk groups, such as youth in foster care, would demonstrate unique benefit from these specialized services. Few of these models have been implemented for specific populations, thus research on the implementation of PMHs in foster youth is limited. However, preliminary results suggest these models show promise in both screening for mental health needs (Jee et al., 2010) and increasing effective and costefficient health care utilization among foster families (Jaudes et al., 2012). More research is needed to determine if these models are in fact reducing barriers to care and increasing foster parent engagement in services. Research on caregiver perceptions of PMHs for foster youth may help facilitate positive health outcomes that PMHs can offer for youth with complex medical needs.

#### CHAPTER III

#### **METHODOLOGY**

# **Participants**

This study included data collection from two unique data sources: 1) individual qualitative interviews with foster caregivers and, 2) EMR review of children in foster care.

Qualitative Participants. Purposive sampling procedures were utilized for qualitative data collection with foster caregivers, yielding 40 foster caregivers. Inclusion criteria for participants in the qualitative portion included: 1) current or previous foster caregiver status, 2) over the age of 18, 3) primary caregiver of the child, 4) completed at least one appointment at the clinic of interest, and 5) English language proficiency.

Participating caregivers' (*N*=40) age ranged from 26-75 years old (*M*=43.50, *SD*=13.41). The majority of participants identified as female (*n*=36, 90%) and White (*n*=26, 65%; Black/African American 16%, Multiracial 10%, Hispanic 5%, Native American 2.5%, Biracial 2.5%). Relationship status of caregivers was predominantly single (*n*=17, 42.5%) or married (*n*=13, 32.5%). Caregivers generally reported completing high school education or above (15% high school education, 25% partial college, 30% college graduate, 22.5% graduate or professional degree), with most of the

caregivers reporting full-time employment (n=22, 55%) and household incomes between \$30,000 and \$59,999 (n=18, 45%). Forty five percent of caregiver's (n=18) stated that this was their first experience with foster care. See Table 1 for complete demographic information on foster caregivers that participated in the study.

Participants completing qualitative interviews reported having a foster child between the ages of 0-15 years old (M=5.55, SD=4.68), that identified primarily as White (n=16, 40%), Black/African American (n=9, 22.5%), or Native American (n=7, 17.5%). According to caregiver report, foster children had been seen at the PMH between 1 and 40 times (M=8.39, SD=10.65). Eleven caregivers (27.5%) reported that their foster child had a chronic medical condition. Foster children were in the present homes between 0 and 144 months (M=36.26, SD=38.24). See Table 2 for descriptive information about the foster youth in the participants' homes.

Quantitative Participants. Stratified sampling procedures were utilized for quantitative data collection of EMRs of children enrolled in a PMH for youth in foster care. Inclusion criteria for EMR review included: 1) child's first appointment between 2014-2018, 2) child age younger than 15 years old, and that 3) the child only utilized the foster care-specific PMH within the larger academic medical center for primary care services. The present sample included 498 children with ages ranging from 0-14.7 years old (*M*=4.60, *SD*=4.06). Children identified as White (*n*=245, 49.2%), Black/African American (*n*=111, 22.3%), and American Indian (*n*=35, 7.0%). Number of appointments at the clinic ranged from 0-21 (*M*=3.87, *SD*=3.35), with the number of providers seen ranging from 2-21 (*M*=5.94, *SD*=3.59) across these appointments. See Table 3 for complete demographic information.

#### Measures

Demographic Form. All caregivers enrolled in the qualitative portion of the study received a demographic measure. This measure assessed participant age, race, occupational status, educational status, income, and relationship status. This form also assessed caregivers' previous involvement as a foster parent and brief information about the foster child in their home (i.e., length of time in home, age of child, ethnicity of child, number of child appointments at the clinic). See Appendix D.

Qualitative Measure. An individual interview guide was developed based on grounded theory analytic concepts, service engagement, and informed by previous qualitative research. Consistent with the conceptual model of parent involvement proposed by McCurdy and Daro (2001; see Figure 1), caregivers were asked about their experiences that led them to enrolling at the PMH, the enrollment process at the PMH, and factors related to sustained engagement, or retention (i.e., personal experiences at the PMH, provider and program factors motivating their continued use of services, as well as benefits and costs for families). The interview guide utilized a semi-structured approach in which interviewers asked a number of questions on topics of interest and employed probing questions to gain additional insight. See Appendix E.

Quantitative Measure. No formal self-report measures were administered for quantitative data collection for youth enrolled in the PMH. However, data was extracted from their EMR via a systematic review. All data extracted was previously collected for medical purposes. Data extracted included appointment dates, health care providers present at appointments, reason for appointments, in addition to demographic data. Data

was extracted from medical records, placed into a data analysis software, and coded based upon appointment frequency and continuity of medical providers.

#### **Procedures**

Participants for both the qualitative and quantitative portions of the study were recruited from an established PMH at a Midwestern university academic medical center. The clinic of interest has been providing coordinated services for youth in foster care for the past 12 years. The clinic is currently designated as an Oklahoma Health Care Authority Tier 3 Medical Home. This designation is the highest level possible and very few clinics in the state have achieved this status. The clinic is also recognized as a Tier 2 Patient Centered Medical Home through the National Committee for Quality Assurance (NCQA). The clinic provides services for youth in child welfare custody in efforts to increase access to continuous, coordinated, and comprehensive health services. Youth and families receive services from an interdisciplinary team consisting of pediatric attending and resident physicians, pediatrics nurses, pediatric psychologists, social workers, and dieticians.

Qualitative Data Collection. Potential participants were invited to participate in the study via on-site recruitment during clinic visits and phone calls from clinic staff.

Research staff attempted to contact 95 caregivers to participate in the present study, however, 17 caregivers were left voicemails but were never able to make direct contact for participation. Of the 78 contacted families, two of those caregivers were excluded due to not having a foster caregiver present at the medical appointment and 27 were interested in participating, but were unable to do so at their appointment time (three cancelled or no showed their appointment, 14 did not have time that day to participate, but were

interested in participating at a future date, and 10 were interested in participating, however due to limitations of having one interviewer, were not contacted at their appointment time). Ten caregivers declined to participate and did not provide a reason. Of the 78 caregivers contacted, 40 caregivers met inclusion criteria, consented and participated in the study. Although recruitment and sampling data is rarely available in published qualitative studies (Twohig & Putnam, 2002), the participation rate for the present study was strong, with an 87.2% participation rate. Given that the data utilized for recruitment included only patient (i.e., foster child) electronic records, there is no available data on demographics of the foster caregivers that declined participation in the study. As such, comparison analyses were not utilized to examine potential differences across participating and non-participating caregivers.

Interested caregivers were contacted during their regularly scheduled clinic appointments and were provided additional information regarding the study procedure. Caregivers provided informed consent, completed a demographic form, and were interviewed in patient rooms and consultation rooms available at the clinic. Skilled facilitators trained in qualitative evaluation methods moderated all individual interviews with caregivers. All interviews were conducted in person, lasted approximately 30 minutes, were audio recorded, and transcribed and crosschecked for dictation accuracy by trained qualitative research assistants. Transcriptions were all password protected, deidentified to protect participant personal information, and stored on a secure server. All participants were compensated with \$25 for their time.

Quantitative Data Collection. Archival data was collected through the systematic review of EMRs of youth enrolled at a PMH for youth in foster care. Participant files

were entered into a data analysis software program (i.e., SAS) for initial data review and cleaning procedures.

# **Statistical Analyses**

Qualitative Data Analysis. Finalized transcriptions were entered into QSR N\*Vivo 11 software for analysis. Two members of the qualitative team created an a priori "code book" to identify common themes as they relate to initial and sustained engagement at services for the PMH. Transcriptions were then coded independently by these two team members using a structured, templated approach (Patton, 2002). Content analysis was utilized to identify important themes across interviews with foster caregivers and refine theme classifications as they emerge. First order, second order, and third order sub-categories were identified and aggregated. Arithmetic inter-rater reliability checks were completed using Miles and Huberman's formula (Huberman & Miles, 1994) in which a minimum of 80% convergence was achieved. Although simple agreement does not account for coding agreement by chance (Lombard, 2002), this procedure is a commonly utilized method for assessing reliability in qualitative studies (Lombard, 2002; Stemler, 2004). Answers within this study were varied, plentiful, and not mutually exclusive to one code, making the probability of coding by chance less likely.

Two sets of percentages were calculated for all coded themes: 1) the percentage of participants that commented on each particular theme to denote what proportion of participants spoke about a particular theme, and 2) the percentage of total comments for each theme to indicate the emphasis and frequency that each theme received across all interviews. For the purposes of this project, the percentage of participants is reported, unless otherwise noted.

Quantitative Data Analysis. Prior to inferential statistical analyses, data was examined for normality and completeness. Shapiro-Wilk tests were used for continuous variables to examine data for normality, and frequencies of missing data were used to examine completeness. Descriptive statistics and regression analyses were used to examine foster youth continuity of care and identify demographic factors related to continuity estimates. Continuity was measured by the Continuity of Care index (COC; Bice & Boxerman, 1977), an algebraic formula utilized by previous continuity researchers in pediatric and adult health care settings (see Figure 2 for the complete formula), in which estimates range from 0-1, with higher values representing increased continuity.

#### CHAPTER IV

#### **FINDINGS**

## **Qualitative Results**

Caregiver interviews were coded for thematic information surrounding three stages of engagement, as outlined by McCurdy and Daro (2001): 1) intent to enroll or factors leading to enrollment, 2) enrollment, and 3) retention or sustained engagement.

Intent to enroll. Caregivers reported seeking several characteristics/traits of medical services following the placement of a foster child in their home. They reported looking for services that have good appointment availability (25%), knowledge of the foster care system (20%), good communication between caregivers and providers (20%), basic medical services (20%), continuity of care (17.5%), high quality care (17.5%), and an understanding of the impact of trauma on child health (12.5%). One caregiver stated they were interested in:

Just people that could give [my children] like excellent health care but then also like, that would understand like kind of where they're coming from like any special needs they had because of like their circumstances. ... just knowing that they had been through trauma and any experiences that they had had that may have led to like medical conditions or anything like that.

Another caregiver stated:

I am looking for somebody who understands the foster care system and um, can be equally accommodating for the biological parents and the foster parents. That's probably our biggest thing, is them understanding what we need to have done through [child welfare] for foster children and the other kinds of paperwork and everything that needs to be filled out and they know what's going on.

Participants also reported looking for specific interpersonal qualities in providers (22.5%) including providers that are caring, empathetic, helpful, nonjudgmental, respectful, and trustworthy. See Figure 3 for all caregiver themes related to desired characteristics of medical care.

Selecting the PMH. Caregivers stated several reasons for choosing to enroll at the PMH including receiving a referral from a trusted source (32.5% of participants commenting on reasons for enrollment), with child welfare referrals holding the most weight for these families (53.8% of participants in reference to referral sources). A participant commented:

... just the recommendations, from my friends and the foster care community. Um yeah. I really like being in foster care, like I think it's a really great thing.

Anything that's like for foster kids, I am always willing to kind of like try that I guess.

## Another caregiver stated:

Oh well this was I guess uh [child welfare] uses this clinic automatically. And so that's why at first I kind of changed... But then once I got to realize how good the doctors were and how they work, that's when I decided to go ahead and change all my kids here.

Another reason for selecting the PMH surrounded the clinic and providers' knowledge about foster care and the impact of trauma on health (27.5%). Representative caregiver quotes include, "...because it was for foster care and adoptive children. I just thought that that would have more resources than other clinics," and, "It is 100% just the fact that they understand what paperwork we need to file with [child welfare] and that they respect and understand the relationship with foster parents, biological parents, and the children." Another caregiver stated:

I knew that they specialized in foster children. ... because they're unique, you know? Most of them come from trauma, and I uh I just assumed, and I was right, that the doctors here would be equipped to handle that and answer questions that we have and point us in the right direction.

Additionally, caregivers stated that they chose this service to maintain continuity of health care for their foster child (17.5%), while others found the location to be a driving factor for selecting this clinic (17.5%). Finally, 10% of caregivers endorsed each of the following reasons for choosing this clinic: 1) the urgency or need for medical services, 2) previous experience with the primary care clinic with other children, or 3) its location within a larger academic medical setting, specifically reporting on the importance of all services being situated in the same building.

Enrollment. The majority of participants reported hearing about the clinic from their caseworker (52.5%). However, in other instances, caregivers reported learning about the clinic from a fellow foster caregiver, an academic medical center staff member, the child's therapist, the child's previous foster placement, or foster care social media. Once hearing about the clinic, caregivers generally reported a quick and easy enrollment

(70%), with 75% of caregivers stating they called to make the initial appointment. In three instances, the participant's caseworker set up the appointment while two participants reported that their child was already enrolled in the clinic through a previous placement, and one reported that the hospital set up the appointment upon the child's birth.

Caregivers reported supports for enrollment including: 1) short or no wait time for initial visit (20%), 2) the caseworker providing the contact information for the clinic (15%), 3) the clinic being flexible with required paperwork (12.5%), 4) the child already being an established patient at the clinic (10%), and 5) having the necessary placement paperwork in their possession at time of visit (10%). A caregiver discussed the support of quick enrollment for children in foster care:

They got us in super fast, which is nice. They understand, cause when you have a foster child and [they] put one in your care, you have one week to get a doctor's appointment before [child welfare] starts getting upset with you. So, when you call and say, "Hey I have a new foster kid in my care," they're like, "Okay, we've got an appointment this day." And it's usually four or five days at the most, so that's nice.

Caregivers reported on the importance of flexibility within the clinic with enrollment paperwork for foster caregivers:

They're not hard to work with because they understand, like I said, they understand that foster parents don't have all of the information. You can't fill out all the paperwork, we don't even have their birth certificate, we don't have their Medicaid numbers, we don't have any of that. Especially when you first get [a

child], you don't know their history, their background. You know nothing. So they just kind of laugh about it and they're like, "Fill it out the best you can, and we'll go from there."

## And another caregiver stated:

She didn't have a [Medicaid] number for like four days after we had her. Which was like crazy because no one would take her. But here, they're like "Just bring her in, we'll figure it out later, we'll hold on the billing." Which was great, because she's a baby and she needed you know like care but everywhere else is like, "We don't have an official, she's not official yet. We can't take her for care," and they're just like, "No, just bring her. You know we'll figure it out later, no worries... like we can bill later or whatever." So that was big because you know she was really underweight when we got her so we needed to get her seen quickly but weren't having luck anywhere else.

The majority (62%) of caregivers stated that there were no barriers to enrollment at the PMH, however, two caregivers reported barriers such as having limited knowledge of the child's medical history and no knowledge of the clinic, while one caregiver stated the amount of paperwork, finding the actual clinic, obtaining the child's insurance card, and navigating parking were all barriers to enrollment. When asked what efforts could be done to ease enrollment at the PMH, 70% said nothing was needed to ease enrollment, while three participants indicated a higher awareness of the clinic would be helpful, and one caregiver reported that increasing parking would be helpful. One caregiver discussed how awareness of the clinic would aid in enrollment:

I know from the foster parent side, I mean if they would just tell you right up front [about the clinic] at the hospital, that would help. I'm trying to call around all the other doctor's offices saying, "Hey, can you take me?" No other carrier takes Medicaid patients. I think it would be easier to just know upfront, "Hey they will always accept them here."

*Retention*. To better understand factors related to retaining caregivers in this model of care, caregivers were asked questions regarding their general experiences with the PMH, advantages and disadvantages of the PMH clinic, as well as factors that influenced their choice to remain in these services.

Overall experiences with the PMH. When asked about their experiences with the PMH, participants overwhelmingly reported positive experiences (82.2% of comments), with 17.8% of comments surrounding negative experiences. See Figure 4 for a word cloud of most frequent words utilized to describe the PMH clinic. The major themes that emerged within positive experiences included: 1) appointments (i.e., good availability, flexible and accommodating scheduling; 50% of participants), 2) good communication (i.e., providers listen to caregivers; 45%), 3) having knowledgeable doctors (22%), 4) continuity of care (20%), 5) doctors taking their time with families (20%), 6) provider and staff familiarity with the child and family (17.5%), and 7) providing needed referrals (17.5%). Interpersonal qualities were also highly endorsed as a positive experience (75%), with characteristics including caring, good with children, helpful, kind, nonjudgmental, and supportive. One caregiver reported an overall positive experience, stating:

Honestly, [I] have not had a bad experience. Um, I feel like, I guess it's been like 3 months since we moved here and have been using it. But just pretty much everyone I've come into contact with has been very helpful and I haven't really had any bad experiences.

### And another stated:

One thing that was nice is every time I've been here, I feel like they've been very interested in like just like the kids' story and not just like brushing them aside, just like "Oh, a foster kid." ... they just seem like they're more invested in them and like just giving them quality care and things like that.

Notably, 50% of caregivers stated that they had no negative experiences at the PMH. However, for those caregivers that did report negative experiences, the major themes included, difficulties with appointments (i.e., scheduling for acute needs or with requested doctor, 17.5%), lack of continuity (i.e., seeing multiple doctors, doctor turnover; 15%), poor provider accessibility (i.e., after hours, via phone; 15%), providers not listening to caregivers (12.5%), and long wait times (i.e., in patient rooms, in waiting room, to schedule an appointment; 10%). One caregiver commented on appointment scheduling difficulties, "It is just hard to get an appointment sometimes though ... if they get sick and need immediate attention, you know, I can't get an appointment that same day. That's the only thing we could say is a negative thing." Another caregiver commented on the lack of continuity:

It wasn't like they said like, "We usually see this person, do you want to continue seeing this person?" It was like a different person every time and I didn't love that. ... But at first I was like, "Well we see a different person every time," and

you know, they were all okay. Some of them were okay, some of them were good, some of them were great. ... like I said, seeing them not regularly, so they didn't know the kids or the history really. Cause we would just see different people.

Advantages and disadvantages. Caregivers overwhelmingly reported advantages (95%) to receiving services at the PMH, with the primary themes surrounding advantages to the location of the PMH within a larger academic medical center (i.e., having all services in the same complex, coordination across clinics at health center, shared medical records; 60%). One caregiver stated:

I do love that everything's in one building. I feel like I only have to remember where one place is, and my kids recognize it. You know, especially with foster care, they get very wary of new places, and things like that. So that is nice to have everything in one place so they know where we're going, and all that kind of stuff.

Additionally, caregivers reported maintaining continuity of care (32.5%), specifically continuity of medical records, as a great advantage to receiving services at the PMH. One caregiver discussed the advantages of continuity of care as it pertains to previous and future foster placements:

And so when I got [my child], I had asked the social worker about the clinic...

And come to find out [my child] had been taken by a prior foster family. It was great because it allowed continuity of her medical chart. When I brought her here for the first time, because they don't share who the child's doctor is when you get a new child, everything starts over from scratch. So, when I brought the child

here, they were like "Oh hey!", because she still had her other name so they had her stuff listed, they just had to get my information as the new custodial.

Caregivers also reported facility-based advantages (i.e., cleanliness of facility, available food options, valet parking, location of clinic; 35%), advantages related to the providers specialization in foster care and trauma (20%), and having quality care provided (i.e., comprehensive, thorough care; 20%). A representative quote regarding the importance of providers understanding trauma and its impact on health includes:

Yeah, it probably would depend on like what your kiddo's experiences were, but like I know probably like for some kids that have been through some tougher situations uhm...if they had been through trauma that was affecting them more, they really had some like medical issues uhm like chronic medical issues. I think that that would be helpful. My parents foster too and I know that they've brought their kids in here with some chronic stuff and they've been able to get that sorted out. ... they understand that those specific things that are shared by a lot of kids that are in those kinds of situations. Those experiences and the conditions that arise from what they've been through.

Participants were probed to understand any health-related benefits seen for their child as a result of using this clinic. Twenty five percent of caregivers stated that there were no specific health benefits for their children, with an additional 7.5% of caregivers being unsure if there were health benefits. Health-related benefits that were endorsed included having easier access to services with all services in the same building (12.5%), comprehensive care (12.5%), and continuity of care (10%).

Fewer caregivers reported on disadvantages of the PMH (27.5%), with concerns primarily surrounding location (20%), seeing multiple providers (5%), having other children seen at a separate location (2.5%), difficulties scheduling appointments for acute needs (2.5%), and having a long wait time (2.5%). Caregivers reported on the location, stating, "Well if we just live around the corner it would be easier," and "...we live like 35 minutes away. So, I tried to actually switch them to one closer. And he went to one appointment and I was like, 'No, we have to go back because they were nice but it was not the same."

Factors that sustained engagement. When asking caregiver what factors keep them at the PMH, caregivers reported that a connection with a specific doctor was a key factor in maintaining their engagement at the clinic (27.5%). A caregiver stated, "We really love [specific doctor]. She's very compassionate. She'll even ask me if like I'm taking care of myself or are there things that I needed, not just about the kids. They are very compassionate to caregivers and that's a big deal." While another stated, "...the relationship with the doctor. I mean I feel like she genuinely cares and she's very thorough, and she helps me understand what's going on."

Additionally, caregivers reported that continuity of care was a main factor in sustained engagement, stating that maintaining a routine for these children was important, and felt it was essential to keep continuous medical records (22.5%). Representative quotes include, "I feel safe coming here because they have all of their medical records here," and:

If given the option of staying here or taking them to a physician [closer to my home], I think I would have them stay here. Just because of the history and

because of the quality of care over convenience, and that's saying a lot too for somebody who doesn't have a lot of time in their schedule for different things.

Finally, caregivers reported that specific interpersonal qualities maintained their engagement (15%), including providers being caring, friendly, helpful, kind, nonjudgmental, and trustworthy.

Recommendation of clinic. Caregivers were asked if they would recommend this clinic to a fellow foster parent. All participants reported that they would indeed recommend this clinic to a peer foster caregiver, with 20% indicating that they already had recommended it to another parent. When probed for specific reasons why they would recommend the clinic, caregivers stated that provider interpersonal qualities (e.g., caring, friendly doctors; 35%) and their specialization in foster care/understanding of trauma was of the highest importance (27.5%). A few representative quotes on the role of foster care specialization include:

They're very familiar with foster care, so that makes a lot of things easier. As far as like paperwork or just anything, like sometimes I'll forget that I need something and they're like, "Oh, you probably need this for a caseworker."

Just like I said. Because they're gonna meet the needs. They're here to help and I think that's why they put this clinic over here to specialize in helping people who will have children in foster care. Cause there's, those kids need more needs. They face a lot of traumatic stress. A lot of abuse. And the clinic over here felt like really um leans towards all those things. Meeting those needs and helping the children.

I just always tell like foster families, "They're really knowledgeable and they really care and they know a lot about trauma. And they know a lot about like, removal, and the whole DHS process. Um and they follow up about like important things like that." So, like whenever we were going back and forth in between like child reunification and then termination like in between that. And because it happens really quick. Sometimes they, I think, they at every single appointment they kind of remembered. This is where we're at, this is what we're going to do. So, it wasn't just like, they were thinking the kids, they cared about their whole situation and not just, "Oh, they have a runny nose cause they have, you know, a cold." It was like they actually cared about their whole situation.

Other reasons for recommending this clinic to a peer included quality care (20%), being situated in a larger academic medical center (15%), good communication with the doctor (12.5%), and familiarity with Medicaid (10%).

### **Quantitative Results**

Continuity of care was calculated using the COC index (Bice & Boxerman, 1977) for the stratified sample of children (N=498). Given that the PMH is part of an academic medical center and is a teaching hospital, COC was estimated separately for attending physicians and resident physicians. Overall COC indices for attending physicians ranged from 0-1 (M=0.41, SD=0.34,95% CI=0.38-0.44) and demonstrated a non-normal distribution (W=0.87, p<0.0001). Similarly, resident physician COC ranged from 0-1 (M=0.39, SD=0.35,95% CI=0.36-0.42) and also demonstrated a non-normal distribution (W=0.86, p<0.0001). A Wilcoxon Rank Sum test was utilized to examine potential differences between attending and resident continuity. Given the non-normal distribution

of COC indices and the binary categorical dependent variable, this analysis is the best fit for the data (Field, 2013). Results of this test suggest that attending physician continuity and resident physician continuity did not significantly differ (W=243599.5, p=0.30). Additional Wilcoxon Rank Sum analyses were utilized to examine if COC significantly differed by child sex. Results revealed no significant differences across sex for either attending physicians or resident physicians (W=56026.0, p=0.31; W=55943.5, p=0.29, respectively).

To better understand differences in COC within our sample, the Kruskal-Wallis test was utilized to examine significant differences by child race and visit type (i.e., wellchild check, sick visit, new visit, return visit). Given the non-normal distribution of our independent variable, COC, and our dependent variable having greater than two categories, this analysis is the best fit to examine group differences (Field, 2013). Results of this analysis suggest that COC indices did not significantly differ by child race for either attending or resident physicians (H=0.1502, p=0.93; H=2.5549, p=0.28, respectively). However, in both groups, continuity significantly differed by visit type (H=52.2065, p<.001 for attendings; H=64.8557, p<.001 for residents), with return visits and well check visits having the highest continuity and sick visits having the lowest continuity estimates. See Table 4 for complete results. Regression analyses were then utilized to examine the effect of age on COC within resident and attending physicians. These results suggest that age was positively associated with COC, with increased age being associated with increased continuity for attending physicians, only, F(1, 496) =4.66, p=.04 (resident physicians: F(1, 4967) = 2.64, p=.10).

Correlational analyses were utilized to examine possible associations of demographic and appointment variables with COC. Analyses suggest attending physician continuity was significantly associated with increased age (r=2.06, p=.04), number of providers seen (r=-13.71, p<.001), and resident continuity (r=33.45, p<.001). Resident continuity was significantly related to number of providers seen (r=-14.19, p<.001) and attending physician continuity (r=33.45, p<.001). See Table 5 for complete results of the correlation analyses.

Finally, COC estimates from our study were compared to extant literature utilizing Bice and Boxerman's (1977) formula within pediatric primary care for general pediatric populations. Included articles were limited to those that utilized the COC index so that direct comparisons could be made to current published data. Comparison of 95% confidence intervals suggest that our COC estimates for attending and resident physicians were significantly lower than estimates from two of the studies (Christakis et al., 2004; Christakis, Wright, Zimmerman, Bassett, & Connell, 2002), and not significantly different than an additional two studies (Christakis, Mell, Koepsell, Zimmerman, & Connell, 2001; Christakis, Mell, Wright, Davis, & Connell, 2000). One article (Christakis, Wright, Zimmerman, Bassett, & Connell, 2003) demonstrated significantly higher estimates when compared to our resident COC, but not significantly different than that of our attending COC. See Table 6 for comparison data across five extant articles examining COC in pediatric primary care for the general pediatric population.

### CHAPTER V

### CONCLUSION

The present study utilized a mixed-methods approach to better understand the utility of PMHs for foster youth and their caregivers. This study examined clinic utility by assessing: 1) foster caregiver engagement at and perceptions of a PMH for youth in care, and 2) foster youth continuity of care at a specialized PMH. Results of this study suggest that foster caregivers generally had very positive experiences with a PMH specializing in foster youth (82.2% of comments; with 17.8% on negative experiences). Most caregivers reported several advantages to receiving services within this model (95%) of participants; with only 27.5% reported on disadvantages), and 100% of caregivers indicated they would recommend this clinic to fellow foster parents. When probing for information regarding initial engagement at the clinic, caregivers described enrollment in services as an easy process, often supported by clinic flexibility of paperwork, quick scheduling of the initial appointment, and caseworkers facilitating enrollment (i.e., providing numbers, scheduling appointments). Enrollment was often driven by caseworker or peer referrals as well as the clinic's specialization for foster youth. Importantly, factors that sustained caregiver engagement included the connections built with specific providers, the importance of maintaining continuity of care for their child,

and interpersonal qualities of providers and staff (e.g., nonjudgmental, caring, welcoming). Collectively, these results demonstrate that caregivers had positive perceptions of the PMH clinic and had strong engagement with services. Our qualitative results are consistent with previous research on caregiver satisfaction with services provided at a general PMH model (i.e., not for youth in foster care) (Palfrey et al., 2004) as well as the pivotal role of provider factors in caregiver engagement in services (Beasley, Silovsky, Ridings, Smith, & Owora, 2014).

Within the qualitative interviews, additional themes emerged surrounding fostercare specific needs in medical care. Caregivers viewed the specialization of services for
youth in foster care to be a key factor in their initial and sustained engagement.

Specifically, caregivers stated that provider and clinic familiarity with child welfare's
policies, procedures, and required paperwork was helpful in bridging the gap between
medical care and child welfare, providing comprehensive care for their child. They also
reported on the importance of provider knowledge of the impact of trauma on child health
and behavior, stating that this training helps provide safe environments for foster
children, often seen through understanding and nonjudgmental practices for children and
families

Other foster care-specific themes that emerged included the need for timely appointments after child placement, the importance of availability for sick visits, the high need for continuity of medical records when children have multiple placements, and comprehensive care to meet complex child health needs. Notably, these caregivers also emphasized the need for convenience in medical care. Caregivers frequently reported on factors related to convenience of services, with fewer comments on the actual model of

services (i.e., interdisciplinary, PMH). This was evident through the main themes of clinic location, all appointments residing in the same building, quick and efficient referrals, food availability in the medical center, valet parking, and all children receiving medical care on the same day. Collectively, these results suggest that caregivers are managing numerous stressors (i.e., ongoing child welfare involvement, foster child behavior problems, caregiver support groups, caregiver mandatory classes/training, and foster child involvement in other health services) and thus convenience of medical care is of utmost importance. Thus, it appears essential for providers to understand the demands on these families, and to develop models of care that accommodate these stressors with flexibility in order to help improve caregiver retention in services.

Notably, caregivers also commented on their personal experiences with the clinic that align with PMHs seven primary tenets (i.e., accessible, coordinated, providing continuous, comprehensive family-centered, and culturally-effective care) (Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002). Specifically, interviews highlighted the importance of having accessible services, with caregiver themes surrounding the academic health centers that offer all services in the same vicinity, desiring more accessibility to the PMH via after hours appointments or phone consultations, and having more medical services available in the community through Medicaid insurance. Caregivers themes also surrounded coordination of care and comprehensive care as important factors, reporting that foster youth often have complex health needs which may require in depth health assessments or enrollment in numerous health service. Additional themes surrounding coordinated and comprehensive care involved the advantage of having shared electronic medical records within an academic

medical center and the PMH's coordination with other clinics at the same health center. Participants reported on family-centered services through themes regarding the need for providers to listen to caregivers, to not feel rushed through appointments, and to be inclusive in services, providing care for all child family members, such as foster caregiver's biological children and foster youth following permanency.

Finally, participants reported on the importance of continuity for these youth, stating that foster caregivers rarely have the necessary medical history for these children, and thus it is imperative to maintain as much continuity with medical providers as possible. Caregivers reported continuity of care as a factor motivating their enrollment in services as well as one that facilitated their retention at the clinic. These results suggest that caregivers of foster youth find continuity of care to be a crucial factor in medical services. Quantitative analyses on youth continuity also suggest that the PMH model of care is producing rates of continuity among foster youth that is either slightly below or similar to other primary care clinics with the general pediatric population. Given that foster youth have substantial barriers to maintaining continuity (i.e., placement disruptions; see Garland et al., 2003; Jaudes et al., 2012), diminished COC rates are expected from foster youth relative to the general pediatric population. However, given that our COC rates appear similar to two other reports examining COC in general pediatrics (Christakis et al., 2001; Christakis et al., 2000), there is promise that this model may indeed be a viable avenue for providing continuity of care among children in foster care.

Quantitative results also suggest that rates of continuity are highest for return and well-child check visits (approximately 50% continuity), lowest for sick visits or acute

care needs (15-18% continuity), and often improve with child age. Although lower rates are expected for acute care needs, due to the urgency of appointments and limited provider availability for these appointments, these visits may be most important at maintaining continuity. Specifically, given the heightened distress associated with acute needs, families may feel more supported, feel that the patient's history if better taken into account, and feel more confident in the care when seeing their primary provider.

Caregivers also stated this through qualitative interviews, as a major area of improvement for the clinic included improving continuity of care and appointment availability for acute needs. Additional research should investigate strategies at improving continuity for acute care visits and provide recommendations for clinic providers at academic medical centers and teaching hospitals.

### Limitations

Although this study represents one of the first to evaluate caregiver perspectives of PMHs for youth in foster care, there are several limitations that should be discussed. First, this study examined caregiver engagement in services, however, due to inherent difficulties in recruitment of caregivers unengaged in services, there is no comparison group to examine factors leading to disengagement from services. Future research should examine caregivers that were not retained through this model of care to better understand factors leading to attrition of services. Similarly, within the continuity analyses, this study lacked a comparison group of foster youth not enrolled in PMH services, and as such, we cannot directly conclude that this model of care improves continuity for foster youth. The available published comparison data originate from the same team of researchers examining continuity within the general pediatric population, as such, we are limited by

not having variable research teams, clinics, and methodology to compare our COC estimates. Future research should extend our findings by examining continuity of care estimates among foster youth utilizing community-based services to better examine the impact of the PMH on foster youth continuity of medical care. Finally, data was procured from one specific PMH situated within a Midwest academic medical center. In this regard, it was difficult to parse apart caregiver reported experiences at the specific PMH versus the academic center as a whole. Additional research should be completed to replicate these findings with PMHs in diverse geographical, economic, and contextual settings.

### **Future directions**

In sum, the present study examined caregiver perceptions and youth health care continuity at a PMH for families involved with child welfare. Future research should incorporate these qualitative findings within PMHs and health clinics designed for families with child welfare involvement to assist in decreasing barriers to care and improve caregiver engagement at health services. If we can improve caregiver engagement in health services, providers may be better equipped to maintain continuity of care with youth in foster care, provide higher rates of preventative health care services, identify and intervene when health concerns arise, and make a larger impact at preventing long-term health consequences for youth in care. Despite the limitations of this study, we believe our results provide a key first step in evaluating PMHs developed for youth in foster care and inform planned future implementation science projects with samples of: 1) foster caregivers who discontinued PMH services, 2) foster youth receiving PMH services, 3) the interdisciplinary team of PMH providers, and 4) key stakeholders,

supervisors, and senior leaders to further enhance access to care for this underserved population.

PMHs have recently demonstrated effectiveness for early health screening and identification for youth across the nation (Jee et al., 2010; Palfrey et al., 2004; Pasztor et al., 2006; Strickland et al., 2011). As such, social reforms have encouraged the implementation of these medical homes for youth and their caregivers (Sia et al., 2004). This study represents one of the earliest efforts examining utility and utilization of these homes for youth affected by child maltreatment. Policies, procedures, and practices of primary care providers have a large potential for impact on the access and continuity of care for youth in foster care. Findings of this study assist in improving the model of care provided to these youth in hopes of providing an interdisciplinary team approach to address short-term and long-term effects of adverse childhood experiences. Results garnered from this project not only inform health interventions for youth following a traumatic event, but also have primary prevention implications, as these medical homes can offer frequent screenings for youth and their caregivers to help increase supports, monitor trauma symptoms, provide appropriate referrals, decrease parenting stress, and prevent additional incidents of child abuse and neglect.

### REFERENCES

- Alcala, H. E., Keim-Malpass, J., & Mitchell, E. (2017). Colorectal cancer screening and adverse childhood experiences: Which adversities matter? *Child Abuse & Neglect*, 69, 145-150. doi:10.1016/j.chiabu.2017.04.026
- Alcala, H. E., Valdez-Dadia, A., & von Ehrenstein, O. S. (2017). Adverse childhood experiences and access and utilization of health care. *Journal of Public Health*, 1-9. doi:10.1093/pubmed/fdx155
- Altshuler, S. J., & Poertner, J. (2003). Assessing child well-being in non-relative foster care with a new outcome measurement tool. *Journal of Family Social Work*, 7(2), 73-85.
- American Academy of Pediatrics. (1999). Committee on Pediatric Workforce. Culturally effective pediatric care: education and training issues. *Pediatrics*, *103*, 167-170.
- American Academy of Pediatrics. (1977). *Standards of child health care*: American Academy of Pediatrics.
- Anctil, T. M., McCubbin, L. D., O'Brien, K., Pecora, P., & Anderson-Harumi, C. A. (2007). Predictors of adult quality of life for foster care alumni with physical and/or psychiatric disabilities. *Child Abuse & Neglect*, *31*(10), 1087-1100.
- Angst, J., & Földényi, M. (1993). The Zurich Study: XVII. Sexual abuse in childhood. Frequency and relevance for adult morbidity data of a longitudinal

- epidemiological study. European Archives of Psychiatry and Clinical Neuroscience, 242, 293-300.
- Arnow, B. A. (2004). Relationships between childhood maltreatment, adult health and pschiatric outcomes, and medical utilization. *Journal of Clinical Psychiatry*, 65, 10-15.
- Auslander, W. F., McMillen, J. C., Elze, D., Thompson, R., Jonson-Reid, M., & Stiffman, A. (2002). Mental health problems and sexual abuse among adolescents in foster care: Relationship to HIV risk behaviors and intentions. *AIDS and Behavior*, 6(4), 351-359.
- Banyard, V. L., Williams, L. M., & Siegel, J. A. (2001). The long-term mental health consequences of child sexual abuse: An exploratory study of the impact of multiple traumas in a sample of women. *Journal of Traumatic Stress*, *14*(4), 697-715.
- Bass, S., Shields, M. K., & Behrman, R. E. (2004). Children, families, and foster care:

  Analysis and recommendations. *The Future of Children*, 5-29.
- Beasley, L.O., Silovsky, J. F., Ridings, L.E., Smith, T. J., & Owora, A. (2014).

  UUnderstanding program engagement and attrition in child abuse prevention. *Journal of Family Strengths*, *14*(1), 20.
- Bice, T. W., & Boxerman, S. B. (1977). A quantitative measure of continuity of care. *Medical Care*, 15(4), 347-349.
- Bonomi, A. E., Anderson, M. L., Rivara, F. P., Cannon, E. A., Fishman, P. A., Carrell, D., . . . Thompson, R. S. (2008). Health care utilization and costs associated with

- childhood abuse. *Journal of General Internal Medicine*, *23*(3), 294-299. doi:10.1007/s11606-008-0516-1
- Bowen, S. (2001). Language barriers in access to health care: Health Canada Ottawa.
- Brewer, E. J., McPherson, M., Magrab, P. R., & Hutchins, V. L. (1989). Family-centered, community-based, coordinated care for children with special health care needs. *Pediatrics*, 83(6), 1055-1060.
- Briere, J. N. (1992). *Child abuse trauma: Theory and treatment of the lasting effects*:

  Sage Publications, Inc.
- Brown, D. S., Fang, X., & Florence, C. S. (2011). Medical costs attributable to child maltreatment: A systematic review of short-and long-term effects. *American Journal of Preventive Medicine*, 41(6), 627-635.
- Burley, M., & Halpern, M. (2001). Educational Attainment of Foster Youth:

  Achievement and Graduation Outcomes for Children in State Care.
- Burns, B. J., Phillips, S. D., Wagner, H. R., Barth, R. P., Kolko, D. J., Campbell, Y., & Landsverk, J. (2004). Mental health need and access to mental health services by youths involved with child welfare: A national survey. *Journal of the American Academy of Child & Adolescent Psychiatry*, 43(8), 960-970.
- Chartier, M. J., Walker, J. R., & Naimark, B. (2007). Childhood abuse, adult health, and health care utilization: Results from a representative community sample.

  \*American Journal of Epidemiologyl, 165(9), 1031-1038. doi:10.1093/aje/kwk113
- Chartier, M. J., Walker, J. R., & Naimark, B. (2009). Health risk behaviors and mental health problems as mediators of the relationship between childhood abuse and

- adult health. *American Journal of Public Health*, 99(5), 847-854. doi:10.2105/AJPH.2007.122408
- Chartier, M. J., Walker, J. R., & Naimark, B. (2010). Separate and cumulative effects of adverse childhood experiences in predicting adult health and health care utilization. *Child Abuse & Neglect*, *34*(6), 454-464. doi:10.1016/j.chiabu.2009.09.020
- Chen, A., Brown, R., Archibald, N., Aliotta, S., & Fox, P. (2000). Best practices in coordinated care. *Princeton, NJ: Mathematica Policy Research, Inc.*
- Chernoff, R., Combs-Orme, T., Risley-Curtiss, C., & Heisler, A. (1994). Assessing the health status of children entering foster care. *Pediatrics*, *93*(4), 594-601. \\\\\\
- Child Information Gateway. (2017). Foster care statistics 2016. US Department of Health and Human Services, Children's Bureau.
- Child Welfare League of America. (1988). Standards for Health Care Services for Children in Out-of-home Care: The League.
- Christakis, D. A., Kazak, A. E., Wright, J. A., Zimmerman, F. J., Bassett, A. L., & Connell, F. A. (2004). What factors are associated with achieving high continuity of care? *Family Medicine*, *36*(1), 55-60.
- Christakis, D. A., Mell, L., Koepsell, T. D., Zimmerman, F. J., & Connell, F. A. (2001).

  Association of lower continuity of care with greater risk of emergency department use and hospitalization in children. *Pediatrics*, 107(3), 524-529.
- Christakis, D. A., Mell, L., Wright, J. A., Davis, R., & Connell, F. A. (2000). The association between greater continuity of care and timely measles-mumps-rubella vaccination. *American Journal of Public Health*, *90*(6), 962.

- Christakis, D. A., Wright, J. A., Zimmerman, F. J., Bassett, A. L., & Connell, F. A. (2002). Continuity of care is associated with high-quality careby parental report. *Pediatrics*, *109*(4), e54-e54.
- Child Information Gateway. (2017). Foster care statistics 2016. US Department of Health and Human Services, Children's Bureau.
- Child Welfare League of America. (1988). Standards for Health Care Services for Children in Out-of-home Care: The League.
- Christakis, D. A., Kazak, A. E., Wright, J. A., Zimmerman, F. J., Bassett, A. L., & Connell, F. A. (2004). What factors are associated with achieving high continuity of care? *Family Medicine*, *36*(1), 55-60.
- Christakis, D. A., Mell, L., Koepsell, T. D., Zimmerman, F. J., & Connell, F. A. (2001).

  Association of lower continuity of care with greater risk of emergency department use and hospitalization in children. *Pediatrics*, 107(3), 524-529.
- Christakis, D. A., Mell, L., Wright, J. A., Davis, R., & Connell, F. A. (2000). The association between greater continuity of care and timely measles-mumps-rubella vaccination. *American Journal of Public Health*, *90*(6), 962.
- Christakis, D. A., Wright, J. A., Zimmerman, F. J., Bassett, A. L., & Connell, F. A. (2002). Continuity of care is associated with high-quality careby parental report. *Pediatrics*, 109(4), e54-e54.
- Christakis, D. A., Wright, J. A., Zimmerman, F. J., Bassett, A. L., & Connell, F. A. (2003). Continuity of care is associated with well-coordinated care. *Ambulatory Pediatrics*, *3*(2), 82-86.

- Clausen, J. M., Landsverk, J., Ganger, W., Chadwick, D., & Litrownik, A. (1998).

  Mental health problems of children in foster care. *Journal of Child and Family Studies*, 7(3), 283-296.
- Committee on Children with Disabilities. (1999). Care coordination: integrating health and related systems of care for children with special health care needs. *Pediatrics*, *104*(4), 978-981.
- Committee on Early Childhood & Care. (2002). Health care of young children in foster care. *Pediatrics*, 109(3), 536-541.
- Cooley, W. C., McAllister, J. W., Sherrieb, K., & Kuhlthau, K. (2009). Improved outcomes associated with medical home implementation in pediatric primary care. *Pediatrics*, *124*(1), 358-364.
- DiGiuseppe, D. L., & Christakis, D. A. (2003). Continuity of care for children in foster care. *Pediatrics*, 111(3), e208-e213.
- Dworsky, A. (2005). The economic self-sufficiency of Wisconsin's former foster youth. *Children and Youth Services Review, 27*(10), 1085-1118.
- Edwards, V. J., Holden, G. W., Felitti, V. J., & Anda, R. F. (2003). Relationship between multiple forms of childhood maltreatment and adult mental health in community respondents: results from the adverse childhood experiences study. *American Journal of Psychiatry*, 160(8), 1453-1460.
- Farruggia, S. P., & Sorkin, D. H. (2009). Health risks for older US adolescents in foster care: The significance of important others' health behaviours on youths' health and health behaviours. *Child: Care, Health and Development, 35*(3), 340-348.

- Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., .
  ... Marks, J. S. (1998). Relationship of childhood abuse and household
  dysfunction to many of the leading causes of death in adults: The Adverse
  Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine*,
  14(4), 245-258.
- Field, A. (2013). Non-parametric models. In M. Carmichael (Ed.), *Discovering statistics using IBM statistics* (213-261). Sage Publishing.
- Flores, G., & Vega, L. R. (1998). Barriers to health care access for Latino children: A review. *Family Medicine*, *30*, 196-205.
- Garland, A. F., Hough, R. L., McCabe, K. M., Yeh, M., Wood, P. A., & Aarons, G. A.
  (2001). Prevalence of psychiatric disorders in youths across five sectors of care.
  Journal of the American Academy of Child & Adolescent Psychiatry, 40(4), 409-418.
- Garland, A. F., Landsverk, J. A., & Lau, A. S. (2003). Racial/ethnic disparities in mental health service use among children in foster care. *Children and Youth Services*Review, 25(5-6), 491-507. doi:10.1016/s0190-7409(03)00032-x
- Greeson, J. K., Briggs, E. C., Kisiel, C. L., Layne, C. M., Ake III, G. S., Ko, S. J., . . . Pynoos, R. S. (2011). Complex trauma and mental health in children and adolescents placed in foster care: Findings from the National Child Traumatic Stress Network. *Child Welfare*, *90*(6), 91.
- Gypen, L., Vanderfaeillie, J., De Maeyer, S., Belenger, L., & Van Holen, F. (2017).

  Outcomes of children who grew up in foster care: Systematic-review. *Children and Youth Services Review*, 76, 74-83.

- Halfon, N., & Klee, L. (1991). Health and development services for children with multiple needs: The child in foster care. *Yale Law & Policy Review*, *9*(1), 71-96.
- Halfon, N., Berkowitz, G., & Klee, L. (1992). Mental health service utilization by children in foster care in California. *Pediatrics*, 89(6), 1238-1244.
- Halfon, N., Mendonca, A., & Berkowitz, G. (1995). Health status of children in foster care. *Archives of Pediatric and Adolescent Medicine*, *149*(4), 386-392.
- Hansen, R. L., Mawjee, F. L., Barton, K., Metcalf, M. B., & Joye, N. R. (2004).

  Comparing the health status of low-income children in and out of foster care.

  Child Welfare, 83(4), 367.
- Huberman, A. M., & Miles, M. B. (1994). Data management and analysis methods. In N.K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 428-444). Thousand Oaks, CA, US: Sage Publications, Inc.
- Jaudes, P. K., Champagne, V., Harden, A., Masterson, J., & Bilaver, L. A. (2012).

  Expanded medical home model works for children in foster care. *Child Welfare*, 91(1), 9-33.
- Jee, S. H., Barth, R. P., Szilagyi, M. A., Szilagyi, P. G., Aida, M., & Davis, M. M. (2006). Factors associated with chronic conditions among children in foster care. *Journal of Health Care for the Poor and Underserved, 17*(2), 328-341.
- Jee, S. H., Conn, A. M., Szilagyi, P. G., Blumkin, A., Baldwin, C. D., & Szilagyi, M. A. (2010). Identification of social-emotional problems among young children in foster care. *Journal of Child Psychology and Psychiatry*, 51(12), 1351-1358. doi:10.1111/j.1469-7610.2010.02315.x

- Kalmakis, K. A., & Chandler, G. E. (2015). Health consequences of adverse childhood experiences: A systematic review. *Journal of American Association of Nurse Practitioners*, 27(8), 457-465. doi:10.1002/2327-6924.12215
- Kendall-Tackett, K. (2002). The health effects of childhood abuse: four pathways by which abuse can influence health. *Child Abuse & Neglect*, 26(6-7), 715-729.
- Kendall-Tackett, K. A. (2003). *Treating the lifetime health effects of childhood victimization*: Civic Research Institute, Inc.
- Kerker, B. D., & Dore, M. M. (2006). Mental health needs and treatment of foster youth:

  Barriers and opportunities. *American Journal of Orthopsychiatry*, 76(1), 138-147.

  doi:10.1037/0002-9432.76.1.138
- Kools, S., & Kennedy, C. (2003). Foster child health and development: Implications for primary care. *Pediatric Nursing*, 29(1), 39.
- Lombard, M., Snyder-Duch, J., & Bracken, C. C. (2002). Content analysis in mass communication: Assessment and reporting of intercoder reliability. *Human Communication Research*, 28(4), 587-604.
- Marrone, S. (2007). Understanding barriers to health care: A review of disparities in health care services among indigenous populations. *International Journal of Circumpolar Health*, 66(3), 188-198.
- McCauley, J., Kern, D. E., Kolodner, K., Dill, L., Schroeder, A. F., DeChant, H. K., . . . Bass, E. B. (1997). Clinical characteristics of women with a history of childhood abuse: Unhealed wounds. *Journal of American Medical Association*, 277(17), 1362-1368.

- McCurdy, K., & Daro, D. (2001). Parent involvement in family support programs: An integrated theory. *Family Relations*, *50*(2), 113-121.
- McGowan, B. G., & Walsh, E. M. (2000). Policy challenges for child welfare in the new century. *Child Welfare*, 79(1), 11.
- McMillen, C., Zima, B.T., Scott, L.D., Auslander, W. F., Munson, M. R., Ollie, M.T., & Spitznagel, E. L. (2005). Prevalence of psychiatric disorders among older youths in the foster care system. *Journal of the American Academy of Child & Adolescent Psychiatry*, 44(1), 88-95.
- Medical Home Initiatives for Children with Special Needs Project Advisory Committee. (2002). The medical home. *Pediatrics*, 110(1), 184-186.
- Mekonnen, R., Noonan, K., & Rubin, D. (2009). Achieving better health care outcomes for children in foster care. *Pediatric Clinics of North America*, *56*(2), 405-415.
- Minnis, H., Everett, K., Pelosi, A. J., Dunn, J., & Knapp, M. (2006). Children in foster care: Mental health, service use and costs. *European Child & Adolescent Psychiatry*, 15(2), 63-70.
- Newton, R. R., Litrownik, A. J., & Landsverk, J. A. (2000). Children and youth in foster care: Disentangling the relationship between problem behaviors and number of placements. *Child Abuse & Neglect*, *24*(10), 1363-1374.
- Palfrey, J. S., Sofis, L. A., Davidson, E. J., Liu, J., Freeman, L., & Ganz, M. L. (2004).

  The pediatric alliance for coordinated care: Evaluation of a medical home model. *Pediatrics*, 113(Supplement 4), 1507-1516.

- Pasztor, E. M., Hollinger, D. S., Inkelas, M., & Halfon, N. (2006). Health and mental health services for children in foster care: The central role of foster parents. *Child Welfare*, 85(1), 33.
- Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work*, 1(3), 261–283.
- Pecora, P. J., Jensen, P. S., Romanelli, L. H., Jackson, L. J., & Ortiz, A. (2009). Mental health services for children placed in foster care: An overview of current challenges. *Child Welfare*, 88(1), 5.
- Pecora, P. J., Kessler, R. C., O'Brien, K., White, C. R., Williams, J., Hiripi, E., . . .

  Herrick, M. A. (2006). Educational and employment outcomes of adults formerly placed in foster care: Results from the Northwest Foster Care Alumni Study.

  Children and Youth Services Review, 28(12), 1459-1481.
- Reid, R.J., Fishman, P.A., Yu, O., Ross., T.R., Tufano, J.T., ... & Larson, E.B. (2009). Patient-centered medical home demonstration: A prospective, quasi-experimental, before and after evaluation. The *American Journal of Managed Care*, *15*(9), e71-e87.
- Roberts, R., O'Connor, T., Dunn, J., Golding, J., & ALSPAC Study Team. (2004). The effects of child sexual abuse in later family life; Mental health, parenting and adjustment of offspring. *Child Abuse & Neglect*, 28(5), 525-545.
- Rosenthal, T. C. (2008). The medical home: Growing evidence to support a new approach to primary care. *The Journal of the American Board of Family Medicine*, 21(5), 427-440.

- Rovi, S., Chen, P.-H., & Johnson, M. S. (2004). The economic burden of hospitalizations associated with child abuse and neglect. *American Journal of Public Health*, *94*(4), 586-590.
- Rubin, D. M., Alessandrini, E. A., Feudtner, C., Mandell, D. S., Localio, A. R., & Hadley, T. (2004). Placement stability and mental health costs for children in foster care. *Pediatrics*, 113(5), 1336-1341.
- Sawyer, M. G., Carbone, J. A., Searle, A. K., & Robinson, P. (2007). The mental health and wellbeing of children and adolescents in home-based foster care. *Medical Journal of Australia*, 186(4), 181-184.
- Scheppers, E., Van Dongen, E., Dekker, J., Geertzen, J., & Dekker, J. (2006). Potential barriers to the use of health services among ethnic minorities: A review. *Family Practice*, 23(3), 325-348.
- Schneiderman, J. U., Smith, C., & Palinkas, L. A. (2012). The caregiver as gatekeeper for accessing health care for children in foster care: A qualitative study of kinship and unrelated caregivers. *Children and Youth Services Review, 34*(10), 2123-2130.
- Schore, A. N. (2001). The effects of early relational trauma on right brain development, affect regulation, and infant mental health. *Infant Mental Health Journal*, 22(1-2), 201-269.
- Shonkoff, J. P., Garner, A. S., Siegel, B. S., Dobbins, M. I., Earls, M. F., McGuinn, L., ... & Committee on Early Childhood, Adoption, and Dependent Care. (2012). The lifelong effects of early childhood adversity and toxic stress. *Pediatrics*, *129*(1), e232-e246.

- Sia, C., Tonniges, T. F., Osterhus, E., & Taba, S. (2004). History of the medical home concept. *Pediatrics*, *113*(Supplement 4), 1473-1478.
- Simms, M. D. (1989). The foster care clinic: A community program to identify treatment needs of children in foster care. *Journal of Developmental and Behavioral Pediatrics*.
- Simms, M. D., & Halfon, N. (1994). The health care needs of children in foster care: A research agenda. *Child Welfare*, 73(5), 505.
- Smith, C., & Thornberry, T. P. (1995). The relationship between childhood maltreatment and adolescent involvement in delinquency. *Criminology*, *33*(4), 451-481.
- Springer, K. W., Sheridan, J., Kuo, D., & Carnes, M. (2003). The long-term health outcomes of childhood abuse. *Journal of General Internal Medicine*, 18(10), 864-870.
- Springer, K. W., Sheridan, J., Kuo, D., & Carnes, M. (2007). Long-term physical and mental health consequences of childhood physical abuse: Results from a large population-based sample of men and women. *Child Abuse & Neglect*, *31*(5), 517-530.
- Springs, F. E., & Friedrich, W. N. (1992). *Health risk behaviors and medical sequelae of childhood sexual abuse*. Paper presented at the Mayo Clinic Proceedings.
- Stahmer, A. C., Leslie, L. K., Hurlburt, M., Barth, R. P., Webb, M. B., Landsverk, J., & Zhang, J. (2005). Developmental and behavioral needs and service use for young children in child welfare. *Pediatrics*, *116*(4), 891-900.
- Starfield, B., & Shi, L. (2004). The medical home, access to care, and insurance: A review of evidence. *Pediatrics*, *113*(Supplement 4), 1493-1498.

- Steele, J. S., & Buchi, K. F. (2008). Medical and mental health of children entering the Utah foster care system. *Pediatrics*, 122(3), E703-E709. doi:10.1542/peds.2008-0360
- Stein, E., Evans, B., Mazumdar, R., & Rae-Grant, N. (1996). The mental health of children in foster care: A comparison with community and clinical samples. *The Canadian Journal of Psychiatry*, 41(6), 385-391.
- Strickland, B. B., Jones, J. R., Ghandour, R. M., Kogan, M. D., & Newacheck, P. W. (2011). The medical home: Health care access and impact for children and youth in the United States. *Pediatrics*, peds. 2009-3555.
- Sullivan, D. J., & van Zyl, M. A. (2008). The well-being of children in foster care:

  Exploring physical and mental health needs. *Children and Youth Services Review*,

  30(7), 774-786.
- Takayama, J. I., Bergman, A. B., & Connell, F. A. (1994). Children in foster care in the state of Washington: Health care utilization and expenditures. *Journal of American Medical Association*, 271(23), 1850-1855.
- Takayama, J. I., Wolfe, E., & Coulter, K. P. (1998). Relationship between reason for placement and medical findings among children in foster care. *Pediatrics*, 101(2), 201-207.
- Twohig, P. L., & Putnam, W. (2002). Group interviews in primary care research:

  Advancing the state of the art or ritualized research? *Family practice*, 19(3), 278-284.
- US Department of Health and Human Services. (2017). The Adoption and Foster Care

  Analysis and Reporting System (AFCARS) Report.

- US Department of Health and Human Services. (2017). Child Welfare Outcomes 2010–2014: Report to Congress.
- US General Accounting Office. (1995). Foster care: Health needs of many young children are unknown and unmet.
- Vinnerljung, B., Hjern, A., & Lindblad, F. (2006). Suicide attempts and severe psychiatric morbidity among former child welfare clients a national cohort study. *Journal of Child Psychology and Psychiatry*, *47*(7), 723-733. doi:10.1111/j.1469-7610.2005.01530.x
- Wulczyn, F., Chen, L., & Hislop, K. B. (2007). Foster care dynamics, 2000-2005: A report from the multistate foster care data archive: Chapin Hall Center for Children at the University of Chicago Chicago, IL.
- Zlotnick, C., Tam, T. W., & Soman, L. A. (2012). Life course outcomes on mental and physical health: The impact of foster care on adulthood. *American Journal of Public Health*, 102(3), 534-540. doi:10.2105/ajph.2011.300285

# APPENDICES

# Appendix A

University of Oklahoma Health Sciences Center Institutional Review Board Approval

Letter



# Institutional Review Board for the Protection of Human Subjects

### **Initial Submission – Expedited Approval**

**Date:** June 29, 2018 IRB#: 9380

**Approval Date:** 06/25/2018 **To:** Stephen R Gillaspy, PhD **Expiration Date:** 05/31/2019

Study Title: Mixed Methods Examination of Foster Caregiver Perceptions of Pediatric

Medical Homes

**Reference Number:** 679803

**Expedited Criteria:** Expedited Category 7

On behalf of the Institutional Review Board (IRB), I have reviewed and granted expedited approval of the above- referenced research study. Study documents associated with this submission are listed on page 2 of this letter. To review and/or access the submission forms as well as the study documents approved for this submission, click *My Studies*, click to open this study, under *Protocol Items*, click to view/access the current approved *Application*, *Informed Consent*, or *Other Study Documents*.

If this study required routing through the Office of Research Administration (ORA), you may <u>not</u> <u>begin your study yet</u>, as per OUHSC Institutional policy, until the contract through ORA is finalized and signed.

As principal investigator of this research study, you are responsible to:

- Conduct the research study in a manner consistent with the requirements of the IRB and federal regulations 45 CFR 46 and/or 21 CFR 50 and 56.
- Request approval from the IRB prior to implementing any/all modifications.
- Promptly report to the IRB any harm experienced by a participant that is both unanticipated and related per IRB policy.
- Maintain accurate and complete study records for evaluation by the HRPP Quality ImprovementProgram and, if applicable, inspection by regulatory agencies and/or the study sponsor.
- Promptly submit continuing review documents to the IRB upon notification approximately
   60 days prior to the expiration date indicated above.

In addition, it is your responsibility to obtain informed consent and research privacy authorization using the currently approved, stamped forms and retain all original, signed forms, if applicable.

If you have questions about this notification or using iRIS, contact the IRB at 405-271-2045 or irb@ouhsc.edu.

Sincerely,

Candaca Marshall, MD

Vice Chairperson, Institutional Review Board

Initial Submission – Expedited Approval [cont'd.]Page 2

### Study documents associated with this submission:

Study Document			
Title	Version #	Version Date	Outcome
Research Protocol	Version 1.0	05/25/2018	Approved
Caregiver Demographic Form	Version 1.0	05/25/2018	Approved
HIPAA Authorization #1	Version 1.0	05/25/2018	Approved
HIPAA Wavier of Authorization	Version 1.0	05/25/2018	Approved
Established Patient Interview Guide	Version 1.0	05/25/2018	Approved
New Patient Interview Guide	Version 1.0	05/25/2018	Approved

Study Consent Form					
Title	Version #	Version Date	Outcome		
Interview Consent Form	Version 1.2	05/25/2018	Approved		

<sup>\*\*</sup>Information for Industry Sponsors: the columns titled Version Number and Version Date are specific to the electronic submission system (iRIS) and should not to be confused with information included in the Document and/or Consent title(s).\*

# Appendix B

University of Oklahoma Health Sciences Center and Oklahoma State University

Institutional Review Boards Reliance Agreement

## Institutional Review Board Authorization Agreement

Name of Institution or Organization Providing IRB Review OUHSC IRB: Board of Regents of the University of Oklahoma Health Sciences Center

IRB Registration #: IRB00000587 IRB00000729 IRB00000588 IRB00000741 and IRB00005046

Federa!wide Assurance (FWA) #: FWA00007961

Name of Institution Relying on the Designated IRB Oklahoma State University FWA #: FWA00000493

The Officials signing below agree that OSU Stillwater may rely on the designated IRB for review and continuing oversight of its human subjects research described below:

(X) This Agreement is limited to the following specific protocol(s):

Name of Research Project: Mixed Methods Examination of Foster Caregiver Perceptions of Pediatric Medical Homes Name of Principal Investigator: Stephen R. Gillaspy, PhD Pediatrics Sponsor or Funding Agency: N/A Award Number, if any: N/A

### Responsibilities of Designated IRB and Deferring Institution

- 1. The review performed by the Designated IRB will meet the human subject protection requirements of the Deferring Institution's OHRP-approved FWA.
- 2. The Designated IRB will follow its written procedures for reporting its findings and aCtions related to the covered research to appropriate officials at the Deferring Institution.
- 3. Relevant minutes of IRB meetings wilt be made available to the Deferring Institution upon request.
- 4. The Deferring Institution remains responsible for ensuring compliance with the Designated IRB's determinations and with the Terms of its OHRP-approved FWA,
- 5. The Designated IRB will serve as the Privacy Board for reviewing and approving HIPAA Authorizations, requests to alter a HIPAA Authorization, requests for HIPAA Waivers, and other issues or requests relying on a Privacy Board. The Designated IRB/Privacy Board will promptly notify the Deferring Institution in writing in the event it becomes aware of a HIPAA violation or suspected violation arising under any Study Covered by this Agreement.
- 6. This Agreement must be kept on file by both parties at least three years after completion of all applicable research, and provided to OHRP upon request.

Either party may terminate this Agreement upon 30 days' written notice to the other. Upon termination, the Designated IRB will no longer be responsible for the oversight of the Deferring Institution's research. For five yeaFs following termination, the parties shall continue to protect and maintain each other's designated confidential and proprietary information in confidence.

Siggradabunee of Siggradabovy Official OUHSC IRB

Date: 8/15/2018

**Sett Davis** 

*//* 11 *//* 11

**Associate Director** 

University of Oklahoma Health Sciences Center

Office of Research

Administration 865

Research Parkway.

URP865-450 Oklahoma

City, OK 73104

S iQnatClre of Signatory-Official OSU Stillwater

Kenneth W. Sewell, PhD. Vice President for Research

405-744-7076

Kenneth.sewell@okstate.edu.

## Appendix C

D	ate: ID:
Interv	viewer:
	Demographic Information Caregiver Information
Please	answer the following questions about yourself.
1. Date	e of Birth: / /
	 :
3. Rac	
3.1140	
0	Hispanic/Latino
0	White
0	Black/African American
0	Asian
0	Pacific Islander/Native Hawaiian
0	Native American
0	Biracial
0	Multiracial
0	Other:
4. Occ	upational Status:
	D. 11 (E)
	Full Time
	Part Time
	Unemployed
	Retired
0	Seeking Employment
	Not Working, Disabled
O	Other:
	upation:
Emplo	-
6. Wha	at is your highest grade completed?
0	7th grade or lower
0	8th or 9th grade
0	10th or 11th grade
0	High School Graduate or GED
0	Partial College
0	College Graduate (BS, BA)
0	Graduate or Professional Degree
0	Other:
	ome Level:

o Less than \$9,999

0	\$10,000-\$19,999
0	\$20,000-\$29,999
0	\$30,000-\$39,999
0	\$40,000-\$49,999
0	\$50,000-\$59,999
0	\$60,000-\$69,999
0	\$70,000-\$79,999
0	More than \$80,000
_	rital Status:
o. Iviai	itai Status.
0	Single
0	Married
0	Divorced
-	Separated
	Widowed
	Living as Married
9 Is th	Other: nere another adult caregiver living in your home?
, , ,	
0	Yes
	No
9a. <b>IF</b>	YES, what is their relationship to you:
9b. IF	YES, what is their relationship to your child:
	ow many individuals are living in the child's primary household?
10.110	ow many marviduals are fiving in the emid's primary nousehold:
D.I	
	e list them below:
Relat	ion to Child Age
11. W	hat is the total household income?
_	I and then \$0,000
0	Less than \$9,999
0	\$10,000-\$19,999
0	\$20,000-\$29,999
0	\$30,000-\$39,999
0	\$40,000-\$49,999
0	\$50,000-\$59,999
0	\$60,000-\$69,999

o \$70,000-\$79,999
<ul><li>\$80,000-\$89,999</li></ul>
o \$90,000-\$99,999
o More than \$100,000
12. Are you currently receiving financial assistance in other ways (i.e., TANF, via Foster
Care, etc.)?
N/
o Yes
o No
12a. <b>IF YES,</b> Please describe:
13. What is the age of the foster child in your home?
14. What is the ethnicity of the child in your home?
o Hispanic/Latino
White
Black/African American
o Asian
o Pacific Islander/Native Hawaiian
<ul> <li>Native American</li> </ul>
<ul> <li>Biracial</li> </ul>
<ul> <li>Multiracial</li> </ul>
o Other:
15. How long has this child been in your home?
o Voorge
<ul><li>Years:</li><li>Months:</li></ul>
O Months.
16. What is your relationship with the foster child in your home (i.e., kinship)?
17. Is this your first experience with a foster child in the home?
17. Is this your first experience with a roster child in the nome:
o Yes
o No
17a. IF NO, Please describe:
18. Do you have other foster children in your home at this time?
o Yes
o No
18a. IF YES, Please list names, ages, and gender
19. Does your foster child have any chronic medical conditions?
o Yes
o No
70
• •

19a. IF YES, what condition do they have? Please write the related diagnosis for the relevant condition. Asthma o Type I Diabetes\_\_\_\_ o Type II Diabetes\_\_\_\_\_ o Sickle Cell Disease o Cystic Fibrosis\_\_\_\_\_ o Obesity\_\_\_\_\_ o Fibromyalgia\_\_\_\_\_ o Juvenile Rheumatic Disease\_\_\_\_\_ Epilepsy \_\_\_\_\_Celiac Disease \_\_\_\_\_ o Inflammatory Bowel Disease (IBD) (including Crohn's disease and ulcerative o Irritable Bowel Syndrome (IBS)\_\_\_\_\_ o Allergies\_\_\_\_\_ o Cancer\_\_\_\_ Other 20. How long have you been receiving services at the Fostering Hope Clinic for this foster child? o Approximate number of appointments: \_\_\_\_\_ Approximate number of years: \_\_\_\_\_\_\_ 21. How long have you been receiving services at the Fostering Hope Clinic for all children in your household? o Approximate number of appointments: \_\_\_\_\_ o Approximate number of years: 22. Rate your overall satisfaction with the Fostering Hope Clinic: Completely satisfied Satisfied Slightly satisfied Neutral Slightly unsatisfied Unsatisfied Completely unsatisfied

23. Please provide the zip code in which you and your family resides:

# Appendix D Interview Guide

Date	Moderator	
ID	Recorder	

Introduction
Honest Opinion
No right or wrong answers
All opinions welcome
Anonymity – your first name or an alias
Confidentiality
Audio taping

Thank you for agreeing to participate in this interview. Everyone being interviewed at some point had a child in foster care that was enrolled in the Fostering Hope Clinic. We will be asking about your experience with medical services available for foster children.

#### Interview Guide

- 1. Please tell us your name and the ages of the foster children in your home.
- 2. Please tell me about available medical services for foster children that you are aware of.
  - a. Probe: Which of these have you personally used?
- 3. Could you tell me a little bit about what you are looking for in medical services for your foster child?
- 4. Tell me about your family's experience with the Fostering Hope Clinic
  - a. Probe: Positive experiences
  - b. Probe: Less Positive Experiences
- 5. Why did you choose to use this service, specifically?
  - a. Probe: Have you utilized other services previously for a child in foster care? **If yes**, what was that experience like? (Probe on types of services utilized)

- 6. How did you hear about the FH clinic?
  - a. Probe: Word of mouth, caseworker, flier
- 7. Please describe how you got enrolled in these services? What facilitated your enrollment? (i.e., caseworker, paperwork)
  - b. Probe: Supports for enrollment
  - c. Probe: Barriers for enrollment (e.g., location, wait list)
  - a. Probe: What could have made enrollment easier?
- 8. What are some words you would use to describe this clinic?
- 9. What are advantages of going to the FH clinic, compared to other places?
  - a. Probe: Relationship with provider, continuity of care, centralized location of records, multidisciplinary clinic, access to care
  - b. Probe: Any health benefits associated with this clinic beyond those of other services?
  - c. Probe: What were some things that helped you keep your foster child at the FH clinic?
  - d. Probe: Were there any costs for you to use this clinic? (i.e., time off work)
- 10. In what ways did this clinic meet (or not meet) the needs of your child and family?
  - a. Probe: Access to resources, multidisciplinary team, health care improvement, management of disease, etc.
- 11. Would you recommend this clinic to a fellow foster parent?
  - a. Probe: If yes, why?

- b. Probe: **If yes**, what are your recommendations for the best ways to let foster parents know about the FH clinic for their foster children?
- c. Probe: **If no**, why not? What other services would you recommend?
- 12. Is there anything you would change about this clinic?
- 13. Is there anything else you would like me to know today?

# Appendix E Tables

Table 1. Descriptive statistics of qualitative participants, foster caregivers (N=40)

*	N	ster caregivers (N=40) <b>M (SD, Range)</b>	
Age	39	45.54 (11.84, 26-75)	
Sex		, ,	
Male	4	10.0%	
Female	36	90.0%	
Race			
Hispanic	2	5.0%	
White	26	65.0%	
Black/African American	6	15.0%	
Native American	1	2.5%	
Biracial	1	2.5%	
Multiracial	4	10.0%	
Marital Status			
Single	17	42.5%	
Married	13	32.5%	
Divorced, separated	4	10.0%	
Widowed	2	5.0%	
Living as married	1	2.5%	
Education			
Below high school	3	7.5%	
High school graduate or GED	6	15.0%	
Partial college	10	25.0%	
College graduate	12	30.0%	
Graduate or professional degree	9	22.5%	
Occupational Status			
Full time	22	55.0%	
Part time	4	10.0%	
Unemployed	6	15.0%	
Retired	2	5.0%	
Not working, disabled	4	10.0%	
Other	2	5.0%	
Household Income			
Less than \$19,999	4	10.0%	
\$20,000-\$39,999	7	17.5%	
\$40,000-\$49,999	9	22.5%	
\$50,000-\$59,999	5	12.5%	
\$60,000-\$79,999	5	12.5%	
More than \$80,000	6	15.0%	

Table 2. Descriptive statistics of qualitative participants' foster child (N=40)

	N	M (SD, Range)
Age (in years)	40	5.55 (4.68, 0-15)
Sex		
Male	19	47.5%
Female	21	52.5%
Race		
Hispanic	2	5.1%
White	16	40.0%
Black/African American	9	22.5%
Native American	7	17.5%
Biracial	2	5.0%
Multiracial	3	7.5%
Presence of chronic medical condition		
Yes	11	27.5%
No	26	65.0%
Time in current placement (in months)	39	36.27 (38.23, 0-144)
Number of foster children in the home	18	2.50 (1.47, 1-8)

Table 3. Descriptive statistics of quantitative participants, foster youth enrolled in the PMH(N=498)

	N	M (SD, Range)
Age (in years)	498	4.60 (4.06, 0-14.7)
Sex		
Male	267	53.6%
Female	231	46.4%
Race		
White	245	49.2%
Black/African American	111	22.3%
Native American	35	7.0%
Asian	1	0.2%
Missing	106	21.3%
Number of appointments at the PMH	498	3.87 (3.35, 1-21)
Number of providers seen at the	498	5.94 (3.59, 2-21)
PMH		•

Note: PMH denotes "Pediatric Medical Home"

Table 4. Results of COC comparison analyses

N=498	Attending Continuity	Comparison Test	<b>Resident Continuity</b>	Comparison Test
	M (95% CI)	Test statistic (p value)	M (95% CI)	Test statistic (p value)
Overall	.41 (0.38-0.44)	W=243599.5 (0.30)	0.39 (0.36-0.42)	W=243599.5 (0.30)
By Sex		W=56026.0 (0.31)		W=55943.5 (0.29)
Female	0.39 (0.34-0.43)		0.37 (0.33-0.42)	
Male	0.42 (0.38-0.46)		0.41 (0.37-0.45)	
By Race		H=0.15(0.93)		H=2.55(0.28)
White	0.40 (0.36-0.44)		0.39 (0.35-0.44)	
African American/Black	0.40 (0.34-0.46)		0.35 (0.29-0.42)	
American Indian/Alaska Native	0.44 (0.31-0.56)		0.46 (0.33-0.59)	
By Visit Type		H=52.21 (<.001)		H=64.86 (<.001)
Well Child Check	0.48 (0.42-0.55)		0.46 (0.40-0.53)	
Sick Visit	0.18 (0.12-0.24)		0.16 (0.10-0.21)	
Return Visit	0.50 (0.44-0.56)		0.53 (0.44-0.56)	
New Visit	0.40 (0.25-0.54)		0.33 (0.20-0.47)	

*Note:* Group comparisons across attending and resident continuity and by sex were examined using the Wilcoxon Rank Sum test (W), while comparisons across race and visit type were examined using the Kruskal-Wallis test (H).

Table 5. Correlations of COC indices and demographic variables

Variable	1.	2.	3.	4.	5.	6.	7.
1. Child sex	1.00	12.15**	0.00	0.12	0.24	1.02	1.13
2. Child race	-	1.00	1.48	0.30	1.21	0.15	2.55
3. Child age	-	-	1.00	-7.20***	-6.52***	2.06*	1.62
4. Number of appointments	-	-	-	1.00	17.13***	027	-0.44
5. Number of providers	-	-	-	-	1.00	13.71***	-14.19***
6. Attending continuity	-	-	-	-	-	1.00	33.45***
7. Resident continuity	-	-	-	-	-	-	1.00

*Note:* \*indicates statistical significance at p<.05\*\* indicates statistical significance at p<.01, \*\*\*indicates statistical significance at p<.01. Chi square analysis examined the relation across two categorical variables (i.e., child race and child sex), linear regression analyses were utilized to assess the relationship between two continuous variables (i.e., age, number of appointments, number of providers, continuity estimates), and ANOVA tests examined the relationship between continuous and categorical variables.

Table 6. Results of COC comparison analyses to extant literature

	M	95% Confidence Interval	<b>Attending COC</b>	<b>Resident COC</b>
Current study			M=0.41	M=0.39
			(0.38-0.44)	(0.36-0.42)
Christakis et al., 2000	0.42	(0.415 - 0.425)	NS	NS
Christakis et al., 2001	0.39	(0.387 - 0.393)	NS	NS
Christakis et al., 2002	0.48	(0.46 - 0.50)	S	S
Christakis et al., 2003	0.46	(0.432 - 0.488)	NS	S
Christakis et al., 2004	0.48	(0.459 - 0.50)	S	S

*Note*: NS denotes "Not significantly different than the present study" while S indicates significantly different than the present findings. "COC" represents the continuity of care index as outlined by Bice and Boxerman (1977).

## Appendix F

Figures

Figure 1. The Conceptual Model of Parent Involvement (McCurdy & Daro, 2001)

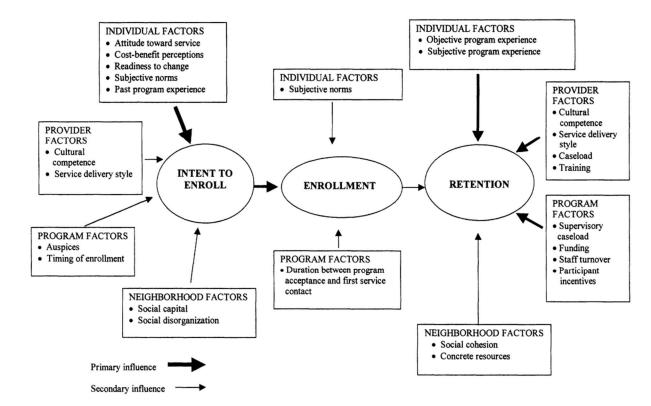
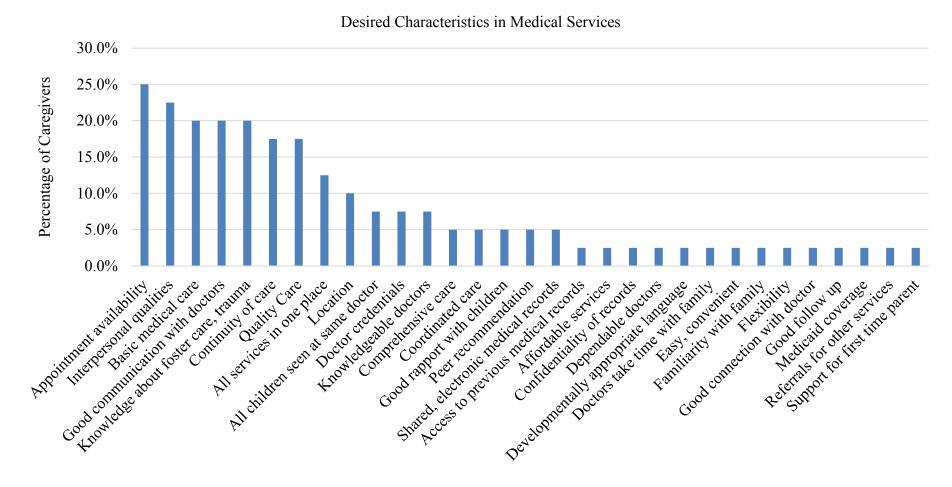


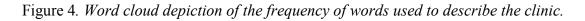
Figure 2. The Continuity of Care index formula (Bice & Boxerman, 1977)

$$COCI = \frac{\sum_{i=1}^{S} (n_j)^2 - n}{n(n-1)}$$

*Note:* n denotes number of visits by patient,  $n_j$  refers to the number of visits with the provider of interest, s denotes the total number of providers. Values range from 0 (minimum continuity) to 1 (maximum continuity)

Figure 3. Caregiver themes related to desired characteristics in medical services







*Note:* Words used to connect duplicate word strands were removed for the purposes of this image (i.e., "and," "the," "may")

### **VITA**

## Hannah Corrine Espeleta

## Candidate for the Degree of

## Doctor of Philosophy

Dissertation: FOSTERING HOPE: A MIXED-METHODS EVALUATION OF PEDIATRIC MEDICAL HOMES FOR YOUTH IN FOSTER CARE

Major Field: Clinical Psychology

Biographical:

Education:

Will complete the requirements for the Doctor of Philosophy in Clinical Psychology at Oklahoma State University, Stillwater, Oklahoma in July, 2020.

Completed the requirements for the Master of Science in Clinical Psychology at Oklahoma State University, Stillwater, OK, USA in 2016.

Completed the requirements for the Bachelor of Arts in Psychology at Miami University, Oxford, Ohio, USA in 2014.

Experience: Graduate Research Assistant to Larry L. Mullins, PhD, Pediatric Health Psychology Laboratory, Department of Psychology, Oklahoma State University, May 2016 to present. Graduate Research Assistant to Lana O. Beasley, PhD, Child Trauma Laboratory, Department of Psychology, Oklahoma State University, August 2014-July 2016. Graduate Research Assistant at the University of Oklahoma Health Sciences Center, Center on Child Abuse and Neglect, August 2014 to July 2016. Clinical practicum experience through Oklahoma State University Psychological Services Center, August 2014 to January 2019, as well as via the Child Study Center (July 2015-June 2018) and OU Children's Hospital (July 2017-June 2018) at the University of Oklahoma Health Sciences Center, and the Saville Center for Child Advocacy (July 2018-May 2019).

Professional Memberships: Society of Pediatric Society, Student Affiliate; American Psychological Association, Division 53: Society of Clinical Child and Adolescent Psychology, Student Affiliate; Association for Behavioral and Cognitive Therapies (ABCT), Student Member.